

# 11<sup>th</sup> INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION CONFERENCE

## Key Messages



**11<sup>TH</sup> INTERNATIONAL  
PRADER-WILLI SYNDROME  
ORGANISATION CONFERENCE**

**6 - 10 July 2022**

**UNIVERSITY OF LIMERICK, IRELAND**



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## **WHAT IS IPWSO 2022?**

Our 11<sup>th</sup> International Prader-Willi Syndrome Organisation Conference is a unique event that, once every 3 years, brings together people from all over the world and from many different backgrounds, to share knowledge, understanding and information about Prader-Willi Syndrome (PWS).

In 2022 our International Conference will be held at the University of Limerick, Limerick City, Ireland from 6 – 10 July 2022 and IPWSO and the Prader-Willi Syndrome Association of Ireland (PWSAI) have pleasure in inviting you to join us.

## **We're all in this together!**

Our rallying call reflects this special gathering of clinicians, researchers, scientists, professional providers and caregivers, parents, adults, and children with PWS, health and allied professionals – dietitians, physiotherapists, psychiatrists, nurses, mental health professionals, clinical and educational psychologists, occupational therapists, social workers, speech therapists, doctors, and the educational sector – everyone who has a desire to support and improve the lives of all those affected by the syndrome.

It is now time for the global PWS community to come together, to reconnect – it is time to share knowledge and understanding, share research and expertise. It is time to give, and receive support, meet old friends and colleagues, and make new and meaningful connections – and have some fun too!

We're all in this together and it is time to get together in Ireland!

# Can you help us spread the news?

## Key Messages:

- **Our rallying call: “We’re all in this together!”**

It is now time for the global PWS community to reconnect, time to share knowledge and understanding, share research and expertise – trusted information. It is time to give, and receive support, meet old friends and colleagues, make new and meaningful connections, and have some fun too! We’re all in this together and it is time to get together in Ireland, where a “Céad Míle Fáilte” – a hundred thousand warm Irish welcomes - awaits you! Register Now!”

- This is a unique event for sharing information about PWS.
- This conference brings together people living with PWS together with experts on the syndrome – clinicians, scientists, researchers, families, professional caregivers, and allied professionals – a unique gathering of all those affected by PWS and those interested in improving the lives of people with the syndrome.
- This will be the first IPWSO conference to take place in Europe since 2013 and our members have chosen Ireland as the venue.
- We have a stellar line up of speakers across all programmes.
- If you are a scientist, researcher, clinician, professional caregiver, a person with PWS, a parent or family member, involved in a PWS Association, this conference will be of interest to you.
- This is an International Conference. By coming together and collaborating, we grow and strengthen the global PWS community. Together we help to reduce inequality by raising

awareness of PWS and setting standards of good practice.

- Ireland is ready to receive and welcome delegates when it is safe to do so.
- **Specific to SUAS:** “SUAS” means “UP” in Irish, and this is a call to step UP - discuss challenges that affect you! What do you want for your future? It’s a chance to meet old friends and meet new people too and have lots of fun!
- **Specific to Interdisciplinary Programme:** Be part of this interactive educational meeting designed to bring together professionals who support adults and children with PWS, but who would not normally have such a unique opportunity to meet and consider the syndrome in a holistic manner. This Conference will be of interest to all those involved in primary, post primary and further education, clinical and educational psychologists, doctors, mental health professionals, nurses, social workers, dieticians, dentists, occupational therapists, speech therapists and physiotherapists – all the allied professionals in health and education who treat and support people living with PWS.
- **Specific to Parents Programme:** Increase your knowledge and understanding of the syndrome; share your experiences; it is a time to reflect; a time to develop new strategies and coping methods; a time to receive support and in return give support by sharing your experiences; a time to reconnect with old friends and meet new families. The conference will help you, your loved one with PWS, your family and other families in your country.
- **Specific to Clinical and Scientific Programme:** (and targeting PhD student audience) Share your expertise; learn about and help advance the research into this rare disorder; refine your

ideas and get feedback on your work; discuss advancing medical technologies; make meaningful connections, be inspired; re-invigorate your practice and get to know others in your field. By collaborating we can help reduce inequality and set standards of good practice.

- **Specific to Professional Providers and Caregivers:** this is a unique opportunity for professional caregivers from across the globe to meet and discuss how best to support people living with PWS. Meet likeminded people, compare models of support, explore best practice, learn from trusted sources about the syndrome - how it affects people with PWS - how best to support the wellbeing of people with PWS. Learn about person-centred planning, independent living, alternative housing, emerging technologies, and smart homes.

# Text for emails

## 1) Clinical and Scientific Conference

Subject: The 11<sup>th</sup> International Prader-Willi Syndrome Conference  
Clinical and Scientific Conference – 7 & 8 July 2022

Dear Friends and Colleagues

Please spread the word! The IPWSO 2022 Clinical and Scientific Conference is now calling for abstracts for presentations to be submitted for the Conference on 7 and 8 July 2022 at the University of Limerick, Limerick City, Ireland.

The Clinical and Scientific Conference aims to include reports of advances in clinical research in the basic and behavioural sciences and in neurosciences with the aim of advancing our knowledge of Prader-Willi syndrome (PWS) and thereby improving our understanding and developing new treatments for people with PWS. The Conference includes invited speakers from relevant fields of science outside of PWS and is truly interdisciplinary in nature. Guidelines and details about submitting your abstract can be found [here](#). The closing date is **5 February 2022**.

Desired topics include, but are not limited to:

### **1. Genetics and Epigenetics**

Examples include:

- Advances in Genetics in PWS
- Epigenetics: influences on brain development and behaviour

### **2. Endocrinology (Growth Hormone, Oxytocin, Ghrelin, etc.)**

Examples include:

- Hormonal studies
- Hypogonadism
- Recent advances in Endocrinology in Adults with PWS

### **3. Gastrointestinal Issues and Nutrition**

Examples include:

- Comprehensive Overview of Digestive Issues in PWS
- Chewing, swallowing, reflux, and aspiration

### **4. Neuroscience, Mental Health and Behaviour**

Examples include:

- Brain structure and function in people with PWS
- Approaches to understanding mental health and behaviour (the IPWSO Mental Health Initiative)
- New findings and treatment approaches to hyperphagia and behaviour

### **5. Recent Advances and New Knowledge in Medical Issues (including Orthopaedics, Urinary Tract etc.)**

Examples include:

- Overview and Evaluation: Infants, Children, Adolescents and Adults with PWS
- The Orthopaedics of PWS

### **6. Animal Models & Use of Induced Pluripotent Stem Cells in PWS**

Examples include:

- Insights into mood and psychosis in PWS
- The hypothalamus and its connections

### **7. Clinical Trials for Hyperphagia and Behaviour**

### **8. The early PWS phenotype**

Examples include:

- Fetal and placenta development
- Infancy

### **9. Transition to Adulthood**

Examples include:

- Hormone replacement therapy



Visit the [IPWSO 2022](#) website for further information about the full Conference Programme, our Keynote Speakers, Online Registration, Accommodation and booking your travel.

It is now time for the global PWS community to come together, to reconnect – it is time to share knowledge and understanding, share research and expertise. We're all in this together and it is time to get together in Ireland! We look forward to meeting you there.

## 2) Professional Providers and Caregivers Conference

Subject: The 11<sup>th</sup> International Prader-Willi Syndrome Conference  
Professional Providers and Caregivers Conference – 7 & 8 July 2022

Dear Friends and Colleagues

Please spread the word! The IPWSO 2022 Professional Providers and Caregivers Conference is now calling for abstracts for presentations to be submitted for the Conference on 7 and 8 July 2022 at the University of Limerick, Limerick City, Ireland.

If you are involved in the professional work of caring for children, young people, adults, and aging adults with Prader-Willi syndrome, please share your vision, successes, challenges, and experiences at this Conference.

Guidelines and details about submitting your abstract can be found [here](#). The closing date is **5 February 2022**.

Desired topics include, but are not limited to:

### **Behaviour:**

Behaviour plays a central role in the social context. In people with Prader-Willi syndrome, unexpected behaviours are often a major challenge for parents and professional caregivers. How can we respond to these unexpected and challenging behaviours so that people with Prader-Willi syndrome can learn to control their behaviour, so they are best equipped to participate in their social environment?

For this, it is necessary to identify the motivation underlying the individual behaviour and which models and methods are suitable and have been proven to support this goal. One key to success lies in the intensive collaboration among the various disciplines such as pedagogues, social workers, educators, psychologists, psychiatrists, doctors, endocrinologists, geneticists and researchers on Prader-Willi syndrome, other therapists and last but not least, the parents.

Suggested topics include what approaches and procedures have proven themselves in practice, the contributions of the various disciplines and what should be the focus for further work.

**Restrictive Practices: the ways in which restrictive practices relate to the professional care of people with PWS.**

Suggested topics include case studies, proposed models of restrictive practice for people with PWS, or academic research into restrictive practices used to manage PWS.

**Social Media**

Social media has become an important part of daily life. Through social media individuals can stay connected to their community, friends, and family. There is also an increased risk for abuse and exploitation. Education for those with PWS and their caregivers can help to minimize the risk and allow for safe and enjoyable participation in social media.

**Wellbeing**

What we think of as wellbeing in the general population can look very different for people with PWS. The environment might include accepted restrictions for the individual's health and safety which will help them to flourish. Allowing for individual choice, providing social opportunities, and recognising the particular strengths of people with PWS and the positive nature of what they contribute, can help to ensure personal wellbeing.

Visit the [IPWSO 2022](#) website for further information about the full Conference Programme, Online Registration, Accommodation and booking your travel.

It is now time for the global PWS community to come together, to reconnect – it is time to share knowledge and understanding, share expertise about how best to support people living with PWS. We're all in this together and it is time to get together in Ireland! We look forward to meeting you there.

### 3) **General – IPWSO Members**

Dear Member

Subject: The 11<sup>th</sup> International Prader-Willi Syndrome Conference  
6-10 July 2022

Please spread the word!

The 11<sup>th</sup> International Prader-Willi Syndrome Organisation Conference is a unique event that, once every 3 years, brings together people from all over the world and from many different backgrounds, to share knowledge, understanding and information about Prader-Willi Syndrome (PWS).

In 2022 the International Conference will be held at the University of Limerick, Limerick City, Ireland from 6 – 10 July 2022 and IPWSO and the Prader-Willi Syndrome Association of Ireland (PWSA) have pleasure in extending an invitation to you. On their behalf (insert your Association name) encourages you to circulate this information to the families and professionals with whom you are in contact.

Full details about IPWSO 2022 – the exciting programmes for the Clinical and Scientific community, for Parents, for Professional Providers and Caregivers, for people living with PWS – adults and children - and for the latest addition to the Conference, the Interdisciplinary Programme for educationalists and health and allied professionals, visit the [IPWSO 2022](#) website. Here you can also find details about social events, travelling to Ireland, accommodation and about how the organisers are working to deliver a safe Conference against the background of the pandemic.

## **Key Dates**

Online registration is now open! The Early Bird Rate closes on **7 April 2022**.

The closing dates for abstracts for the Clinical and Scientific Conference and the Professional Providers and Caregivers Conference is **5 February 2022**.

If you would like to show your support for IPWSO 2022 visit the IPWSO website for some inspiration ideas to spread the word to the wider PWS community.

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We're all in this together and it is time to get together in Ireland!

We look forward to seeing you there.

#### 4) **Parents**

Dear Parents

Subject: The 11<sup>th</sup> International Prader-Willi Syndrome Conference –  
Parents Conference 9 & 10 July 2022

Please spread the word!

The 11<sup>th</sup> International Prader-Willi Syndrome Organisation Conference is a unique event that, once every 3 years, brings together people from all over the world and from many different backgrounds, to share knowledge, understanding and information about Prader-Willi Syndrome (PWS).

In 2022 the International Conference will be held at the University of Limerick, Limerick City, Ireland from 6 – 10 July 2022 and IPWSO and the Prader-Willi Syndrome Association of Ireland (PWSA) have pleasure in extending an invitation to you. On their behalf (insert your Association name) encourages you to circulate this information to the families and professionals with whom you are in contact.

The Parents Conference will increase your knowledge and understanding of the syndrome. It is a time to reflect, a time to develop new strategies and coping methods and a time to receive support and in return give support by sharing your experiences. It is a time to reconnect with old friends and meet new families. The conference will help you, your loved one with PWS, your family and other families in your country.

The [IPWSO 2022](#) website provides more information about the various programmes including SUAS – the Stepping UP Adult Symposium, for people living with PWS, and the programme for Children, the online registration process, travel, accommodation and social events, as well as the content of the Parent's Conference, which will include the following themes:-

- current knowledge and research
- the genetics of PWS
- supporting children and families in the early years
- supporting the child in the school environment
- supporting teenagers and adults
- food security and problem behaviours
- orthopaedics – typical treatments and what needs to be monitored
- sleep patterns and disorders
- keeping children, teenagers, and adults healthy: nutrition and physical activity
- behavioural challenges
- mental health and illness
- growth hormone treatment and other hormone deficiencies
- health and medical issues: gastro-intestinal problems, obesity management, oedema, oral health, and orthodontics
- Body functions – stimulation, sensory integration, hygiene, and body perception
- Autism and ADHD and other related symptoms of PWS
- Multidisciplinary teams and good practice in integrating health and social care.

There is a stellar up of speakers with plenty of opportunities for discussion and debate.

We look forward to this exciting Conference and hope to see you there!

#### 4) **Interdisciplinary Conference**

Dear (Insert Specialism)

Subject: The 11<sup>th</sup> International Prader-Willi Syndrome Conference – Interdisciplinary Conference – 9 July 2022

Please spread the word!

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In 2022 the International Conference will be held at the University of Limerick, Limerick City, Ireland from 6 – 10 July 2022 and IPWSO and the Prader-Willi Syndrome Association of Ireland (PWSA) have pleasure in extending an invitation to you.

Be part of this interactive one-day educational meeting designed to bring together professionals who support adults and children with PWS, but who would not normally have such a unique opportunity to meet and consider the syndrome in a holistic manner.

This Conference will be of interest to all those involved in primary, post primary and further education, clinical and educational psychologists, doctors, mental health professionals, nurses, social workers, dieticians, dentists, occupational therapists, speech therapists and physiotherapists – all the allied professionals in health and education who treat and support people living with PWS.

The Conference themes will explore:

- Changing perspectives on the support of people with PWS;
- Clinical characteristics health problems and the genetics of PWS;



- Why people with PWS overeat: causes, consequences, and management;
- Making sense of mental health and challenging behaviours;
- Monitoring and treating diverse physical health needs with particular reference to hormone deficiencies;
- Understanding how people with PWS learn;
- Supporting children and families in the early years;
- The complexity of need: supporting older teenagers and adults;
- School matters: supporting the pupil with PWS in the school environment;
- The right diet and exercise to the right person at the right time;
- Maintaining good mental health and wellbeing, and detecting and treating mental illness;
- Pedagogical matters: responding to learning strengths and needs in PWS;
- Food security and problem behaviours: balancing choice and control and what are the options if it all goes wrong?
- Orthopaedics: what's the difference in PWS and what should be monitored and when to intervene?
- Supporting safe and successful participation in employment, further education, and lifelong learning;
- The way ahead: rethinking the system to reflect the need.

Visit the [IPWSO 2022](#) website for further information about the full Conference Programme, Online Registration, Accommodation and booking your travel.

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## How to show your support for IPWSO 2002

Visit our website for some inspirational ideas to support IPWSO 2022.

## Thank you!

By coming together and collaborating, we grow and strengthen the global PWS community. We raise awareness of PWS, and we help set standards of good practice.

We're all in this together and together we can create better outcomes for all those living with and affected by PWS.

Thank you for all your support in spreading the word about IPWSO 2022!