

Wolfram Syndrome Annual Conference 2025

Programme

Mercure Daventry Court Hotel

Saturday 20th September 2025

Funded by



and



By your side

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

MORNING SESSION

- 9:00 – 9:25 am:** Registration – tea and coffee on arrival **D3**
- 09:30 – 09:40 am:** **CONFERENCE OPENS** **D1 & 2**
Welcome and Introduction to the day (09:30 – 09:40)
Tracy Lynch – CEO & Co-Founder of Wolfram Syndrome UK
- 09:40 – 11:15 am:** **Presentations**
- (09:40– 10:10 am:)** **ORION Project**
Dr Riddhima Gautam, Senior Ophthalmic Technician, NIHR Cambridge Clinical Research Facility
- (10:15 – 10:40 am:)** **Living with WS**
Panel presentation by some of our younger WS community – Tom Darley, Asal Fallah Damavandi, Jay Jenkins
- (10:45 – 11:15 am:)** **Developing new therapeutics for Wolfram Syndrome using patient-derived brain cells**
Dr Sovan Sarkar, Department of Cancer and Genomic Sciences, School of Medical Sciences, College of Medicine and Health, University of Birmingham, UK
- 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) P	11:45 - 12:25pm	WS Affected Combined Workshop All WS professionals D1	11:45 – 1:15pm	Sports Taster Sessions RNC W	11:45 - 12:25 pm	Support Co-ordinator Drop in sessions Olivia Edwards C

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		12:30 - 1:15 pm	WS Parents/Carers Combined Workshop All WS professionals D1			12:30 - 1:15 pm	Psychology Dan Kent, Counselling Training Lead - RNIB C
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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) P	2:20 - 3:05 pm	WS Parents/Carers Combined Workshop All WS professionals D1	2:20-3:50 pm	Sports Taster Sessions RNC W	2:20-3:05 pm	Support Co-ordinator Drop in sessions Olivia Edwards C
		3:10 - 3:50 pm	Free session – chance to chat with others D1			3:10 - 3:50 pm	Psychology Dan Kent, Counselling Training Lead – RNIB C

3:50 – 4:25pm: **Refreshments**

D3

4:30 – 5:30 pm: **Presentations**

D1 & 2

(4:30- 5:00 pm)

TREATWolfram – What next?

Prof Timothy Barrett, Leonard Parsons Professor of Paediatrics, NIHR Senior Investigator. Director, Centre for Rare Disease Studies. Department of Cancer and Genomic Sciences - University of Birmingham, UK.
Honorary Consultant Paediatric Endocrinology and Diabetes - Birmingham Women's and Children's Hospital NHS Trust

(5:00 – 5:30 pm)

Update from Amylyx: HELIOS Trial

Jamie Timmons,MD; Senior Vice President, Medical Affairs. Amylyx, USA. **Via Zoom**

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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 during the day.

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