



## FAMCARE Information Session: Managing Challenging Behaviour

**Saturday 22<sup>nd</sup> April, 2023**

**09:00 London, UK time**

09:00	Welcome: by <b>Verena Wanker-Gutmann</b> , PWS Austria, Chair, IPWSO Famcare Board, Austria
	Moderator <b>Georgina Loughnan</b> , physiotherapist/healthy lifestyle clinician, Metabolism & Obesity Services, Royal Prince Alfred Hospital, Sydney, Australia

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### ***Listening up - what a PWS behavioural challenge could be.***

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**09:05 Susanne Blichfeldt, MD.**

Susanne is a paediatrician with many years' experience of diagnoses, clinical treatment, education and advising families and professionals about PWS in Denmark and abroad. She has undertaken research about growth hormone treatment in PWS and has published widely. She is co- founder of the PWS Danish Association, and leader of the Advisory Board in the Association. She has been involved with IPWSO since 1991, and is currently a member of the IPWSO Clinical and Scientific Advisory Board and the of the IPWSO Famcare group. Susanne is married with children and grandchildren and has a son who is 43 years-old, living with PWS.

Susanne will be presenting on ***Behavioural challenges in young children***

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**09:20 Tony Holland**

Tony Holland is President of IPWSO, and Emeritus Professor of Psychiatry at the University of Cambridge, UK. In 2002 was awarded the Health Foundation Chair in Learning (Intellectual) Disability establishing the Cambridge Intellectual and Developmental Disabilities Research Group. His specific research interests include the eating, behavioural and mental health problems associated with having Prader Willi Syndrome; the relationship between Down's syndrome and Alzheimer's disease, and also clinical/legal issues relevant to the needs of people with intellectual disabilities.

Tony will be presenting on ***Behavioural challenges in older children and adults***

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09:35	Discussion and Q&A
<b><i>Preventing Challenging Family Life.</i></b>	
09:50	<b>Yvonne Rochford</b> <p>Yvonne is based in Donegal, Ireland, and has an honours degree in Management and Business Studies from The Queen's University, Belfast. Yvonne has worked in operations on a national level for almost 10 years. Her most recent role has provided consultancy to both public and private sector businesses. Yvonne joined the board of PWSAI in 2020, and the Famcare board of IPWSO in 2022. She has two children, and her daughter was born with PWS in 2019.</p>
10:05	<b>Karin Clarke</b> <p>Karin graduated with a bachelor's degree in economics and psychology from the University of Cape Town (UCT). She worked in marketing research, at Kantar TNS until her daughter with PWS was 2 years old. When her daughter was diagnosed with PWS at the age of four she joined the local SA PWS association. She started the Facebook page in 2015 and became increasingly involved. In 2017 the association had a structural change and she became the chairperson of a support group under the umbrella of Rare Diseases SA (RDSA). She works with RDSA as a Rare Ambassador for PWS as there is poor support for all Rare Diseases in South Africa and by working together a louder voice can be achieved. Karin also became a Trustee of IPWSO in 2022.</p>
10:20	Discussion and Q&A
10:30	Close