

DRAFT FOR CONSULTATION

Our strategy

2027–2032

Uniting the global Prader-Willi syndrome community

A draft strategy shared with our member associations and stakeholders worldwide for consultation, before final publication.

Introduction to our strategy

Who we are and our purpose

IPWSO, the International Prader-Willi Syndrome Organisation, was established in 1991. Since then, we have supported and connected national Prader-Willi syndrome (PWS) associations, as well as people with PWS, their families, and the professionals who work with them.

PWS is a complex genetic disorder present from birth, associated with low muscle tone, short stature, intellectual disability, behavioural and psychiatric challenges, and an impaired sense of fullness that can lead to excessive food intake (hyperphagia) and severe obesity if not carefully managed. Life expectancy and quality of life for people with PWS vary considerably between countries, depending on the availability of early diagnosis, information, treatment, services and support.

We have 47 member associations and contacts in over 120 countries. However, there are many countries where we have no known contact with people with PWS, their families, associations or professionals. Closing this gap, while ensuring that people in the countries we already reach have access to good information and support, sits at the heart of this strategy.

Our journey so far

Our previous strategy, covering 2023 to 2026, was built around four objectives: Building Communities, Equal Opportunities, Research for All, and Funding to Meet Needs. It helped us grow our educational outreach, advice service and events programme, and it reaffirmed the values that unite us as an organisation.

This strategy builds on that foundation rather than replacing it. Our vision, mission and values remain unchanged, but our priorities have become broader and more focused.

Over the past year we have drawn on evidence from across our network, including a global survey of member associations on the needs of adults with PWS, detailed findings from our Latin America region, and data already held on our membership and global access to growth hormone treatment. We have combined this with a review of the wider PWS treatment and research landscape, the policies of international bodies such as the World Health Organization, and the approaches taken by peer organisations and other rare-disease federations.

This strategy was shaped through discussion with our Strategy Working Group and reviewed by our Board of Trustees. We are now sharing it with our wider membership and stakeholders for consultation, before publishing the final version.

Our vision and mission

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.

Our values

Our values are unchanged from our previous strategy. They are fundamental to how we work and guide every priority in this document.

Global solidarity. We are committed to working towards a more equitable world where all people with PWS can achieve their full potential regardless of their economic, geographic or family circumstances.

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.

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.

Respect for all. We are committed to equality for all people regardless of their sex, sexual orientation or gender identity, their race, colour or religion, their disability, marriage status or age.

How we approach our work

Two principles guide how we will deliver every priority in this strategy:

1. We will build our evidence base while acting on what we already know.

Our priorities support one another, rather than running in sequence. Building our evidence base is foundational to this strategy, but we will not wait for that work to be complete before acting. Our other priorities will draw on existing knowledge and relationships and move forward alongside this work.

2. Our ambition is phased and proportionate to our size.

IPWSO is a small organisation, largely run by volunteers alongside a handful of staff. Not every priority will move at the same pace, and some activity may not begin in earnest until later in the strategy period. We would rather commit honestly to what we can deliver than promise more than we can achieve.

Why this strategy, why now?

The world around PWS is changing in ways that make this a particularly important moment for IPWSO to sharpen its priorities.

New treatments, and a widening access gap

In 2025, the first-ever treatment for hyperphagia in PWS was approved in the United States, the first new medical treatment for the condition in over twenty years. Several more treatments are in development. This is genuinely welcome news, but history suggests it brings a new risk: growth hormone, approved more than two decades ago, is still not consistently available in many parts of the world. As new treatments are approved, the gap between where they are approved and where they are genuinely accessible and affordable is likely to widen rather than close, unless organisations like IPWSO actively work to prevent it.

A global policy window

In May 2025, the World Health Assembly adopted its first-ever resolution on rare diseases, calling for the development of a ten-year global action plan, to be presented in 2028. It calls for measures including expanded newborn screening and the involvement of people with rare diseases and their representative organisations in policy development. This gives our member associations a new, internationally endorsed basis on which to engage their own governments and gives IPWSO a global role in supporting them to do so.

A gap we cannot see

Despite nearly 35 years as an organisation, IPWSO still lacks visibility of people with PWS in many countries. We hold valuable but incomplete data, including a map of our own membership and a partial survey of global growth hormone access, and we believe the time has come to build this into something more systematic.

A lifespan we are not yet serving equally

Our own recent survey of member associations confirms what families have told us for years: support for children with PWS is far more developed than support for adults, and this pattern holds true even in well-resourced countries. Associations are already running strong local models, from peer-led adult advisory boards to intergenerational family camps, but there is currently no structured way for associations to learn from one another's successes.

Taken together, this evidence points to five priorities: **Understand, Influence, Support, Connect and Sustain**. Together, they focus our work on understanding where the need is, influencing equitable access to treatment, supporting people with PWS and their families across the whole of life, connecting our member associations more effectively, and sustaining IPWSO itself as an organisation capable of delivering all of the above.

Our strategic priorities

Our strategy has five priorities, each drawn from the evidence set out above and designed to cascade into clear annual workplans and targets.

Priority 1

Understand: building the global evidence base

We cannot direct our efforts, or make the case for change, without a clearer picture of where people with PWS live, how they are diagnosed, and what treatment and support is available to them. This is a *foundational* priority that the other four priorities will draw on as it develops, but it will not hold them back: we already have knowledge and relationships we can act on today, and we will use them while this evidence base is being built.

Objective 1

Build a standardised, continuously growing picture of PWS prevalence, diagnosis, and access to treatment and care globally, so that IPWSO and its member associations can identify needs, track progress, and make the case for change.

We will:

- Bring together what we already know, including our existing membership map and a previous survey of global growth hormone access, as a starting baseline.
- Agree a simple, standardised way for associations to share comparable information, without collecting any personally identifiable data.
- Build connections with the health agencies, government departments and associations in each country or region that hold, or could hold, relevant information.
- Explore new technology, including AI-assisted tools, to help keep this picture updated over time, alongside IPWSO's own relationships.
- Seek dedicated funding and, over time, dedicated expertise to lead this work, recognising its scale.
- This is a long-term undertaking that will continue beyond 2032. During this strategy, our focus is on establishing the foundations: an agreed data-collection approach, a growing baseline of information, and the funding and capability to sustain the work.

Priority 2

Influence: awareness and advocacy towards equitable access

As new treatments for PWS reach the market, IPWSO's role is not to promise access we cannot control, since decisions on regulatory approval, reimbursement and pricing sit with governments and industry, not with us. Our role is to build awareness of what is emerging, help our member associations advocate effectively in their own countries, and make sure new treatments are understood and discussed alongside the broader nutritional, educational and social support that people with PWS and their families also need.

Objective 2

Build awareness of emerging treatments and the evidence behind them, support member associations' own advocacy for equitable access, and foster international research collaboration that translates findings into better treatment, care and support.

We will:

- Map treatment availability, reimbursement and affordability by country, to give associations and families a realistic picture.
- Gather and share real examples of how associations and countries have improved access, so others can learn from what has worked.
- Equip associations with advocacy and information materials, rather than seeking to negotiate access on their behalf.
- Share clear, independent information on safety and emerging evidence as new treatments become available.
- Support international research collaboration, including a new global research forum bringing together researchers, clinicians and families to accelerate the translation of research into practice.

Priority 3

Support: lifespan care, birth through older adulthood

People with PWS need support for their whole lives, not only in childhood. Evidence from our own network, and from the wider research literature, consistently shows that support falls away once childhood ends, often at the exact point when new health and social challenges emerge. This priority covers the full lifespan, from birth through to older adulthood, and recognises the growing number of ageing parents and carers still supporting adult children with PWS.

Objective 3

Improve the information, resources and peer support available to people with PWS and their families at every stage of life, from birth through to older adulthood, while addressing the particular gaps in support for adults and ageing carer support.

We will:

- Identify and share proven models of adult support already running successfully within our network, so other associations do not have to start from scratch.
- Revive and modernise simple, practical family guides, including everyday guidance such as basic dietary and eating-plan support, in formats that are easy to share and do not depend on access to specialists.
- Where funding allows, develop a fuller patient navigator resource covering the whole journey from diagnosis through childhood, adolescence and into adulthood.
- Pay particular attention to the needs of ageing parents and carers, an area we believe deserves further dedicated research.

Priority 4

Connect: stronger member-association infrastructure

No other organisation plays the same role as IPWSO in connecting national PWS associations to one another and to global policy. Associations vary hugely in size, maturity and resources, and currently have no structured way to learn from each other's experience. We intend to change that.

Objective 4

Strengthen IPWSO's network of member associations through mentoring, shared resources and, where helpful, regional coordination, so that associations at every stage of development can learn from one another.

We will:

- Build a structured mentoring pathway to support the growth of new and developing associations.
- Package existing governance and association-building materials, such as constitution templates, into ready-to-share resources for groups wanting to formalise or strengthen their organisations.
- Explore informal regional networks or hubs that can coordinate data-gathering and resource-sharing within a region, building on models already emerging in some parts of the world.
- Review what membership of IPWSO offers and ensure that becoming and remaining a member brings clear and valued benefits.

Priority 5

Sustain: a strong and resilient organisation

Every priority in this strategy depends on IPWSO itself being sustainable, and sustainability means more than funding alone. It means strong governance, reliable systems, and the right people and expertise to deliver what we promise.

Diversifying and growing our income

Funding has been a significant constraint on IPWSO's ambitions for many years, and it remains one. Delivering this strategy, particularly Priority 1, will very likely require funding beyond what we currently receive.

Objective 5a

Diversify and grow IPWSO's income, so that our funding is resilient and matched to our ambitions.

- Increase applications to trusts and foundations aligned with our priorities.
- Strengthen engagement with industry partners as more treatments approach approval, in a way that protects our independence.
- Review and strengthen the value of membership.

Digital systems and ways of working

Objective 5c

Invest in the digital systems and data infrastructure IPWSO needs to deliver this strategy, including the tools that underpin Priority 1.

- Ensure IPWSO has the right digital tools to manage membership information, data gathered under Priority 1, and communication with associations worldwide.
- Explore how new technology, including AI, can help us make the most of our limited staff time.

Strong, modern governance

Objective 5b

Maintain strong, transparent governance that gives members, donors and partners confidence in how IPWSO is run.

- Review and refresh our policies on relationships with industry to safeguard our independence as new treatments reach the market.
- Continue to strengthen the role of our Board and committees as this strategy is delivered.

Our people and expertise

Objective 5d

Build the people, skills and expertise, among staff and volunteers, that this strategy requires, recognising that this will likely include new dedicated roles.

- Identify where dedicated expertise, such as a research or data role, is essential to deliver specific priorities, and prioritise funding for these roles.
- Continue to recognise and invest in the significant contribution of our volunteer Trustees, committee members and association leaders.

Our resources

IPWSO is currently a small organisation: two full-time and two part-time staff, supported by a largely volunteer-led Board and network of committees. We are proud of what this model has achieved, and we also want to be honest about what it means for this strategy.

Not every priority can move at full pace from day one. Some activity, particularly the deeper stages of Priority 1, will depend on securing new, dedicated funding, and may not begin in earnest until later in this strategy period. We would rather set out a realistic, phased plan than commit to a pace we cannot sustain.

We will pursue funding for this strategy through multiple routes in parallel, including trusts and foundations, individual giving and major donors, and, where appropriate and consistent with our governance policies, industry partners. We do not intend any single priority to depend on a single funding source.

How will we evaluate our success?

Each priority in this strategy will be translated into annual workplans, with specific, measurable targets. We have been deliberate about the kind of targets we will set.

Where a priority depends mainly on IPWSO's own effort, such as building a data-collection tool, publishing a resource, or running a mentoring programme, we will track our direct delivery against clear annual targets.

Where an outcome depends on factors beyond IPWSO's control, such as a government's decision to fund a treatment, or an individual association's access to its own health system, we will track what we can influence, such as the advocacy materials we provide or the success stories we share, rather than promise an outcome we cannot guarantee alone.

Given the scale of some of this strategy's ambitions, particularly Priority 1, we propose an early progress review at the 2028 IPWSO Conference in Brazil, allowing us to check progress, adjust our approach where needed, and confirm priorities for the remainder of the strategy period.