



Wolfram Syndrome Annual Conference 2019

Programme

Whittlebury Hall

Saturday 28th September 2019

Funded by



In partnership with



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

MORNING SESSION

9.00 – 9.50 am:	Registration, tea, coffee and bacon rolls on arrival	I & H
10.00 – 10.10 am:	CONFERENCE OPENS Welcome and Introduction to the day Jody Blake, WellChild WS Family Coordinator	M
10.15 – 10.45 am:	Updates on US clinical trials Dr Fumi Urano MD, PhD Washington University/Barnes Jewish Hospital, St Louis	M
10.45 – 11.15 am:	Tea, coffee and pastries	I & H
11.20 – 12.05 am:	Wolfram Syndrome & The Brain: What have we learned from the WU Wolfram Research Clinic? Tamara Hershey, PhD - James S. McDonnell Professor of Cognitive Neuroscience, Director, McDonnell Center for Systems Neuroscience, Co-Director, Neuroscience PhD Program, DBBS, Washington University School of Medicine. ????????? Dr Bess Marshall – Endocrinologist Washington University Hospital	M
12.10-12.50pm:	Modeling Wolfram syndrome with patient-derived stem cells and building gene therapy tools for preventing vision loss Dr Vania Broccoli. Head of the stem Cells and Neurogenesis Unit at the San Raffaele Institute, Milan.	M

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12.50-2.00 pm **Lunch**

I & H

AFTERNOON SESSION (Workshops will run from 2.00-5.00pm)

Workshops 2.00-3.35pm

	OPTION 1		OPTION 2		OPTION 3
2.00-2.40pm	Combined workshop for WS affected only (M) All Doctors	2.00-2.45pm	Female to Female (mums, wives, partners, siblings etc.) (S) Mediator – Dr Gina Isherwood	2.00-2.45pm	Male to Male (dads, husbands, partners, siblings etc.) (N) Mediator – Michael Chandler
2.50-3.30pm	TreatWolfram Q&A (S) All Doctors	2.50-3.30pm	Psychology workshop – for WS affected only (M) Gayle McKerracher Consultant Clinical Psychologist	2.50-3.30pm	Ophthalmology (N) Talia Dewhurst

3.30 – 4.00pm

Afternoon refreshments

I & H

Workshops 4.05 – 4.50pm

	OPTION 1		OPTION 2		OPTION 3
4.05-4.50pm	TreatWolfram Q&A (S) All Doctors	4.05-4.50pm	Psychology workshop – for parents/carers only (M) Gayle McKerracher Consultant Clinical Psychologist	4.05-4.50pm	Ophthalmology (N) Talia Dewhurst

4.50-5.10 pm: **Thank yous & goodbyes**

Tracy Lynch - WSUK and Jody Blake - WellChild

M

Evening (for those staying over)

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6.45 pm: Meet before dinner in Silverstone Bar / reception

7.00 pm: **Dinner in the Courtyard Restaurant**

Complimentary three course dinner for those staying overnight.

LOCATION KEY

I & H - Indianapolis and Hungaroring

M – Monza

S - Suzuka

N - Nurburgring

We'd like to say a big thank you to Penfold Verrall for help with funding this conference



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