

# MPSII Hunter

## Expert and patient meeting

28–29 April 2018,  
Hilton, Northampton



This event has been kindly supported by Shire and Sanofi Genzyme

### 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 MPSII.

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 MPSII. There will be presentations on orthopaedic complications, airway and ENT management and therapeutic treatments. This event also offers the chance for families and professionals to meet together to share experiences and knowledge.

### 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 MPSII 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.

### 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



Society for Mucopolysaccharide Diseases

[mps@mpssociety.org.uk](mailto:mps@mpssociety.org.uk) • 0345 389 9901 • [www.mpssociety.org.uk](http://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

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### Saturday 28 April

11.00 Registration

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12.00 Lunch

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13.00 Welcome and opening remarks

Chairs: Alex Broomfield and Bob Stevens

13.15 Clinical aspects of MPSII where progressive CNS is present – Simon Jones

13.35 Clinical aspects of the attenuated MPSII – Alex Broomfield

14.00 Surgical interventions for managing the MPSII spine – Neil Oxborrow\*

14.25 Improving the Cardiovascular disease management in MPSII – Peter Woolfson\*

14.50 Surgical interventions for managing the MPSII hips and legs – Elaine Robinson

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15.15 Break

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15.30 Improving poor hand function in MPSII – Andrea Jester

15.55 Managing the MPSII airway and new developments – Rob Walker

16.20 ENT problems in children and adults with MPSII – Ian Bruce

16.45 Ask the experts

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17.15 Close

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18.30 Dinner and Learn

Adam Turner – Isaac MPSI post HSCT becoming an adult

Louis Garthwaite – Living and breathing MPSII

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### Sunday 29 April

9.00 Welcome

Chairs: Jane Roberts and Elaine Murphy

9.10 Psychosocial Outcomes for MPSII patients – Julie Eisengard

9.35 Managing Behaviour in MPSII – Stewart Rust

9.55 Emerging therapies and therapeutic concepts for MPSII – Brian Bigger

10.20 In vivo gene editing approach to gene therapy in MPSII – Joseph Muenzer\*

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10.50 Break

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11.00 Intrathecal ERT in MPSII where is it taking us? – Joseph Muenzer\*

11.25 Effect of Adalimumab on physical function and musculoskeletal disease in MPSII – Lynda Polgreen

11.50 HSCT – current experiences and what the future holds – Rob Wynn and Robert Chiesi\*

12.15 What role do antibodies play in treating MPSII patients with Enzyme Replacement Therapy – Simon Heales

12.40 My MPSII pregnancy and HSCT journey – Jasmin Price

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13.00 Picnic lunch

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\* to be confirmed

# Booking form for MPSII expert meeting

## Members of the UK MPS Society

(choose either the residential OR non-residential option)

<b>Residential</b> Includes Saturday night accommodation, Saturday lunch and dinner, Sunday breakfast and lunch, and Saturday and Sunday meetings.	<b>price per room</b>	<b>quantity</b>		<b>subtotal</b>
<b>Double room for single occupancy</b> For members aged 18+ attending the weekend alone.	£60			
<b>Double/Twin room</b> Maximum two persons, must include one adult (Double room: one double bed, Twin room: two beds)	£100	double	twin	
<b>Family room (max 4 people sharing)</b> 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			

<b>Non-residential options</b> 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.		<b>price per person</b>	<b>quantity</b>	<b>subtotal</b>
Saturday meeting with lunch	£20			
Saturday meeting with lunch and dinner	£50			
Sunday meeting with lunch	£15			

<b>Total</b>				
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## Professionals, non-member of UK MPS Society, international delegates

(choose either the residential OR non-residential option)

<b>Residential</b> Includes Saturday night accommodation, Saturday lunch and dinner, Sunday breakfast and lunch, and Saturday and Sunday meetings.	<b>price per room</b>	<b>quantity</b>		<b>subtotal</b>
<b>Double room for single occupancy</b>	£150			
<b>Double/Twin room</b> Maximum two persons, must include one adult (Double room: one double bed, Twin room: two beds)	£200	double	twin	
<b>Family room (max 4 people sharing)</b> For two adults and two children under 18 years of age	£250			

<b>Non-residential options</b> 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.		<b>price per person</b>	<b>quantity</b>	<b>subtotal</b>
Saturday meeting with lunch	£40			
Saturday meeting with lunch and dinner	£100			
Sunday meeting with lunch	£30			

<b>Total</b>				
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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](mailto:events@mpssociety.org.uk)

For any queries call 0345 389 9901

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## Details of main contact

Name:

Organisation (if applicable):

Address:

Post code:

Phone:

Email:

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## 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="text"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>	<input type="text"/> / <input type="text"/> / <input type="text"/>	<input type="checkbox"/>
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<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>	<input type="text"/> / <input type="text"/> / <input type="text"/>	<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](mailto:mps@mpssociety.org.uk) or find out more about Our Donor and Fundraiser Promise at [www.mpssociety.org.uk/about/promise](http://www.mpssociety.org.uk/about/promise)

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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

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## Payment by card (\*required information)

Name on card\*:

Address of card holder\*:

Post code\*:

Card number\*:

Issue number:

Valid from: /

Expiry date\*: /

Security code\*:

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