

# Wolfram Syndrome Annual Conference 2025

## Programme

Mercure Daventry Court Hotel

Saturday 20th September 2025

Funded by



and



  
Birmingham Women's  
and Children's  
NHS Foundation Trust

**By your side**

**Please note this programme may be subject to changes on the day**

## MORNING SESSION

**9:00 – 9:50 am:** Registration – tea and coffee on arrival

**D3**

**10:00 – 10:10 am:** **CONFERENCE OPENS**

**D1 & 2**

**Welcome and Introduction to the day (10.00 - 10.10)**

Tracy Lynch – CEO & Co-Founder of Wolfram Syndrome UK

**10:10 – 10:45 am:** **Presentations**

**(10:10– 10:35 am:)** **Living with WS**

Panel presentation by some of our younger WS community – Tom Darley, Asal Fallah Damavandi,

**(10:40 – 11:15 am:)** **ORION Project**

Dr Riddhima Gautam, Senior Ophthalmic Technician, NIHR Cambridge Clinical Research Facility

**11:15 – 11:40 am:** **Refreshments**

**D3**

**Workshops** **11:45 – 1:15 pm**

	OPTION 1		OPTION 2		OPTION 3		OPTION 4
11:45 - 1:15 pm	First Aid Workshop  (12 places only - pre – booked)	11:45 - 12:25pm	WS Affected Combined Workshop  All WS professionals <b>D1</b>	11:45 – 1:15pm	Sports Taster Sessions   RNC <b>W</b>	11:45 - 12:25 pm	Support Co-ordinator Drop in sessions  Olivia Edwards <b>P</b>
		12:30 - 1:15 pm	WS Parents/Carers Combined Workshop  All WS professionals <b>D1</b>			12:30 - 1:15 pm	Psychology  Dan Kent, Counselling Training Lead - RNIB <b>P</b>

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1:15-2:15 pm: **Lunch**

**Restaurant**

## **AFTERNOON SESSION**

### **Workshops 2:20 – 3:50pm**

	OPTION 1		OPTION 2		OPTION 3		OPTION 4
2:20 - 3:50 pm	First Aid Workshop  (12 places only - pre – booked)  <b>C</b>	2:20 - 3:05 pm	WS Parents/Carers Combined Workshop  All WS professionals <b>D1</b>	2:20-3:50 pm	Sports Taster Sessions  RNC <b>W</b>	2:20- 3:05 pm	Support Co-ordinator Drop in sessions  Olivia Edwards <b>P</b>
		3:10 - 3:50 pm	Free session – chance to chat with others  <b>D1</b>			3:10 - 3:50 pm	Psychology  Dan Kent, Counselling Training Lead - RNIB <b>P</b>

3:50 – 4:25pm: **Refreshments**

**D3**

4:30 – 5:30 pm: **Presentations**

**D1 & 2**

(4:30- 5:00 pm)

**WS Research**

Dr Sovan Sarkar, University of Birmingham

(5:00 – 5:30 pm)

**TREATWolfram – What next?**

Prof Timothy Barrett, University of Birmingham

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## **Evening** (for those staying over)

**6:20 pm:** Meet before dinner in the bar / reception

**6:40 pm: Please find your seats in Danetree 3** - Complimentary three course dinner for those staying overnight.

**6:45 pm: Dinner served**

## **LOCATION KEY**

D1 & 2 - Danetree 1 & 2

D3 – Danetree 3

C – Charles

P- Priestly

W – Westerburg

D- Dickens

**Activities available in Dickens**

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