OUR VISION

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

OUR 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.

CONTACT US

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Registered as a charity in England & Wales: 1182873

PLEASE SUPPORT OUR WORK

Our work is made possible through the generosity of donors.
Please consider making a contribution at www.ipwso.org/make-a-donation

OUR KEY PROJECTS

- We provide free genetic screening for PWS to families in countries where this is not available locally.
- We engage with international organisations to advocate on behalf of people with PWS at a global level.
- We facilitate a programme of online meetings for the PWS community to share practice-driven knowledge, information and support.
- We offer a free advice line for parents, families, associations, caregivers and healthcare professionals.
- We distribute information and resources in various languages.
- We conduct and support research.
- We provide grants for conferences and small projects that will benefit PWS communities at local and national levels.
- We hold international conferences every three years that bring together people with PWS, parents, professional caregivers, scientists, clinicians and allied health professionals.
- We engage in educational outreach activities to raise awareness of PWS within the medical profession, and we support the attendance of medical professionals from underserved communities at PWS conferences.

IPWSO
International Prader-Willi Syndrome Organisation

RAISING AWARENESS OF PRADER-WILLI SYNDROME AROUND THE WORLD

WHAT IS PRADER-WILLI SYNDROME (PWS)?

Prader-Willi syndrome is a complex and rare neurodevelopmental condition. Studies have shown that between 1 in 15,000 and 25,000 people are born with PWS and it affects all races and sexes equally.

WHAT CAUSES PWS?

PWS occurs when there is lack of expression of one or more genes in a specific region of chromosome 15.

SIGNS AND SYMPTOMS

- Low muscle tone and failure to thrive at birth
- Short stature, if not treated with Growth Hormone
- Learning disabilities
- Incomplete sexual development
- Behavioural and psychiatric challenges
- An excessive drive to eat (hyperphagia)

DIAGNOSIS

PWS is usually suspected on the basis of the clinical signs and symptoms and can be confirmed by genetic screening. IPWSO provides free genetic screening for PWS at the Baschirotto Institute for Rare Diseases in Italy for people living in countries where it is not available.

TREATMENT AND SUPPORT

There is no cure for PWS but a supportive and empathetic environment with tailored treatment and support can reduce many of the challenges.

- Early diagnosis and intervention
- Informed medical care and therapeutic services
- Growth hormone therapy, when available
- Lifetime weight control through a carefully monitored diet, environmental controls, and exercise
- Informed behavioural support
- Educational provision that takes account of the person's individual needs

THE FUTURE

With well-informed care, treatment and support, people with PWS can live long, full and happy lives. However, access to diagnosis, information, care and support varies hugely around the world. We are working to reduce these inequalities and to support people with PWS and their families whatever their needs and wherever they live.

ABOUT IPWSO

We are an international, parent-led, non-profit membership organisation supporting national PWS associations, as well as people with PWS, their families and the professionals who work with them.

Founded in 1991, we provide information and support and share best practice around the world.