

Strategic Plan

2020-2023



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Background to the International Prader-Willi Syndrome Organisation (IPWSO)

Since 1991 IPWSO has supported national PWS associations, as well as people with PWS, their families and the professionals who work with them. 38 national PWS associations make up IPWSO's current membership and IPWSO also supports families and professionals in over 70 other countries.

While IPWSO is proud of its heritage and recognises that many people with PWS now achieve far better outcomes than in the past, it is conscious too that people with PWS and their families continue to face serious challenges, particularly in countries where knowledge is limited and treatments, services and supports difficult to access.



In some countries, early diagnosis and good health have become common and a generation of adults with PWS is emerging for whom traditional models of care and support may no longer be adequate. In other countries, early diagnosis remains rare and life-threatening levels of obesity are routinely observed.

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



Background to Prader-Willi syndrome (PWS)

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 the development of a chronic feeling of hunger that results in over-eating and in severe obesity and associated health problems.

Multiple studies have shown that between 1 in 15,000 to 30,000 people in the populations studied have PWS, which occurs equally across all races and both sexes, although life-expectancy and population prevalence globally may differ depending on the availability of an early diagnosis and of information, treatments, services and supports.



IPWSO is committed to supporting all people with PWS and their families, whatever their needs, and wherever they live.

This plan was created following engagement with IPWSO stakeholders throughout the world and sets out how IPWSO aims to enhance its supports, promote evidence-based interventions, and further build a global PWS community where access to reliable information and timely and appropriate medical care, social care and social support, and therapeutic services are available to all people with PWS and their families.

Vision, Mission, Values

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.

Values

Equality and Diversity

IPWSO commits to working for a more equal world where people with PWS and their families can achieve their full potential regardless of their economic, geographic or family circumstances, their sex, sexual orientation or gender reassignment, their race, colour or religion, their disability, marriage status or age.

Commitment to the Global Community

While IPWSO strives to help people with PWS and their families wherever they live, it will also provide targeted assistance to families, professionals and PWS associations in underserved countries in an effort to reduce global inequality.





Collaboration and Solidarity

IPWSO seeks to promote an organisational culture based on sharing strengths, fostering new relationships, willingly supporting others, and working cooperatively with diverse stakeholders in pursuit of common goals.

Honesty and Integrity

IPWSO commits to engage respectfully and truthfully with its stakeholders, to consider the impact of its actions on others, to remain true to its mission, and to own and learn from its mistakes.

Transparency and Accountability

IPWSO aims to stand the test of scrutiny by all its stakeholders and to maintain an atmosphere of openness that enables everything that it does to be scrutinised.

Excellence and Innovation

IPWSO aims to maximise the quality of all its initiatives, to remain continuously responsive to the changing needs of its stakeholders and to foster an organisational culture where its work can easily evolve by creatively harnessing new resources and ideas.

Respect and Gratitude

IPWSO seeks to foster an organisational culture where there is discernible respect and gratitude shown for the outstanding individual and collective efforts of its Staff, Trustees and other Volunteers, Members, Donors, Collaborators, and all those who engage with it worldwide.

What we want to achieve

Responsive and Effective Supports

Goal 1: Provide responsive and effective supports to the associations that form IPWSO's membership, as well as to people with PWS, their families, and the professionals who work with them.

» Provide free diagnostic testing to those who cannot access it in their own countries as well as guidance and support to laboratories aiming to offer PWS testing.

» Produce culturally appropriate and useful educational materials and training in multiple languages and formats for people with PWS, their families and the professionals who work with them.

» Provide mentoring opportunities for PWS associations and those who support people with PWS by means including Project ECHO®.

» Provide expert responses to queries from people with PWS, their families and professionals by drawing on IPWSO's international network.

» Support national and regional conferences through the provision of financial aid and advice and host an international conference every 3 years.





Evidence-based Interventions

Goal 2: Promote the development of evidence-based interventions in medical care and social care and social support, while also advocating directly, and facilitating the advocacy of others, for improved and greater availability of treatments, services and supports and heightened awareness and understanding of PWS.

» Foster research and collaboration between scientists, clinicians, professional caregivers, people with PWS and families by means including international conferences and focused workshops.

» Facilitate social care, social support and medical care research aimed at improving the lives of people with PWS by means including directly overseeing research, and providing assistance to researchers, pharmaceutical companies and others engaged in PWS research.

» Actively promote the rights of people with PWS in accordance with the United Nations Convention on the Rights of Persons with Disabilities.

» Strive to influence social policies that affect people with PWS through research and the development of guidance to support advocacy nationally and internationally.

» Actively engage with international organisations whose work aligns with IPWSO to promote the interests of people with PWS and their families.

Global PWS Community

Goal 3: Grow and strengthen the global PWS community and work to reduce global inequality in the availability of information, treatments, services and supports for people with PWS and their families.

- » Research and highlight inequalities in the availability of information, treatments, services, and supports between countries and provide targeted assistance to families, professionals and PWS associations in underserved countries.

- » Facilitate connections, understanding and learning between people and PWS associations around the world by means including interactive social media, Project ECHO® programs, and national, regional, and international conferences.

- » Share best practice and research updates in multiple languages and formats to ensure that current information is accessible to audiences around the world.

- » Encourage professionals to focus on PWS in their clinical and other work and as part of their research agendas by means including hosting information booths at conferences and supporting the participation of professionals in PWS workshops and conferences.

- » Support the development of national and regional expert teams and foster the development of new associations and support networks in countries where there are none.



How we will enable our work

People

Goal 4: Foster a collaborative, innovative and representative staff and volunteer team that is passionate about supporting people with PWS and their families and delivers meaningful benefits.

- » Make IPWSO a great place to work and volunteer by ensuring that all voices are listened to and that an atmosphere of transparency is nurtured.
- » Invest in training to build the capacity of our staff and key volunteers.
- » Develop succession plans for both staff and volunteer positions to minimise the impact of transitions.



Funding

Goal 5: Develop and grow diverse income sources to ensure financial stability and sustainable growth, and to make possible the achievement of our strategic goals.

- » Build long-term partnerships with individuals and organisations who support IPWSO's work.
- » Increase the engagement of our supporters and foster increased individual giving.
- » Encourage the development of Friends of IPWSO organisations.



Technology

Goal 6: Harness the potential of technology to increase efficiency, improve governance and enable IPWSO to better serve people with PWS and their families.

» Build IPWSO's capacity to connect the global PWS community virtually both by engaging our stakeholders on the platforms they are already using and by using technologies and platforms that offer additional benefits.

» Secure and optimise the value of IPWSO's information to enable seamless cooperation between staff and volunteers wherever they are based in the world.

» Future-proof IPWSO's systems to ensure that it remains relevant to its members and can withstand and take advantage of changing circumstances.

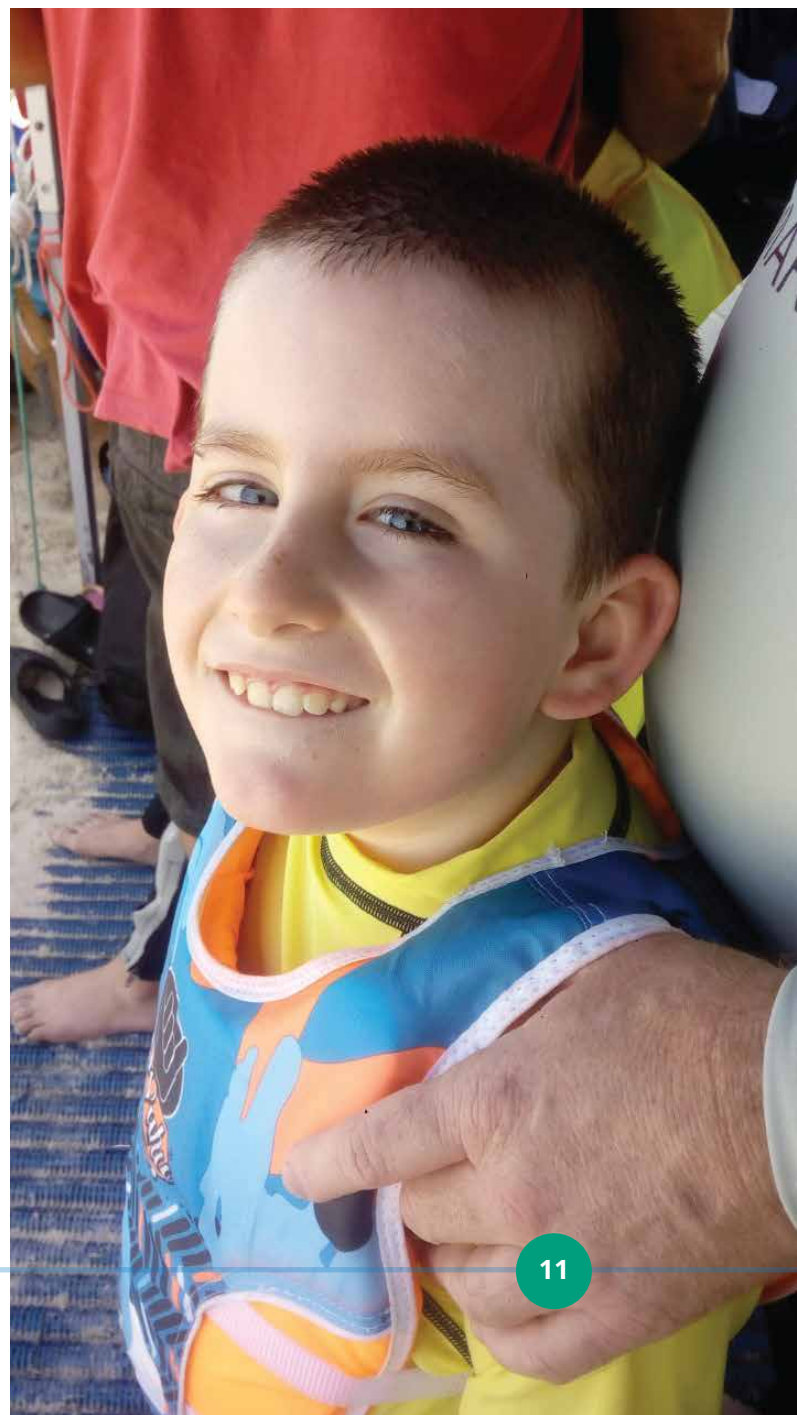
Reputation

Goal 7: Enhance IPWSO's reputation as a reliable source of information and support for individuals and organisations around the world

» Encourage the ongoing involvement of world-renowned experts on PWS in IPWSO.

» Promote evidence-based interventions and declare the basis for IPWSO recommendations and advice.

» Maintain robust systems of governance that are regularly reviewed and updated.



Looking to the future

Looking to the future

This strategic plan seeks to reflect both short-term and long-term objectives. It is a living document that will be regularly revisited by IPWSO's Board of Trustees and adjusted according to changing needs and circumstances.

To achieve our goals we work with many people and organisations around the world. We would like to thank all our association members, delegates, volunteers, advisers, partners, supporters and donors. We look forward to working with you all from 2020 to 2023.



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