

IPWSO MENTAL HEALTH ECHO



IPWSO Mental Health ECHO Summary March 28 2023: Wellbeing, quality of life and mental health

"Thanks for putting today's program together. The concept and execution of the Mental Health ECHO was brilliant. Very thoughtful presentations. The young mother was brave."

Feedback via email

IPWSO was so pleased to welcome new as well as familiar faces to the 1st Mental Health in Prader-Willi syndrome ECHO on the 28th of March, 2023.

IPWSO President Tony Holland presented on the work Mental Health Network and the ECHO methodology.

Brian Hughes, Professor of Psychology at the University of Galway, Ireland, presented **"Well-being and Prader-Willi Syndrome"**

This presentation addressed:

- The various concepts intertwined with the idea of 'well-being';
- The different domains within which a person's well-being can be considered;
- The specific challenges presented by PWS with respect to these domains of well-being;
- Well-being as more than 'the absence of mental ill-health'

Marco O. Bertelli, MD, Scientific Director of the Research and Clinical Centre (CREA) of Fondazione San Sebastiano, Misericordia di Firenze, Florence, Italy, presented **"Relating Quality of Life measurement to the lived experience of persons with PWS and their families"**

The presentation included:

- Quality of life outcome measures using the scores derived from quality of life indicators to assess ongoing and lasting changes to the "goodness" of people's lives;

- There is no absolute method to measure quality of life and different approaches to measuring quality of life as an outcome may be taken according to the purpose of applying the measure;
- Different approaches to QoL conceptualization and measurement can be grouped into two: those based on shared aspects and those based on personal aspects;
- Whatever measure is used, it is best to interpret the results through the lens of the lived experience of individuals and families.

Sabika Shaban, who lives in Qatar and is a parent of two beautiful neurodiverse children and the founder of the Qatar Disability Resource (QADR), presented the **Challenge of service responses which don't always incorporate the wider picture.**

Her talk covered:

- Obstacles in Integration into mainstream
- Support through different life phases
- Diagnosing root causes of behavioural challenges
- Connecting behaviour challenges to the individual's experience as a whole (accounting for lived experiences at school, home, and other spaces)

Reflections on all 3 presentations can be heard in the video summary linked below.

Video links

Tony Holland: [Introduction to the IPWSO Mental Health ECHO Programme](#)

Brian Hughes: [Well-being and Prader-Willi Syndrome](#)

Marco Bertelli: [Relating Quality of Life measurement to the lived experience of persons with PWS and their families](#)

Tony Holland: [IPWSO Mental Health ECHO Summary March 28, 2023](#)

Upcoming Mental Health ECHO sessions

April 25	Atypical brain development, cognitive impairment, and hypothalamic dysfunction Challenge: Cognitive development research in PWS	Deepan Singh, Vice Chair, Ambulatory Psychiatry Services, Maimonides Medical Center, USA Elizabeth Roof, Senior Research Specialist, Vanderbilt University, USA
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 behaviours in people with PWS	Norbert Hödebeck-Stuntebeck, PhD, Psychologist, PWS-InterNational, Germany
		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 25 April.

Ends.