

IPWSO MENTAL HEALTH ECHO



IPWSO Mental Health ECHO Summary April 25 2023: Atypical brain development, cognitive impairment, and hypothalamic dysfunction

"This was my first ECHO and I have found it all very interesting and informative and appreciate the responses from the group. I really feel that this kind of forum is essential to progress the understanding of PWS and developing best practice to meet their needs."

Feedback in meeting Chat

IPWSO was happy to again welcome a large number of participants at our 2nd Mental Health in Prader-Willi syndrome ECHO on the 25th of April, 2023. At this ECHO meeting the aim was making sense of the biological basis of behaviour and mental ill-health in PWS.

Deepan Singh, MD, Child, Adolescent, & Adult Psychiatrist, Vice-Chair of Ambulatory Psychiatry, Maimonides Medical Center, New York, USA, presented "Neurobiology of Prader-Willi Syndrome: Arriving at a Phenomenological Explanatory Model with Mechanistic Insights"

The learning objectives for this presentation were:

- 1. Understanding the genetic and neurobiological causes of behavioural abnormalities in Prader-Willi syndrome;
- 2. Appreciating the central role of the hypothalamus and its connected brain structures in the behavioural, and cognitive manifestations of Prader-Willi syndrome;
- 3. Discussing the challenges and limitations of current treatments for Prader-Willi syndrome, and exploring potential new approaches;
- 4. Discuss a novel phenomenological explanatory model for abnormal response monitoring in PWS, based on the interplay between genetic, neural, and environmental factors.

Elizabeth Roof, MA, Research Associate, Department of Psychology at Vanderbilt University, Tennessee, USA presented a Clinical Challenge "Compulsions in Prader-Willi Syndrome"

The discussion explored:

- Best way to evaluate compulsions in PWS?
- What are the challenges to making a diagnosis of OCD in PWS?
- Best practices interview vs. observation vs. questionnaire.
- Are we measuring symptoms or making a diagnosis in PWS?

Reflections on both presentations can be heard in the video summary linked below.

Video links

Deepan Singh: <u>Neurobiology of Prader-Willi Syndrome</u>: <u>Arriving at a Phenomenological</u> <u>Explanatory Model with Mechanistic Insights</u>

Elizabeth Roof: Clinical Challenge: Compulsions in Prader-Willi Syndrome

Patrice Carroll: IPWSO Mental Health ECHO Summary April 25, 2023

Upcoming Mental Health ECHO sessions

May 30	Behaviours of concern and mental ill-health	Janice Forster MD, Developmental Neuropsychiatrist, Pittsburgh Partnership, USA
	Case presentation	Christian Eberlein, Psychiatrist, Hannover Medical School, Germany
June 27	The design of services to meet the behavioural and mental health needs of children and adults with PWS	Louise Gallagher PhD, Chief, Child and Youth Mental Health Collaborative, The Hospital for Sick Children, Toronto, Canada
		Maximilian Deest, Psychiatrist, Hannover Medical School, Germany
	Case presentation	Tony Holland, President of IPWSO, University of Cambridge, UK
July 25	The application of psychological models in the understanding of adaptive and maladaptive	Norbert Hödebeck-Stuntebeck, PhD, Psychologist, PWS-InterNational, Germany
	behaviours in people with PWS	Kasey Bedard, BCBA, University of Florida, USA
	Challenge: Putting psychological interventions into practice	Marguerite Hughes, CEO, IPWSO

September 26	Early intervention for children with PWS	Anastasia Dimitropolis, Professor of Psychology, Case Western Reserve University, USA
		Kate Woodcock, Reader in Applied Clinical Psychology, University of Birmingham, UK
	Challenge: Early intervention in practice	Karin Clarke, Chairperson PWS Support Group, South Africa

Thank you very much to everyone who attended the session and participated. We look forward to seeing you again at the next session on 30 May.

Ends.