



MPS Matters 2025

27–29 June 2025, DoubleTree by Hilton, Coventry, UK

Funding towards this conference has been provided by:





Welcome

We are truly delighted to welcome you to our first MPS Conference since 2019, a long-awaited opportunity for our community of families, individuals and professionals to come together once again.

This year's conference marks a fresh chapter. Inspired by the invaluable feedback from our MPS community, we've reimagined the programme to better reflect your hopes, needs and voices. We've placed a stronger emphasis on education, meaningful connection and the sharing of lived and professional experience. Whether you are joining us as someone living with an MPS condition, a parent, a sibling, a carer, a clinician, or a researcher, this is your conference.

We know that MPS and related conditions bring many challenges. These conditions are rare, complex, and often progressive, affecting individuals and families in unique and personal ways. But this weekend is about more than the medical journey, it's about community, connection and shared strength. It's about learning and listening, creating new memories, meeting new friends and reconnecting with familiar faces.

Alongside our core programme of expert-led sessions, discussions and family-focused activities, we're introducing some new experiences designed to make this event not only informative, but also relaxing, enriching and inspiring. Whether you're here to deepen your understanding, share your story, or simply be in the company of others who understand, we're honoured to have you with us.

Thank you for being part of this very special event. Together, we continue to move forward connected, informed, and never alone.

With our warmest wishes and welcome,

Bob Stevens
Group Chief Executive

Overview of the weekend

Friday 27 June	15.00–20.00	Arrival and registration (Foyer)
	18.00–20.00	Buffet dinner (Minster 1 and 2)
	19.30–20.00	Welcome to MPS Matters (Minster 1 and 2)
	20.00–21.30	Children's party (Minster 1 and 2)
Saturday 28 June	07.30–09.30	Breakfast (Restaurant)
	09.10–18.30	Conference programme
	18.30–23.00	Dinner and entertainment (Minster 1 and 2)
Sunday 29 June	07.30–10.30	Breakfast (Restaurant)
	09.20–12.40	Conference programme
	12.40–13.00	Closing remarks, takeaway lunch and departure

Saturday 28 June

Session 1 – Parent carer track

Chair: Fiona Stewart | Location: Minster 1 | 09.10 to 10.50

A rare life: clinical updates

- 09.10 Beginning of a rare life (walkthrough of LSD service) – [Fiona Stewart](#), [Kelly Mills](#), [Catherine Rice](#), [Holly Lewis-Vale](#), [Yvette Mellalieu](#)
- 09.30 The importance of clinical guidelines – [James Davison](#) and [Sophie Thomas](#)
- 09.50 Treatment updates – [Alex Broomfield](#)
- 10.10 Research – where are we now? – [Simon Jones](#)
- 10.20 Childhood dementia – [Gail Hilton](#)
- 10.30 Q&A

Session 1 – Adult track

Chair: Alison Wilson | Location: Minster 2 | 09.10 to 10.50

Taking ownership – taking control of your health

- 09.10 Community at the MPS Society – [Alison Wilson](#)
- 09.30 Navigating adult care – [Uma Ramaswarmi](#)
- 10.00 Ownership and self-advocacy – [Royal Free Nursing Team](#)
- 10.30 Clinical Q&A

10.50 to 11.20 Break

Session 2 – Breakout sessions

Locations: see below | 11.20 to 12.30

Tracheal update

Speaker: [Johnny Kenth](#)
Facilitator: [Sophie Thomas](#)
Location: Litchfield Room, first floor

Gene therapy: Insights so far

Speaker: [Simon Jones](#)
Facilitator: [Fiona Stewart](#)
Location: Minster 2, ground floor

Finding my strength – an independent infusions journey

Speaker: [Yvette Mellalieu](#)
Facilitator: [Sally Briody](#)
Location: Minster 1, ground floor

Meet the expert

Facilitators: [Alison Wilson](#)
and [Derralynn Hughes](#)
Location: Alcove, ground floor

Childhood dementia

Speaker: [Gail Hilton](#)
Facilitator: [Steve Cotterell](#)
Location: Lincoln Room, first floor

Where
should I be?

The alcove and Minster 1 and 2 are on the ground floor. All other rooms are on the first floor accessed via the lift or stairs, or on the mezzanine level.

12.30 to 13.30 Lunch

Session 3 – Parent carer track

Chair: Sally Briody | Location: Minster 1 | 13.30 to 14.30

A rare life: advocacy

- 13.30 Principles of access to education – [IPSEA representative Lisa Coaten](#)
13.50 Mental Capacity and Decision Making – [Lucy MacBrayne and Amy Chater](#)
14.10 Q&A

Session 3 – Adult track

Chair: Alison Wilson and Hannah Farrell | Location: Coventry Suite | 13.30 to 14.30

Future choices – what's next?

- 13.30 Self-advocacy and independence – [Alison Wilson](#)
Panel: Archie (MPS IV), Faye (MPS IV), Tyler (MPS II), Aryanna (MPS I HS), Sam (MPS II)
14.00 Employment and Disability – [EDGE representatives Nicky Harding and Jennifer Brown](#)

Session 3 – Professional track

Chair: Sophie Thomas | Location: Minster 2 | 13.30 to 15.15

- 13.30 Simulation training – [Florian Lagler](#)
14.30 Palliative care – [Karolina Stepien and Janet Gorton](#)

15 min break incorporated into workshops

Session 4 – Workshops

Locations: see below | 14.30 to 16.00

Dads and lads session

Facilitator: Bob Stevens
Location: Restaurant, mezzanine

Simulation training (how to respond in an emergency)

Facilitators: Florian Lagler and Uma Ramaswami
Location: Litchfield Room, first floor

IPSEA workshop

Facilitator: Sally Briody
Location: Worcester Room, first floor

EDGE workshop

Facilitators: Alison Wilson and Hannah Farrell
Location: Coventry Suite, first floor

Relaxation and pamper session

Facilitators: Nita Tailor and Fiona Stewart
Location: Alcove, ground floor

Arts and crafts

Facilitator: MPS Society staff
Location: Restaurant area, ground floor

Gaming zone

Facilitator: Phil Pearson
Location: Main foyer, ground floor

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Where should I be?

Session 5

Locations: see below | 16.00 to 23.00

- 16.00–17.00 Dragon's Den
Location: Minster 1 and 2
Chair: Fiona Stewart
- 17.00–18.00 Poster session
Location: Restaurant area
Chairs: Simon Heales and Simon Jones
- 17.30–18.30 Young people's social drop in with drinks and nibbles
Location: Mezzanine level
Chairs: Support and Advocacy Team
- 18.30–23.00 Dinner and entertainment
Location: Minster 1 and foyer

Sunday 29 June

Session 1 – Parent carer track

Chair: Steve Cotterell | Location: Minster 1 | 9.20 to 11.00

A rare life: support

- 09.20 Talking Transition: why it's important – [Uma Ramaswami](#)
- 09.40 Q&A
- 09.50 Preventing burnout as a parent/carers – [Claire Garthwaite](#)
- 10.10 Q&A
- 10.20 Understanding sensory needs – [Simply Sensory](#), [Julie Cowpe-Stephens](#) and [Helen Dillon](#)
- 10.40 Q&A
- 10.50 Discussion

Session 1 – Adult track

Chair: Alison Wilson | Location: Minster 2 | 09.10 to 11.00

Identity and relationships – finding yourself and your people

- 09.10 Drama games ice breaker – [Sam Jamil](#)
- 09.20 Mental health and identity – [Lynne Aitkenhead](#)
- 09.50 Relationships – [Rareminds](#) representative [Zubyda Azzam](#)
- 10.20 Discussion time

Session 1 – Professional track

Chair: Sophie Thomas | Location: Coventry Suite | 09.20 to 11.00

- 09.20 Feedback on MARS data findings – [Johnny Kenth](#)

11.00 to 11.30 Break

Session 2 – Workshops

Locations: see below | 11.30 to 12.30

How to better look after yourself on your journey

Speaker: Zubyda Azzam (Rareminds)
and Claire Garthwaite
Facilitator: Sally Briody
Location: Minster 1, ground floor

Post-transition and self-advocacy

Facilitators: Alison Wilson and
Uma Ramaswami
Location: Minster 2, ground floor

Simply Sensory session

Speakers: Julie Cowpe-Stephens and
Helen Dillon
Facilitators: Steve Cotterell and Hannah Farrell
Location: Winchester Suite, first floor

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Where
should I be?

Session 2 – Professional track

Chair: Sophie Thomas | Location: Coventry Suite | 11.30 to 12.30

11.30 Case study discussion – [Derralynn Hughes](#)

12.30 Closing remarks and lunch in the restaurant (takeaway options available)

Children and young person's programme

Saturday 28 June 2025 | 08.50 to 17.00

08.50 Children and young people are dropped off (Canterbury suite, first floor)
10.30 Break (stay with volunteers on first floor)
12.30 Lunch till 13.30 (parents to collect and return after lunch)
15.45 Break (stay with volunteers on first floor)
17.00 Children and young people collected
18.30 Dinner and activities

Sunday 29 June 2025 | 09.00 to 13.00

09.00 Children and young people dropped off (Canterbury suite, first floor)
10.30 Break (stay with volunteers on first floor)
13.00 Children collected

Activities

Saturday

Creation station (arts and crafts open all day)
Cinema and games rooms
Sensory room
Quiet / chill out zone
Entertainer / Party (15.00 to 17.00)

Sunday

Wild science (10.00 to 12.00)
Cinema and games rooms
Sensory room
Quiet / chill out zone
Arts and crafts

Information for attendees

Personal belongings

The hotel and MPS Society cannot accept responsibility for the security, damage or loss of personal possessions.

Payments

Settle all bills before departure and do not charge any additional costs to the MPS Society. Our contract with the hotel is for booked accommodation on a bed and breakfast rate, dinner on Friday and Saturday and lunch on Saturday and Sunday, plus refreshments provided during breaks.

Leisure facilities

Use of the leisure facilities of the hotel are at your own risk. We do not accept responsibility for any injury or loss. Children under 16 years of age will not be admitted to the swimming pool unless accompanied by a responsible adult. The pool will be in use for swimming lessons over the weekend but is still accessible at these times. Exclusive use of the pool is available 15.00 to 17.00 on Friday and 12.00 to 13.00 and 15.00 to 17.00 on Saturday. The leisure club is open 07.00 to 20.00 on the weekends and last entry is 19.00.

Conference rooms

Please try to enter and leave the conference room quietly and where possible leave between speakers rather than during a presentation. Children 15 years and above are welcome to join the conference sessions. They remain the responsibility of a responsible adult.

Checkout

Checkout is 11am on the day of departure.

Conference lanyards and wrist bands

Wear your lanyards and wrist bands at all times during the weekend to help the organisers know you are part of our group.

Parking

You will need to enter your number plate in the vehicle registration software via the tablet or QR code at the hotel in order to avoid any parking charges. If you leave and re-enter the car park at any point remember to add your registration again as this will count as another visit. If you are accidentally charged for parking please let MPS Society staff know.

Bringing food into the hotel

Some people attending have a severe nut and seed allergy so these must not be brought into the hotel during the weekend.

Safety of children and young people

All parents are responsible for their child outside of the organised childcare programme. Please be mindful that there are several exits to the hotel.

Childcare programme

We're excited to be able to offer an onsite childcare and young person's programme throughout the weekend, supported by our amazing team of volunteers! My name is Steve, I will be working with our lead volunteer and the team to ensure that your children and young people have fun making friends and memories while you enjoy the event. Please note that whilst we are able to offer this service, parents and carers may be called upon at any time during the day to assist in the care of their child/young person. Should the need arise please make yourselves available as quickly as possible.

For general enquiries, please speak to Barbara. For anything specific about childcare arrangements speak to Steve. If you're unable to speak to someone in person or need urgent help, please call.

Barbara: 07770 384 035
Steve: 07712 653 258

Photography and filming policy

For the protection of everyone attending please make sure that any images or videos taken at the conference are for personal use (unless you have the express permission of the people in the photo) and are not uploaded to the internet, posted on social networking sites or openly shared in other ways. Some attendees have not given permission for photos to be taken and we are all responsible to ensure the privacy of others is upheld.

During the weekend we will be taking photographs, videos and recordings of some

of the sessions. Please let us know if you do not want any images of you to be shared in the following ways:

- On our website
- On our social media channels
- In our publications
- In digital communications
- In marketing for future events

To make sure we don't use your photo in these ways, please visit us at the check-in desk so we can identify you.

Get the app

NAVIGATE the event agenda and logistics, even without wifi and access the Community Board

NETWORK effectively. Plan whom to meet by exploring attendee profiles and sending out messages

PARTICIPATE in event activities through session likes, comments, ratings, live polling and more



Download Whova

Scan the QR code to download the app or ask a member of staff for help. You can also visit: mpssociety.org.uk/mps-matters-2025

Share your experiences
of the weekend using
#MPSMatters2025



MPS Society

Society for Mucopolysaccharide Diseases
www.mpssociety.org.uk

Registered charity 1143472 and SCO41012
Company Reg 7726882



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