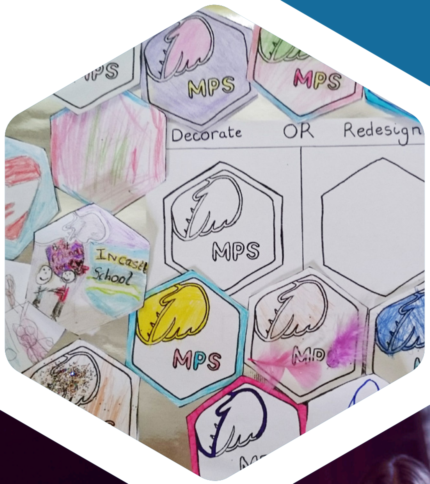
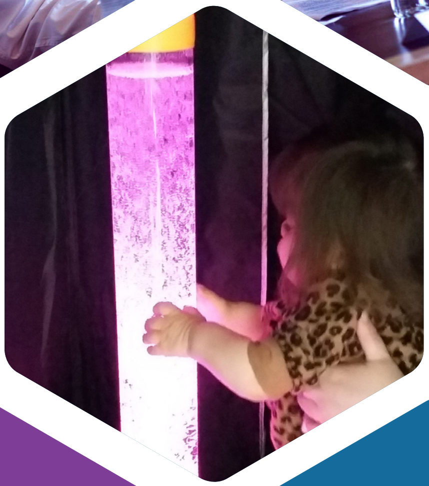
Expert and patient meeting on Maroteaux Lamy disease (MPS VI)



15–16 October 2016

Hilton, Northampton



Programme and booking form

About the conference

This event has been kindly supported by Biomarin

BIOMARIN

The MPS Society is holding an expert and patient meeting, from Saturday 15th to Sunday 16th October, that is dedicated to the sharing of information on MPS VI, Maroteaux Lamy Disease.

This is a wonderful opportunity for individuals, parents, partners, carers and professionals to listen to presentations from experts in the field, as well as from those who have been directly affected by Maroteaux Lamy Disease, with the aim of learning more about the clinical presentation of Maroteaux Lamy Disease, orthopaedic complications, airway and ENT problems, support for those affected, prenatal diagnosis and therapeutic treatments. This event also offers the chance for families and professionals to meet together to share experiences and knowledge.

To help everyone make the most of the weekend, children and vulnerable adults suffering with diseases and their siblings, aged 17 and under, will have their own social programme.

The venue

The conference venue is the Hilton Hotel Northampton, conveniently located at Junction 15 of the M1 motorway, and just 10 minutes' drive to Northampton town centre and 20 minutes to Milton Keynes.

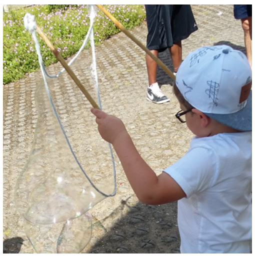
The hotel facilities will be available to all guests over the course of the weekend. Guests arriving on the Saturday will be able to use the hotel facilities, however bedrooms are not guaranteed to be ready until 3pm.

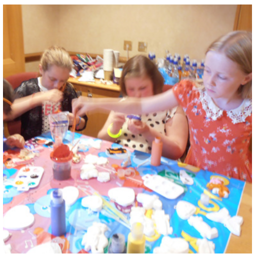
Hilton Hotel
100 Watering Lane
Collingtree
Northampton
NN4 0XW

01604 700666

Please note that the MPS Society reserves the right to alter the programme at any time

Children and vulnerable adults' programme





As no children under 18 years are permitted into the conference, the Society has alternative childcare arrangements in place so that parents and carers can attend the conference in a relaxed manner, knowing that their children are safely cared for and entertained.

Children suffering with Maroteaux Lamy Disease and their siblings aged 17 and under will have their own social programme. This programme will also accommodate young adults over the age of 18 years who are unable to participate in the conference due to health and care needs. Other young adults over the age of 18 years who wish to be included in the childcare programme may do so by prior agreement of the Society.

The Society will endeavour to offer a programme that is suitable to all the children and young people attending. This could include both onsite and offsite activities. At present we are still planning the children's programme as this is dependent on the numbers of children booked and the types of needs each child attending has. Further information will be sent along with childcare forms for completion after your booking has been made.

For babies, children under 3 years of age who are not able to go on the outing or who have complex care needs, a crèche room will be provided. This will include a dedicated care space, sensory area and activities suitable for individual needs. Although we will endeavour to meet all care needs, we are bound by the constraints of the hotel and therefore facilities may be limited.

Volunteers will be at the conference throughout the expert meeting to support the children's and vulnerable adults programme; Volunteers are recruited directly by the MPS Society and undergo a number of checks including an enhanced DBS check. Volunteers are given information on the condition as well as training on basic moving and handling and safeguarding.

Please note that individuals will be assessed on an individual basis and any decisions made in relation to childcare will be made following an assessment of need and the availability and experience of volunteers enrolled. Childcare volunteers will be allocated on a first come, first served basis. If your child has complex care needs, please contact the MPS Society before booking to discuss needs and resources required.

Speaker information

Brian Bigger – Stem Cell & Neurotherapies, Manchester Centre for Genomic Medicine
Stewart Rust – Consultant Clinical Psychologist, Royal Manchester Children's Hospital
Rob Wynn – Consultant Paediatric Haematologist, The University of Manchester
Maureen Cleary – Consultant Metabolic Paediatrician, Great Ormond Street Hospital for Children
Jane Roberts – Clinical Nurse Specialist, Royal Manchester Children's Hospital
Jane Ashworth – Consultant Opthalmologist, Manchester Royal Eye Hospital
Fiona Stewart – Consultant in Genetic Medicine, Belfast City Hospital
Debbie Cavell – Senior Advocacy Support Officer, MPS Society
Samantha Howard – Director of Nursing, BUPA Home Healthcare
Paul Moody – MPS VI family and Trustee, MPS Society
Lucy Brock – MPS VI family

Saturday 15 October

11.00 Registration open
12.00 Lunch

Chair: Paul Moody

13.30 Welcome/opening remarks (Paul Moody)
13.45 Overview and how our understanding of MPS VI has developed over the years (Maureen Cleary)
14.15 Orthopaedic management (tbc)
14.35 Ophthalmic presentations in MPS VI and how to treat (Jane Ashworth)
14.55 Cardiovascular and pulmonary complications (tbc)

15.15 Break (questions to be submitted for Q&A)

15.40 Hannah's operations from head to toe (Lucy Brock)
16.00 Meeting the psychological challenges of young people (Stewart Rust)
16.20 Appropriate care versus transition – getting a balance (tbc)
16.50 Getting the right support in education (Debbie Cavell)
17.00 Ask the experts (panel discussion)

17.30 Close

19.00 Dinner

Sunday 16 October

Chair: Fiona Stewart

9.15 Treatment overview for MPS VI (tbc)
9.35 ERT versus HSCT (Rob Wynn)
9.55 Emerging treatments and therapies (Brian Bigger)
10.15 10 years of Naglazyme (Jane Roberts)

10.35 Break

10.55 The good and the bad. My son's journey from clinical trial to treatment today (Paul Moody)
11.15 Day in the life of an infusion nurse (Samantha Howard)
11.35 How self-infusing benefits our family (tbc)
11.45 Closing remarks and conclusions (Fiona Stewart)

12.15 Lunch

13.15 MPS VI patient experiences session – Biomarin

14.45 Close

Booking form

Individual and family booking for UK members

Residential Includes Saturday night accommodation, Saturday lunch and dinner, Sunday breakfast and lunch, and Saturday and Sunday meetings.	**price per room**	**quantity**		**subtotal**
Single room For members aged 18+ attending the weekend alone.	£25			
Double/Twin room Maximum two persons, must include one adult (Double room: one double bed, Twin room: two beds)	£50	double	twin	
Family room For two adults, MPS sufferers and siblings under 18 years of age	£70			
An additional adult sharing a family room (price per additional person)	£50			
Non-residential options Please note that Saturday and Sunday meetings are for adults only and we are unable to accommodate children on the childcare programme if you have not booked for the residential weekend.	**price per person**	**quantity**		**subtotal**
Saturday meeting with lunch	£10			
Saturday meeting with lunch and dinner	£35			
Sunday meeting with lunch	£10			
Total				

Professionals, non-members and international delegates

Residential Includes Saturday night accommodation, Saturday lunch and dinner, Sunday breakfast and lunch, and Saturday and Sunday meetings.	**price per room**	**quantity**		**subtotal**
Single room	£150			
Double/Twin room Maximum two persons, must include one adult (Double room: one double bed, Twin room: two beds)	£199	double	twin	
Family room For two adults and two children under 18 years of age	£250			
Non-residential options Please note that Saturday and Sunday meetings are for adults only and we are unable to accommodate children on the childcare programme if you have not booked for the residential weekend.	**price per person**	**quantity**		**subtotal**
Saturday meeting with lunch	£10			
Saturday meeting with lunch and dinner	£80			
Sunday meeting with lunch	£10			
Total				

Please complete contact and payment information overleaf and return completed forms to:

MPS Society, MPS House, Repton Place, White Lion Road, Amersham, Bucks, HP7 9LP

Fax: 0345 389 9902
Email: mps@mpssociety.org.uk

For any queries call 0345 389 9901

Details of main contact

Name:

Organisation (if applicable):

Address:

Post code:

Phone:

Email:

Delegate information (for everyone in your party)

First name	Surname	Special dietary requirements	Wheel chair	DOB (if under 18)	MPS VI
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			☐	/ /	☐
			☐	/ /	☐

Payment method

Total to pay: £

☐ Pay by cheque (made payable to: MPS Society)

☐ Invoice hospital or institution (professionals only)

☐ Pay by credit or debit card (complete form below) Diners/Discover, JCB, Maestro, Mastercard, Visa, and Visa Electron accepted

Payment by card (*required information)

Name on card*:

Address of card holder*:

Post code*:

Card number*:

Issue number: Valid from: / Expiry date*: / Security code*:

Our promise

We want to keep you up to date with our news, events, fundraising campaigns and other things we're proud of but only with your permission. We promise to keep your data safe and never ever sell it on. If you're happy with this please tell us how you would like to be contacted by ticking all the relevant boxes below.

☐ by email ☐ by mobile/text ☐ by telephone ☐ by post

To change these options at any time call us on 0345 389 9901 or email mps@mpssociety.org.uk or find out more about Our Donor & Fundraiser Promise at www.mpssociety.org.uk/about/promise