

Wolfram Syndrome Annual Conference 2024

Programme

Mercure Daventry Court Hotel

Saturday 21st September 2024

Funded by



and




Birmingham Women's
and Children's
NHS Foundation Trust

By your side

In memory of Amy Hawkins – WSUK are using funds raised and donated in Amy's memory to fund the family conference which she loved to attend and be part of.

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 D2 & 3
- 10:00 – 10:10 am:** **CONFERENCE OPENS** D2 & 3
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**
Speech and Language – pre-recorded
 Sharnea Salmon Speech and Language Therapist, Queen Elizabeth Hospital
(questions to be given to WSUK to be sent to SaLT for answering)
- 10:45 – 11:15 am:** **Living with WS**
 Panel presentation by some of our WS community – Abby Gardner, Georgina Carolan, Naomi Bennett
- 11:15 – 11:40 am:** **Refreshments** D2 & 3
- 11:45 – 12:20 pm:** **Presentation** D2 & 3
Benefits
 Zoe Bates (QEH ECLO) and Talia Treen (BCH ECLO)

Workshops 12:30 – 1:15 pm

	OPTION 1		OPTION 2		OPTION 3
12:30 - 1:15 pm	Sight Awareness Training and Guiding Aids C Zoe Bates and Talia Treen	12:30 - 1:15 pm	WS Affected session D3 All WS professionals	12:30 – 1:15 pm	Support Co-ordinator Drop in sessions P Georgina King and Phillippa Farrant

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

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AFTERNOON SESSION

Workshops 2:20 – 3:05pm

	OPTION 1		OPTION 2		OPTION 3
2:20 -3:05 pm	Sight Awareness Training and Guiding Aids C Zoe Bates and Talia Treen	2:20 - 3.:05 pm	WS Parents/Carers D3 All WS professionals	2:20-3:05 pm	Support Co-ordinator Drop in sessions P Georgina King and Phillippa Farrant

3:10 – 3:45pm:

Presentation

Amylyx HELIOS Trial – Update
Dr Mathias Leinders - Amylyx

D2 & 3

3:50 - 4:20 pm:

Afternoon refreshments

D2 & 3

4:25 – 4:50 pm:

Presentation

TREATWolfram update
Prof Tim Barrett

D2 & 3

4:50 – 5:00 pm:

Conclusion

D2 & 3

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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 & 2** - Complimentary three course dinner for those staying overnight.

6:45 pm: Dinner served

LOCATION KEY

D2&3 – Danetree 2 & 3

C – Charles

P- Priestly

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