

Wolfram Syndrome Annual Conference 2026

Programme

Mercure Daventry Court Hotel

Saturday 26th September 2026

Funded by



and



NHS
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 – 9:25 am:** Registration – tea and coffee on arrival D1
- 09:30 – 09:35 am:** CONFERENCE OPENS D2 & 3
Welcome and Introduction to the day (09:30 – 09:40)
 Tracy Lynch – CEO & Co-Founder of Wolfram Syndrome UK & John Isherwood – Chair of Trustees
- 09:40 – 11:15 am:** Presentations
- (09:40– 10:10 am:)** **Overview of Wills, Trusts, Powers of Attorney and Court Protection Matters**
 Philip Warford – Managing Director, Renaissance Legal
- (10:15 – 10:30 am:)** **Living with WS**
 Panel presentation with some of our parents and younger WS community – Andrea & Tom Darley;
- (10:35 – 11:15 am:)** **Reproductive health in young people with WS and
 New Study Highlights the Impact of Diabetes Technology in Wolfram Syndrome**
 Dr Anne de Bray. Academic Clinical Lecturer, MSS, University of Birmingham and Dr Renuka Dias, WS clinical lead & Birmingham Children’s Hospital
- 11:15 – 11:40 am:** Refreshments D1

Workshops 11:45 – 1:15 pm

	OPTION 1		OPTION 2		OPTION 3		OPTION 4
11:45 - 12:45pm	Planning for the Future with Wills and Trusts Philip Warford D3	All Day	Sports taster sessions RNC W	All Day	AI & VI Technology, VI hints etc Drop in Humanware, New College Worcester, RNC Hereford. P	11:45 - 12:25pm	Parents discussion WS Clinicians C
12:45 – 1:15 pm	Social Chat / Discussions Community D3	11:45 – 12:25 pm	Parents Get Lost’ Young person’s Session Support Co-ordinators D			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 - 3:20 pm	Decision Making for Disabled and Vulnerable People Philip Warford D3	All Day	Sports Taster Sessions RNC W	All Day	AI & VI Technology, VI hints etc Drop in Humanware, New College Worcester, RNC Hereford. P	2:20-3:05 pm	Psychology Dan Kent, Counselling Training Lead - RNIB C
3:20 – 3:50 pm	Social Chat / Discussions Community D3	2:20 - 3:50 pm	Drop-In Session – All community All Support Co-ordinators D			3:10 - 3:50 pm	Life Skills Microwave cooking Emma Williams - NCW C

3:50 – 4:25pm: **Refreshments**

D1

4:30 – 5:40 pm: **Presentations**

D2 & 3

(4:30- 5:00 pm) **Update from Amylyx on the HELIOS Trial and AMX0035**
Jamie Timmons, MD; Senior Vice President, Medical Affairs. Amylyx, USA.

(5:00 – 5:30 pm) **International Wolfram Consensus Guidelines**
Prof Timothy Barrett, University of Birmingham

(5:30 – 5:40 pm) **Close of Day**
John Isherwood Chair of Trustees & Tracy Lynch

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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 1 - Complimentary three course dinner for those staying overnight.

6:45 pm: Dinner served

LOCATION KEY

D2 & 3 - Danetree 2 & 3 D1 – Danetree 1 C – Charles P- Priestly D- Dickens W - Westerberg

Westerberg – Sports taster sessions all day

Activities available in Dickens during the day when not used for Workshops.

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