

STRATEGIC PLAN

2024-2026



IPWSO

International
Prader-Willi Syndrome
Organisation

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BACKGROUND AND CONTEXT

IPWSO was established in 1991. Since then, we have supported and connected national PWS associations, as well as people with PWS, their families and the professionals who work with them.

Forty-six national PWS associations make up our current membership and we support individuals in over seventy other countries. While we are proud of our heritage and recognise that some people with PWS now achieve far better outcomes than were believed possible in the past, we are acutely aware that people with PWS and their families continue to face serious challenges, particularly in countries where knowledge is limited and treatments, services and support are difficult to access.

We believe that timely and consistent access to reliable information, as well as early diagnosis, informed medical care and therapeutic services, and access to social care and support are all necessary to enable people with PWS and their families to achieve the best possible outcomes.

In some countries, early diagnosis and good health have become common and a generation of adults with PWS is emerging for whom new models of care and support may be needed. In other countries, early diagnosis remains rare and life-threatening levels of obesity are routinely observed.



We operate in a challenging environment. Despite the outstanding commitment of our volunteers, it is difficult to raise adequate funds to meet the needs of our community.

The heterogeneity of people with PWS, the diversity of opportunities available to them and their families, cultural differences around the world, and the environmental crisis all strain our limited resources and force us to prioritise key objectives.

This plan was created following extensive engagement with IPWSO stakeholders worldwide. It sets out our commitment, over the next three years, to work for a world where all people with PWS and their families receive the services and support they need to fulfil their potential and achieve their goals. It also expresses the core values that bring us together as IPWSO and inspire our work.

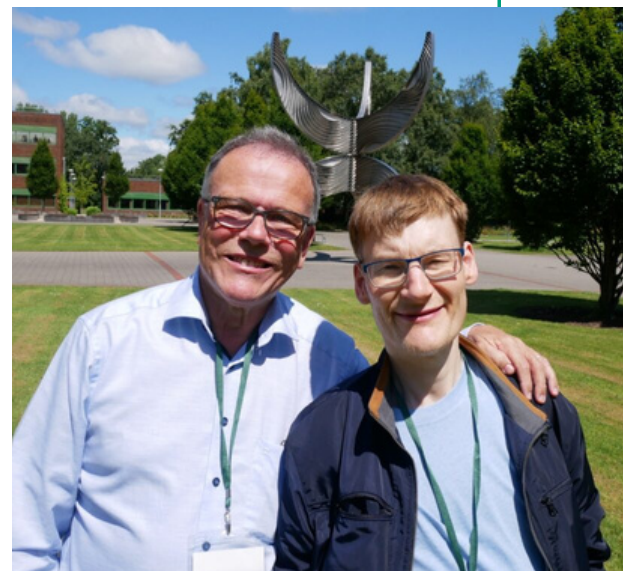
PRADER-WILLI SYNDROME

Prader-Willi syndrome (PWS) is a complex genetic disorder characterised by low muscle tone and failure to thrive at birth, and later evidence of short stature, intellectual disabilities, behavioural and psychiatric challenges, and impaired satiety.

The latter is associated with excessive food intake (hyperphagia) that results in severe obesity, if access to food is not carefully controlled. Where severe obesity is a problem this can lead to additional health problems, such as type 2 diabetes mellitus and sleep apnoea.

Relative growth and sex hormone deficiencies are very common requiring hormone replacement and monitoring for other health problems is required, such as severe spinal curvature.

Research has shown that between 1 in 15,000 and 30,000 people in the populations studied are born with PWS. PWS occurs across all races and both sexes, although life-expectancy may differ between countries depending on the availability of early diagnosis, information, treatments, services and support.



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.

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.

VISION, MISSION AND VALUES

Values

- 1 | Global Solidarity.** We are committed to working for a more equal world where all people with PWS can achieve their full potential regardless of their economic, geographic or family circumstances.
- 2 | Commitment to Science.** We believe that people with PWS and their families deserve clinical care, treatment recommendations, services and support that are based on rigorous empirical research and we will promote scientific reasoning throughout our organisation.
- 3 | Collaboration.** Premised on a belief that we can all learn from each other and benefit from each other's work, we are committed to fostering new relationships, willingly supporting others, and working cooperatively with diverse stakeholders in pursuit of common goals.
- 4 | Respect for all.** We are committed to equality for all people regardless of their sex, sexual orientation or gender reassignment, their race, colour or religion, their disability, marriage status or age.



STRATEGIC OBJECTIVES

- 1 | Building Communities.** To support the growth of new and existing PWS associations and unite the global PWS community for the benefit of all its members.
- 2 | Equal Opportunities.** To strive for a world where people with PWS have equal opportunities to their peers, and all people with PWS, and their families, have access to current, evidence-based knowledge, treatments, services and support.
- 3 | Research for all.** To disseminate research findings in ways that make current knowledge accessible to all and foster research that reflects the diverse needs of people with PWS and their families around the world.
- 4 | Funding to meet needs.** To attract adequate and sustainable IPWSO funding to enable us to better support people with PWS and their families, in particular those most in need.



WE WILL BUILD COMMUNITIES BY:

- fostering the growth of new and existing PWS associations by means including the provision of financial support, information, advice, and input from relevant experts;
- providing online educational meetings designed to share information, encourage collaboration, and better understand the diverse needs of our community;
- hosting an international professional caregivers' conference in 2024 aimed at facilitating peer learning and strengthening the PWS caregiver community;
- co-hosting an international conference in 2025 aimed at bringing together our global community of families, clinicians, scientists, professional caregivers, educators and allied health professionals;
- engaging with international organisations whose work aligns with IPWSO to promote the interests of people with PWS and their families.



WE WILL PROMOTE EQUAL OPPORTUNITIES BY:

- operating an advice service that enables families and professionals to receive advice from international experts;
- providing diagnostic testing services to anyone who cannot access or afford testing in their own country;
- developing, translating and distributing educational resources;
- granting financial support for conferences, workshops and a range of other projects in under-served countries;
- engaging in educational outreach by hosting information tables at scientific meetings.

WE WILL ATTRACT FUNDING TO MEET NEEDS BY:

WE WILL PROMOTE RESEARCH FOR ALL BY:

- disseminating research findings in ways that make current knowledge accessible to families and professionals worldwide;
 - undertaking research on topics of importance to the global PWS community that fall outside the remit of other organisations;
 - fostering research that reflects the needs of the global PWS community and, in particular, amplifies the voices of families and professionals in under-served communities;
 - supporting, in collaboration with diverse stakeholders, the development of treatments, support structures and understanding to enable people with PWS worldwide to fulfil their potential and achieve their goals.
- dedicating staff time to fundraising activities and fostering more active engagement in fundraising by IPWSO Trustees and volunteers;
 - exploring fundraising collaborations with IPWSO members;
 - working closely with existing donors including individuals, pharmaceutical companies, and Friends of IPWSO;
 - submitting an increased number of applications to trusts and foundations;
 - promoting targeted individual giving campaigns.



RESOURCING OUR WORK

The commitments in this strategy will enable us to remain true to our mandate 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.

Our plan is purposefully flexible so that – as a diverse and complex organisation – we can adapt as needed across contexts and over time, while being bound by the strong values that unite us.

Since IPWSO's foundation we have relied on the support of individuals and organisations around the world. We would like to thank all our association members, delegates, volunteers, supporters and donors.

To fully execute this plan, we need your help more than ever. You can advance the implementation of this plan by volunteering for IPWSO, making a personal contribution, and fundraising to support our work.



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