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 every 15,000 and 1 in every 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 testing. IPWSO provides free genetic testing for PWS at the Baschirotto Institute for Rare Diseases in Italy for people living in countries where it is not available.

CARE AND TREATMENT

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

- Early diagnosis and intervention.
- Monitoring of scoliosis.
- Lifetime weight control through a strictly monitored diet, environmental controls (limiting access to food), and exercise.
- Growth Hormone replacement therapy, when available.
- Informed management of behaviour.
- 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.

OUR KEY PROJECTS

- We provide free diagnostic testing for PWS for 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 provide online telementoring programmes via Zoom based on the Project ECHO® format.
- We run a free advice line for parents, families, associations, caregivers and professionals.
- We provide information and resources in different languages.
- We conduct research and also support and commission others to undertake research to benefit people with PWS.
- We fund workshops and award grants to improve access to key conferences and events.
- We hold international conferences every three years that bring together people with PWS, parents, professional caregivers, scientists, clinicians and allied health professionals.

PLEASE SUPPORT OUR WORK

We rely on the generous support of our donors to achieve our work. Please consider donating at www.ipwso.org/make-a-donation

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

office@ipwso.org
www.ipwso.org

Registered as a charity in England & Wales: 1182873