

# United in Hope: PWS 2025 – Clinical and Scientific Conference

## Keynote Speaker

### **Anthony J Holland, MD**

President, International Prader-Willi Syndrome Organisation

Past Health Foundation Chair in Learning Disabilities in the Department of Psychiatry

Professor Emeritus, University of Cambridge, Cambridge, UK

**Background:** Tony Holland trained in medicine at University College and University College Hospital, London, qualifying in 1973. After some years in General Medicine, he trained in Psychiatry at the Maudsley Hospital and Institute of Psychiatry in London. From 1992 to 2002 he held a university lecturer's post in the Section of Developmental Psychiatry at the University of Cambridge, and in 2002 was awarded the Health Foundation Chair in Learning (Intellectual) Disability establishing the Cambridge Intellectual and Developmental Disabilities Research Group ([www.CIDDRG.org.uk](http://www.CIDDRG.org.uk)). His specific research interests include the eating, behavioural and mental health problems associated with Prader-Willi syndrome (PWS). With colleagues he has published research extensively on these topics in academic and practice-based journals. He is Patron of the UK PW|S Association and since 2016 he has been President of IPWSO. Since October 2015 he has held an Emeritus position at the University of Cambridge.

**Title of Presentation: Maintaining well-being, improving mental health, and managing challenging behaviours: outcomes from the IPWSO Mental Health Initiative.**

**Abstract:** IPWSO's vision is to achieve a world where people with PWS and their families receive the services and the support they need to fulfil their potential and achieve their goals. In recognition of the impact of what has become known as the 'neuropsychiatric phenotype' of PWS on the lives of people with PWS and their families, IPWSO established an international and multi-disciplinary group to develop a consensus document to address these issues. The discussions that followed led to expanding the work of the group beyond what was seen as a narrow concept of mental health to include personal well-being and quality of life. This talk will reflect on the outcomes of these deliberations and consider our present understanding of the PWS neuropsychiatric phenotype and how the needs of children and adults with PWS and their families extends beyond that provided by health services. There is the need for effective health care, informed support, and meaningful opportunities to optimise personal well-being and quality of life.