



# IPWSO

International  
Prader-Willi Syndrome  
Organisation

## 30<sup>th</sup> Anniversary Workshop

Preparing for the next 30 years  
supporting people with PWS and their families



# Key dates

20 July

## Online registration opens

On this date expect an email with details on how to register for the online event.

You need to be registered for the event in advance in order to pre-view videos for the workshop sessions and to create your personal profile.

Detailed instructions will be sent via email in the weeks leading up to the event.

15 August

## Videos available to view

From this date all participants will have access to the videos created for the workshop.

Watch in your own time in the 2 weeks prior to the event.

29 August

## Workshop Day 1

Includes:

- Developments in the understanding of Prader-Willi syndrome over the last 30 years
- Global inequalities
- Emerging research and practice

**See the full agenda below**

30 August

## Workshop Day 2

Includes:

- Meeting needs and challenging global inequality
- Planning for the future
- Networking

**See the full agenda below**



# Agenda

Sunday 29 August, 3pm London, UK time

## Session 1: Setting the Scene **1 hour: 3pm - 4pm UK time**

To focus on:

- a) Developments in the understanding of PWS and developments in IPWSO over the past 30 years
- b) Global inequalities in knowledge, services and supports for people with PWS and their families

Discussion points:

1. What do you consider the most important advances in the last 30 years?
2. Are these advances universally available and, if not what can and should IPWSO and others do to help reduce these global inequalities?
3. Overall, what do you consider the top developments you would most like to see for people with PWS and their families globally in the next 30 years?

## Films to watch before the session:



1. How IPWSO Began
2. Prader-Willi Syndrome: Milestones from the last 30 Years
3. Raising a Child with Prader-Willi Syndrome

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**15-minute break: 4pm - 4:15pm UK time**

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## Session 2: Research Part A 1 hour: 4:15pm - 5:15pm UK time

To focus on:

Emerging research and gaps in research

Discussion points:

1. What do you consider the top priorities for research in the next 30 years?
2. What do you consider the top challenges for research?
3. Should IPWSO contribute to these research initiatives and if yes, how?

## Films to watch before the session:



4. Prader-Willi Syndrome Around the World
5. Learning from People with Prader-Willi Syndrome
6. Research Updates July 2021

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## 15-minute break: 5:15pm - 5:30pm UK time

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## Session 3: Research Part B 1 hour: 5:30pm - 6:30pm UK time

To focus on:

Emerging research and practice and challenges in the development of evidence-based practice

Discussion points:

1. What do you consider the top priorities in terms of developing and promoting evidence-based practice in the next 30 years?
2. What do you consider the top challenges in terms of developing and promoting evidence-based practice?
3. Should IPWSO contribute to developing and promoting evidence-based practice and if yes, how?

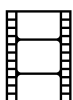
## Films to watch before the session:



7. Emerging Clinical Research and Practice in Prader-Willi Syndrome
8. Emerging Social Care Research and Practice in Prader-Willi Syndrome
9. Emerging Behaviour and Mental Health Research and Practice in Prader-Willi Syndrome

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## Workshop Day 1 ends 6:30pm UK time



Instructions on where to find and view all films will be sent via email on 15 August.



# Agenda

Monday 30 August, 3pm London, UK time

## **Session 4: Meeting Needs and Challenging Global Inequality 1 hour: 3pm - 4pm UK time**

To focus on:

The role of IPWSO, PWS Associations and advocacy in challenging national and global inequalities.

Discussion points:

1. What are our responsibilities to underserved families and communities within our own countries and around the world?
2. How should IPWSO fulfil its responsibilities towards underserved families and communities around the world?

## **Films to watch before the session:**



10. The Role of Prader-Willi Syndrome Associations
11. The Role of Advocacy in Helping People with Prader-Willi Syndrome and their Families

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## **15-minute break: 4pm - 4:15pm UK time**

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## **Session 5: Planning for the Future 90 minutes: 4:15pm - 5:45pm UK time**

To focus on:

Strengthening the Global PWS Community

Discussion points:

1. What do you consider the top strengths of the international PWS community?
2. What do you consider the top challenges facing the international PWS community in the next 30 years?
3. What part can we all play in helping improve the lives of people with PWS around the world?

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## **Session 6: Networking From 5:45pm UK time**

\*Following the workshop, we will share conclusions, once prepared, with all participants via email.

This event has been made possible by a grant from Novo Nordisk for the purpose of scientific exchange between patients, caregivers and Health Care Providers. The event may not involve promotion of any pharmaceutical product.



For almost 100 years, Novo Nordisk has been translating the unmet medical needs of people living with a serious chronic disease into innovative medicines and delivery systems, such as insulin pens. Novo Nordisk's treatments today are benefiting millions of people living with diabetes, obesity, and rare blood and endocrine diseases. Novo Nordisk prides itself on discovering and developing innovative biological medicines and making them accessible to patients throughout the world.