



# International Prader-Willi Syndrome Organisation

Programs, Supports, Community

5<sup>th</sup> Asia Pacific PWS Conference, October 2021

James O'Brien, Vice President

Registered as a charity in England and Wales

Charity number: 1182873

Declarations: Chair, Prader-Willi Syndrome Australia

Father to Ashley who lives with PWS

# Outline of talk

- IPWSO at 30
- IPWSO: global reach and core objectives
- Evolution of IPWSO as a global organisation
- Online resources
- Current and new Projects

# IPWSO at 30

- **1991 1<sup>st</sup> International Conference in the Netherlands with support from NATO**
  - Suzie Cassidy
  - Jean-Phillips-Martinsson
- **IPWSO conferences**
  - Oslo, Norway, 1995
  - Lido de Jesolo, Italy, 1998
  - Minnesota, USA, 2001
  - Christchurch, New Zealand, 2004
  - Cluj-Napoca, Romania, 2007
  - Taipei, Taiwan, 2010
  - Cambridge, UK, 2013
  - Toronto, Canada, 2016
  - Havana, Cuba, 2019
- **11<sup>th</sup> Conference, Limerick, Republic of Ireland, 2022**

## Presidents

- 1991 Jean Phillips-Martinsson
- 1998 Giorgio Fornasier
- 2004 Pam Eisen
- 2010 Suzie Cassidy
- 2016 Tony Holland

## Important dates

- 1992 IPWSO's newsletter 'Wavelength' first published – Linda Thornton
- 1996 creation of IPWSO's first website
- 1998 IPWSO's first logo – Tiina Silvast
- 2018 Friends of IPWSO (USA) established – Joan Gardner, Suzie Cassidy
- 2019 IPWSO registered as a Charity
- 2020 Marguerite Hughes appointed CEO
- 2020 Launch of Project ECHO

# 11th International Conference

## We're all in this together

- University of Limerick
- Limerick, Ireland
- 6-10<sup>th</sup> July 2022
- <https://ipwso.org/news-events/conference-2022/>



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



# Vision and Mission

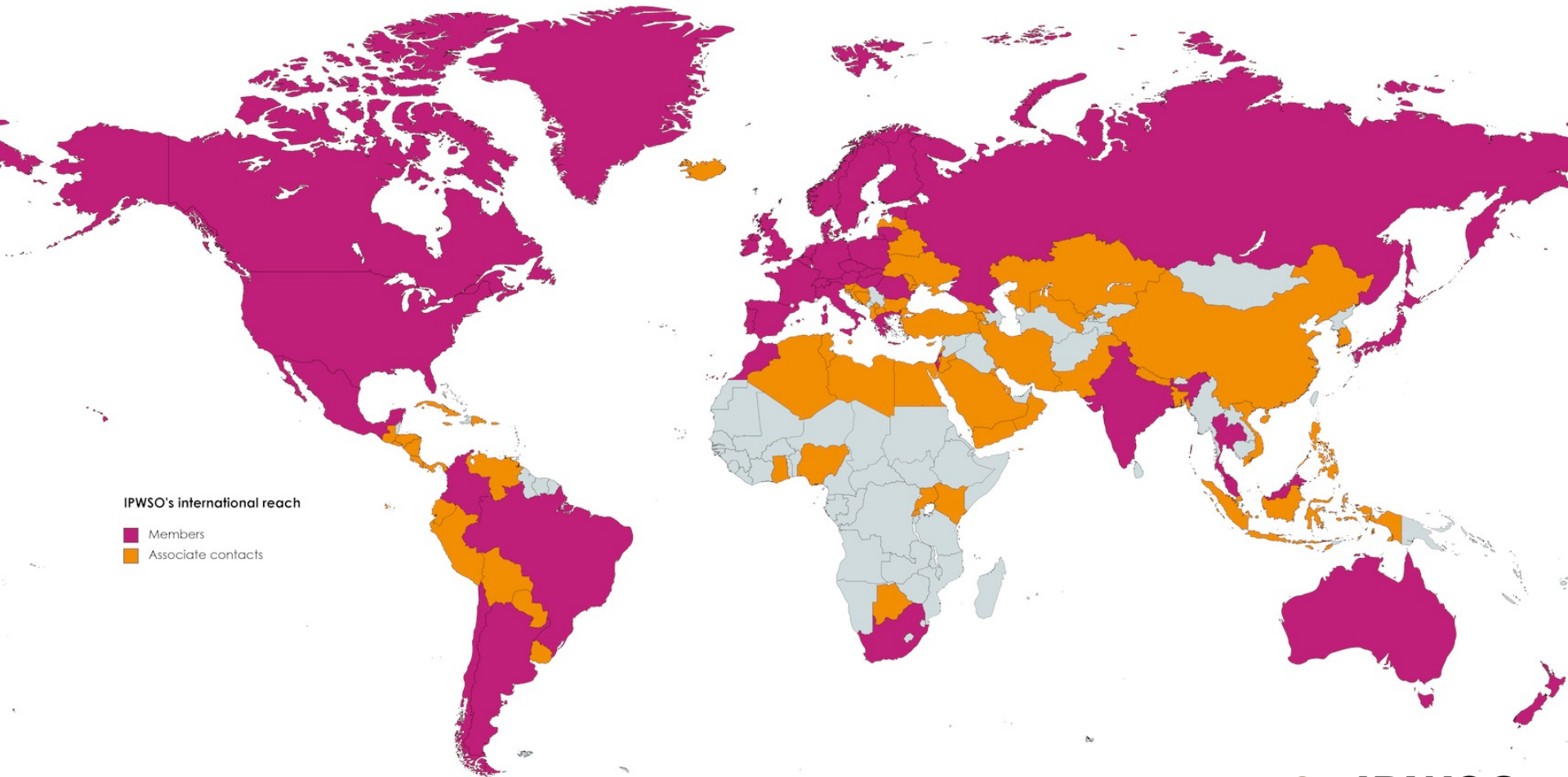
## VISION

- A world where people with PWS and their families receive the services and support they need to fulfill their potential and to achieve their goals.

## MISSION

- To unite the global PWS community to collectively find solutions to the challenges of the syndrome and to support and advocate for people with PWS and their families, PWS Associations, and professionals who work with people with PWS

40 full members  
Contacts in 100+ countries

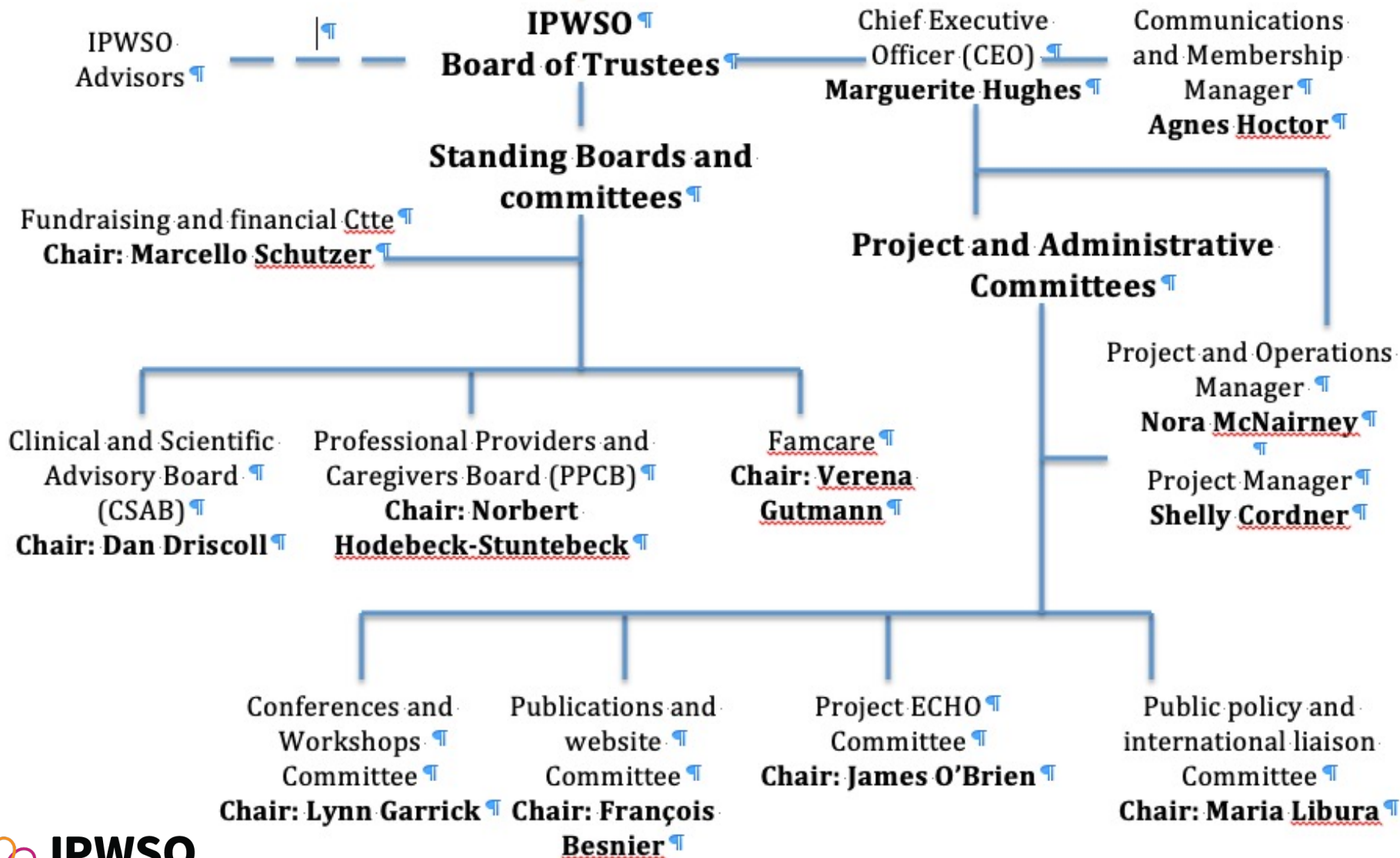


IPWSO's international reach

- Members
- Associate contacts

**Members and Associate Members of IPWSO**

**People with PWS as advisors to their National PWSA**



# Core tasks and activities

To **advocate** for our members, international and regional

- Rare Diseases international
- NORD, Eurordis
- WHO Universal Health Coverage initiative

To **support** people with PWS, families, professionals and care providers globally

- Diagnosis (access to genetic testing)
- Information (different languages and formats, website, social media)
- Support national groups to develop local services
- Promote PWS at clinical and academic conferences
- Workshops, international conferences (Cuba 2019, Ireland 2022)

Provide a **helpline** to families and professionals in countries with no PWS Associations



# Emerging roles

- Developing, supporting and maintaining **communities of good practice**
  - To reduce health inequalities (**Project ECHO**)
- To act as a catalyst for, and to **enable research**, including clinical trials, disseminate research findings globally to parents and professionals – research into practice
- Developing **social policies** specific to people with PWS - to be adapted according to local needs: e.g. ethics of food security, hyperphagia as a 'disability' etc
- **Special initiatives**: mental health network, evaluating PWS specific models of support etc
- Innovations in the delivery of health and social care globally
  - New genetic technologies
  - Telemedicine, telementoring
  - Remote monitoring
- Horizon scanning
  - New research in related fields (e.g. obesity, neuroscience)
  - Developments in communication technologies and in social media
  - Funding models and disability related policies
  - Translation technologies

# IPWSO Website

- Google Translate
  - Over 100 languages
  - Mistakes possible
- Famcare
  - 21 languages
  - Need your help

# ipwso.org

The screenshot shows the ipwso.org website with a language selection dropdown menu open. The website header includes the IPWSO logo (International Prader-Willi Syndrome Organisation), a 'Donate' button, and a 'Sign up to our newsletter' link. The navigation menu contains: PWS Information, How we can help, Get Involved, Membership, and About Us. The main content area features the headline 'Providing free PWS diagnosis to families who need it' and a sub-headline 'We provide free diagnostic testing to those who cannot access it in their own countries.' The language dropdown menu lists the following options: Afrikaans, Shqip, አማርኛ, العربية, Հայերեն, Azərbaycan dili, Euskara, Беларуская мова, বাংলা, Bosanski, Български, Català, Cebuano, Chichewa, 简体中文, 繁體中文, Corsu, Hrvatski, Čeština, Dansk, Nederlands, English, Esperanto, Eesti, Filipino, Suomi, and a downward arrow.

ipwso.org

**IPWSO**  
International Prader-Willi Syndrome Organisation

Donate

Sign up to our newsletter

PWS Information ▾ How we can help ▾ Get Involved ▾ Membership ▾ About Us ▾

**Providing free PWS diagnosis to families who need it**

We provide **free diagnostic testing** to those who cannot access it in their own countries.

Language Selection Menu:

- Select Language
- Afrikaans
- Shqip
- አማርኛ
- العربية
- Հայերեն
- Azərbaycan dili
- Euskara
- Беларуская мова
- বাংলা
- Bosanski
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- Hrvatski
- Čeština
- Dansk
- Nederlands
- English
- Esperanto
- Eesti
- Filipino
- Suomi
- ▾

Policy

Privacy - Terms



## What is PWS?

### Information for Families

New Parents

Siblings

Education and Transition

Diet and Nutrition

Behaviour and Mental Health

Physical Health and Exercise

Sexual Development

Adult Life

Famcare Board

### Information for Health Professionals

Guides for Doctors:  
Consensus Documents

Medical Alerts Booklet

Research Papers

Clinical Research

Common Medical Issues

Clinical and Scientific Advisory Board

### Information for Professional Caregivers

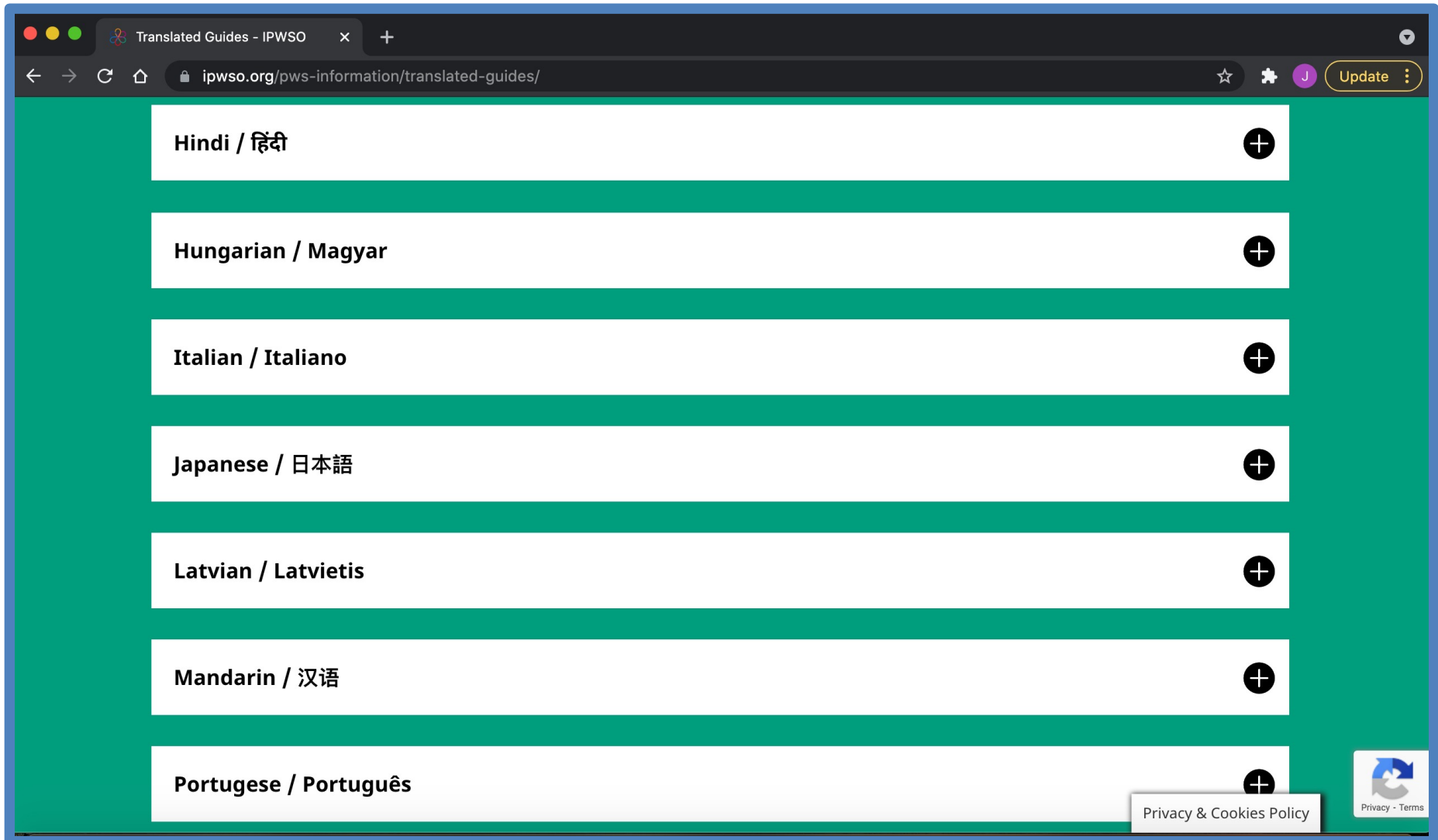
Caregiver Delegate Role

Best Practice Guidelines for Residential Care

Professional Providers and Caregivers Board

### Translated Guides

# ipwso.org



The screenshot shows a web browser window with the URL [ipwso.org/pws-information/translated-guides/](https://ipwso.org/pws-information/translated-guides/). The page features a green background with a list of language options, each in a white box with a plus icon on the right. The languages listed are Hindi / हिंदी, Hungarian / Magyar, Italian / Italiano, Japanese / 日本語, Latvian / Latvietis, Mandarin / 汉语, and Portugese / Português. At the bottom right, there is a 'Privacy & Cookies Policy' link and a 'Privacy - Terms' icon.

Hindi / हिंदी	+
Hungarian / Magyar	+
Italian / Italiano	+
Japanese / 日本語	+
Latvian / Latvietis	+
Mandarin / 汉语	+
Portugese / Português	+

# IPWSO ECHO<sup>®</sup> Projects

Supported by an educational grant from Pfizer

ECHO<sup>®</sup> Institute, University of New Mexico

Four principles

- **Amplification** –use technology to amplify knowledge
- Share **Best Practice** to reduce disparities
- **Case Based Learning** – to master complexity
- Web based **Database** – to Monitor Outcomes

**Uses zoom-based technology to ‘democratize knowledge’**

**Built around the concept of “All teach all learn”**

Four IPWSO ECHO<sup>®</sup> projects

- Leadership
- Health
- Latin American (in Spanish)
- Professional Care Providers

# IPWSO Leadership ECHO<sup>®</sup>

Supported by an educational grant from Pfizer

A screenshot of a Zoom meeting grid showing 20 participants in a 5x4 layout. The participants are: Marguerite Hughes, James O'Brien (with IPWSO and ECHO logos), Tony Holland, Dan Dorica, Georgian Apostol, Nora McNairney, Susanne Blichfeldt, Lynn Garrick, Jean Phillips-Martinez, sandradekeijzer, francoisbesnier, Ludmila / Czech R..., Tünde Liplin, Fernando Blázquez, karin, Verena gutmann, Cornelia Anzengruber, Lantz Yap Malaysia, andreina comoretto, and Susan Pwsa (with PWSA logos). The meeting interface includes a 'Recording' indicator, a 'View' button, a volume slider on the left, and a control bar at the bottom with icons for Mute, Stop Video, Participants (28), Chat, Share Screen, Record, Reactions, and Leave.

# Examples of content

## Leadership ECHO®

1. Virtual clinics in the COVID era and beyond

Overview of ECHO

2. Clinical trials in PWS

GH for adults in Bulgaria

3. Food is a poisonous drug

Enabling the voices of people with PWS

## Health ECHO®

1. The diagnosis and genetics of PWS

Case study from Kenya

2. The care of the infant with PWS

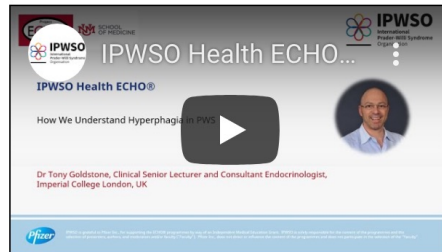
Supporting the needs of families

3. Making Sense of hyperphagia

Lessons from the Coroner's Court



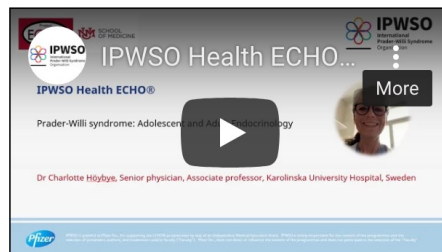
# IPWSO ECHO Resources



## **Dr Tony Goldstone, Clinical Senior Lecturer and Consultant Endocrinologist, Imperial College London, UK**

### **"How We Understand Hyperphagia in PWS"**

Presented at the IPWSO Health ECHO on May 18, 2021. In this session we gained an understanding of the nature of hyperphagia and overeating in PWS, the importance of control of the food environment in management of hyperphagia in PWS, and the current situation regarding potential new treatments for hyperphagia in PWS. The PDF of this PowerPoint is available [here](#). To read the Q&A following the session please refer to the abridged [abstract summary](#).



## **Dr Charlotte Höybye, Senior physician, Associate professor, Karolinska University Hospital, Sweden**

### **"Prader-Willi syndrome: Adolescent and Adult Endocrinology"**

Presented at the IPWSO Health ECHO on April 20, 2021. In this session we learned how PWS is associated with documented hormone deficiencies which should be monitored and treated when indicated, and that hormone therapy offers an opportunity to reduce some of the adverse consequences of PWS. Please note some pictures have been removed for privacy. The PDF of this PowerPoint is available [here](#). To read the Q&A following the session please refer to the abridged [abstract summary](#).

# Mental Health Initiative

## Terms of reference

- To report to the IPWSO Board and its membership on all matters relevant to our understanding of, and the assessment, treatment and prevention of mental ill-health in people with PWS, as broadly defined.
- To advise how IPWSO can best work with the research community to advance our knowledge and develop effective and safe interventions.

## WHO definition of mental health

(Galdeseri et al 2015 Towards a Definition of Mental Health. World Psychiatry DOI:10.1002/wps.20231)

Good mental health is **more than** ‘the absence of mental disorder’. It includes....

- A dynamic internal state or equilibrium
- The ability to maintain harmony in line with universal values
- The ability to recognise, express and modulate emotions
- The ability to cope with adverse events and function socially

# Mental Health Initiative

## Expert Group

- 58 participants from 22 countries representing
  - Different cultures and socio economic circumstances
- Expertise
  - Behaviour Specialists,
  - Developmental Paediatricians,
  - Endocrinologists,
  - Neuropaediatricians,
  - Parents,
  - PhD students,
  - Psychiatrists,
  - Psychologists,
  - Research Fellows,
  - Speech and Language Therapists.
- Scientists to attend w'shop in Ireland

# Mental Health Initiative

Three themes

1. Agree the **definition** of mental health and the terminology used to describe mental ill-health in people with PWS and the interrelationship with family health and wellbeing.
2. Identify possible **causative mechanisms** for mental ill-health and the interrelationship between the vulnerability of the individual and past and present environment
1. Establish best practice in the **assessment** of mental ill-health and its **prevention and treatment** in people with PWS and the promotion of wellbeing.

# Do PWS care environments make a difference?

Project led by Brian Hughes

- IPWSO receives requests from different countries to provide evidence
- Little published information on outcomes for different models of support but lots of anecdotal evidence
- Limited potential for commercial funding unlike medication trials
- IPWSO's Professional Providers Caregivers Board (PPCB) access to organisations globally supporting people with PWS

# Social Care Initiative

## Participating services

- 3 large PWS specific services
  - All target variables
- 14 smaller PWS-specific services
  - Some target variables
- 10 non-PWS specific services
  - Basic variables (weight, medication use)

# Thank You

## IPWSO's strengths

- History
- Partnerships
- Global reach

## Funding

- Membership
- Friends of IPWSO
- Donations
- Jean Phillips-Martinsson
- Industry
- Foundations

## People

- Staff
- Trustees
- Advisors
- Members of committees
- Volunteers
- **You, the families and PWS community**

## Further Information

- [www.pwso.org](http://www.pwso.org)
- [james\\_Obrien@ipwso.org](mailto:james_Obrien@ipwso.org)



*Sipping Champagne Donated by the Spanish Embassy at Sormarka Conference Centre, Andreas Prader and JPM*

