

MPSI post HSCT Hurler Scheie & Scheie

Expert and patient meeting

28–29 April 2018, Hilton, Northampton

This event has been kindly supported by Shire, Sanofi Genzyme and donations in memory of Helen Skidmore



About the expert meeting

The MPS Society is holding an expert patient meeting from Saturday 28 April to Sunday 29 April 2018 that is dedicated to the sharing of cutting edge information on MPSI.

This is a unique and wonderful opportunity for individuals, parents, partners, carers and professionals to hear presentations from internationally recognised experts in the field as well as from those who have been directly affected by MPSI. There will be presentations on orthopaedic complications, airway and ENT management, pregnancy and therapeutic treatments. This event also offers the chance for families and professionals to meet together to share experiences and knowledge.

The venue

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

The hotel facilities will be available to all guests over the course of Saturday and Sunday. 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

Children and vulnerable adults' programme

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

Children suffering with MPSI 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 expert meeting due to health and care needs.

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.

Volunteers will be helping throughout the expert meeting to support the programme for

children and vulnerable adults. 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.



Society for Mucopolysaccharide Diseases

mps@mpssociety.org.uk • 0345 389 9901 • www.mpssociety.org.uk

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

Programme

Saturday 28 April

11.00 Registration

12.00 Lunch

13.00 Welcome and opening remarks

Chairs: Maureen Cleary and Sukhi Bhachu

13.15 Clinical aspects of MPSI Hurler post HSCT – James Davison

13.35 Clinical aspects of MPSI Hurler Scheie and Scheie – Chris Hendriksz

14.00 Managing the MPSI airway and new developments – Rob Walker

14.25 ENT problems in children and adults with MPSI – Ian Bruce

14.50 Improving poor hand function in MPSI – Andrea Jester

15.15 Break

15.30 Improving Cardiac management for MPSI – Perry Elliott*

15.55 Surgical interventions for managing the MPSI hips and legs – Elaine Robinson

16.20 Understanding the MPSI eye and surgical interventions – Jane Ashworth

16.45 Ask the experts

17.15 Close

18.30 Dinner and Learn

Adam Turner – Isaac MPSI post HSCT becoming an adult

Louis Garthwaite – Living and breathing MPSII

Sunday 29 April

9.00 Welcome

Chairs: Jean Mercer and Suresh Vijay

9.10 HSCT – current outcomes and what the future holds – Rob Wynn and Robert Chiesi*

9.35 Clinical trial ERT post HSCT update – where do we go from here? – Paul Orchard

10.00 What role do antibodies play in treating with Enzyme Replacement Therapy – Simon Heales

10.25 A study of Intrathecal ERT for cognitive decline in MPSI – Agnes Chen

10.50 Break

11.05 Psychosocial outcomes for MPSI patients – Julie Eisengard

11.30 Emerging therapies and therapeutic concepts for MPSI – Brian Bigger

11.55 In vivo gene editing approach to gene therapy in MPSI – Joseph Muenzer*

12.20 Pregnancy in MPSI – Alison Wilson

12.35 The challenges, triumphs and dream – Simran Bhachu

12.45 Inspiring others living with MPSI – Aaryanna Lever

13.00 Picnic lunch

* to be confirmed

Booking form for MPSI expert meeting

Members of the UK MPS Society

(choose either the residential OR non-residential option)

Residential Includes Saturday night accommodation, Saturday lunch and dinner, Sunday breakfast and lunch, and Saturday and Sunday meetings.	price per room	quantity		subtotal
Double room for single occupancy For members aged 18+ attending the weekend alone.	£60			
Double/Twin room Maximum two persons, must include one adult (Double room: one double bed, Twin room: two beds)	£100	double	twin	
Family room (max 4 people sharing) For two adults, and up to two children under 18 years of age	£100			
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	£20			
Saturday meeting with lunch and dinner	£50			
Sunday meeting with lunch	£15			

Total				
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Professionals, non-member of UK MPS Society, international delegates

(choose either the residential OR non-residential option)

Residential Includes Saturday night accommodation, Saturday lunch and dinner, Sunday breakfast and lunch, and Saturday and Sunday meetings.	price per room	quantity		subtotal
Double room for single occupancy	£150			
Double/Twin room Maximum two persons, must include one adult (Double room: one double bed, Twin room: two beds)	£200	double	twin	
Family room (max 4 people sharing) 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	£40			
Saturday meeting with lunch and dinner	£100			
Sunday meeting with lunch	£30			

Total				
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Please complete the booking form and payment information overleaf and return completed forms to:

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

or Fax: 0345 389 9902 or Email: events@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 including main contact)

First name	Surname	Special dietary requirements	Wheel chair	DOB (if under 18)	MPSI/MPSII
_____	_____	_____	<input type="checkbox"/>	____ / ____ / ____	<input type="checkbox"/>
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Contact preferences

We want to keep you up to date with our news, events, campaigns and other things we're proud of (including the MPS Magazine) 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](tel:03453899901) or email mps@mpssociety.org.uk or find out more about Our Donor & Fundraiser Promise at www.mpssociety.org.uk/about/promise

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*:
