

**11<sup>th</sup> International Prader-Willi Syndrome Conference 2022**  
**INTERDISCIPLINARY CONFERENCE PROGRAMME**  
**Saturday 9 July 2022, University of Limerick, Ireland**



**An interdisciplinary approach to the treatment, education and support  
of children and adults with Prader-Willi syndrome**

*An interactive, educational meeting supporting competency development and knowledge sharing  
as part of the wider 11<sup>th</sup> International Prader-Willi Syndrome Organisation Conference*

This programme is for teachers, clinical and educational psychologists, doctors, mental health professionals, nurses, social workers, early educators, paediatric dentists and other professionals and clinicians interested in the holistic treatment and support of people with Prader-Willi syndrome.

Jonathan Swift Theatre – Main Building		Session Chairs - Jane Cox and Tony Holland
09:15-09:20	<b>Welcome Address:</b> Jane Cox, PWSAI	
09:20-09:45	<b>Changing perspectives on the support of people with PWS</b> Norbert Hödebeck-Stuntebeck, PhD, PWS-InterNational, Germany	
09:45-10:15	<b>An overview of the clinical characteristics, health problems and genetics of PWS</b> Jennifer Miller, Paediatric Endocrinologist, University of Florida, USA	
10:15-10:45	<b>Why people with PWS over-eat: causes, consequences, and management</b> Tony Goldstone, Consultant Endocrinologist, Imperial College, London, UK	
10:45-11:15	<b>Making sense of mental health and challenging behaviours</b> Janice Forster, Developmental Neuropsychiatrist, Pittsburgh Partnership, USA	
11:15-11:45	Refreshments	
Parallel Presentation A – Johnathan Swift Theatre – Main Building Session Chair – Tony Holland		Parallel Presentation B – C1060 Session Chair – Jane Cox
11:45-12:15	<b>Monitoring and treating diverse physical health needs with particular reference to hormone deficiencies</b> Charlotte Höybye, Endocrinologist, Karolinska University Hospital and Karolinska Institute, Sweden	<b>The Rest of PWS: The Impact of Learning Difficulties on Behaviour</b> Linda Gourash, Paediatrician, Pittsburgh Partnership, USA

### Interdisciplinary Workshop 1

	Parallel Workshop A – Jonathan Swift	Parallel Workshop B – C1060	Parallel Workshop C – C1061
12:15-13:00	<b>A Good Start: supporting children and families in the early years</b> Edna Roche, Paediatric Endocrinologist, Trinity College Dublin and Rory Tierney, Parent	<b>The Complexity of Need: supporting older teenagers and adults</b> Susanne Blichfeldt, Paediatrician, The Danish Prader-Willi Association and the Centre for Rare Diseases, Denmark and Jackie Gill, Parent	<b>School Matters: supporting the pupil with PWS in the school environment</b> Elizabeth Roof, Dept of Psychology, Vanderbilt University, Tennessee, USA and Emma Walsh-Tierney, Parent
13:00-14:00	Lunch		

### Interdisciplinary Workshop 2

	Parallel Workshop A – Jonathan Swift	Parallel Workshop B – C1060	Parallel Workshop C – C1061
14:00-14:45	<b>'The right diet and exercise to the right person at the right time': what do we need to consider in PWS?</b> Christina Meade, Senior Paediatric Dietician, TUH, and Ann O'Neill, Parent	<b>Maintaining good mental health and wellbeing, and detecting and treating mental illness, including differences between genetic subtypes of PWS</b> Max Deest, Dept of Psychiatry, Hannover Medical School, Germany and William Noone, MHID Clinical Nurse Manager, HSE, Ireland	<b>Pedagogical Matters: Responding to learning strengths and needs in PWS</b> Larry Genstil, Sha'are Zedek Medical Centre, Israel and Jane Cox, St Catherine's Special School and Parent

### Interdisciplinary Workshop 3

	Parallel Workshop A – Jonathan Swift	Parallel Workshop B – C1060	Parallel Workshop C – C1061
15:00-15:45	<b>Food security and problem behaviours: balancing choice and control and what are the options if it all goes wrong?</b> Tony Holland, Psychiatrist, University of Cambridge & Marguerite Hughes, CEO IPWSO, and Parent	<b>Orthopedics: what's the difference in PWS and what should be monitored and when to intervene?</b> Harold van Bosse, Orthopaedic Surgeon & Member of the Clinical and Scientific Advisory Board, IPWSO	<b>Supporting safe and successful participation in employment, further education, and lifelong learning.</b> Simon Harris, Minister for Further and Higher Education, Ireland (video link), Lynn Garrick, Programme Director, AME Community Services, Minnesota, USA, and Donnchadh Clancy, Principal, Inchicore College of FE and Parent

15:45-16:00 Refreshments

16:00-16:40 **The Way Ahead: rethinking the system to reflect the need – panel and Q&A**  
 Susanne Blichfeldt, Jane Cox, Tony Holland, Norbert Hödebeck-Stuntebeck, Marguerite Hughes and Mac MacLachlan

16:40-16:45 **Close and Thank You**, Tony Holland

16:45-17:30 **Drinks Reception sponsored by PWSAI**

The structure of the workshops will include very brief presentations from the facilitators (usually a parent and a professional) to set the scene followed by discussion and debate. We encourage you to reflect on your own experiences in whichever country you live and work and be prepared to share your thoughts and ideas. This is an opportunity to both inform others and be informed.

Please note: The Conference Planning Committee reserve the right to amend the content and timings of the programme, if deemed necessary.

## **NOTES**