

STRATEGIC PLAN 2025 - 2030

OUR VISION

All people living with Prader-Willi syndrome can receive high quality healthcare, education, disability, social and wellbeing supports that enable and empower them to live full, productive, safe and happy lives.

OUR PURPOSE (MISSION STATEMENT)

To enhance the lives of New Zealanders living with Prader-Willi syndrome, and their families / whānau by:

- providing advocacy, education and support services,
- collaborating with other organisations that have similar objectives, both in New Zealand and overseas,
- encouraging research, projects, and the exchange of ideas and experiences that build knowledge and understanding of PWS and/or improve the quality of care and support for persons living with PWS.

OUR GOALS

(What we are going to do toward achieving our purpose.)

KEY PRIORITIES

PERFORMANCE INDICATORS (OUTCOMES)

1. Support and connect families and whānau through regional network hubs, whilst also building connections and developing relationships with regional support and care services.	<ul style="list-style-type: none">▪ Establish regional hubs (Initially 3 main centres).▪ Create regional connector / coordinator roles.▪ Regional whānau support and connection days.▪ Build regional fundraising and awareness opportunities.	Regional connectors would have been appointed and are well supported by the Committee. There would be regular regional get togethers, events, and opportunities for networking. Each region will have its own plans and be self-directed by its members' needs.
2. Improve opportunities for access to specialised PWS specific residential support services.	<ul style="list-style-type: none">▪ Work with residential provider organisations to establish their interest in investing in a suggested PWS support model.	We will have new PWS specific residential group home opportunities for people living with PWS.

	<ul style="list-style-type: none"> Investigate possibilities for the building of purpose-built housing for PWS specific services. Partnership with services (and other agencies) in establishing the set-up and managing of new homes (ongoing education / training). 	Partnerships with residential services will be in place to more easily manage and establish new homes nationwide.
3. a.) Improve the quality of care for people living with PWS by encouraging the development of national clinical and professional expertise in PWS.	<ul style="list-style-type: none"> Establish a PWSA medical advisory board. Extend the connection of NZ clinical specialists to PWRFA Centre of Expertise. Explore RDNZ CofE options for PWS care. Encourage the development of national standards of care for patients with PWS. <p>Partnership with MoH / professional / clinical team developing SOC.</p> <ul style="list-style-type: none"> Partnership with MoH / Health NZ / Te Whatu Ora to ensure PWS SOC integration with patient health data systems. Encourage professional PWS training opportunities for psychiatrists and dietitians. 	<p>A PWSA medical advisory board will have been established consisting of members from different specialisms related to PWS. The board provides advice to PWSA and assists PWSA with clinical care and expertise development projects.</p> <p>More national specialists are connected to the PWRFA Centre of Expertise, and possibly to a RDNZ future Centre of Expertise.</p> <p>MoH / Health NZ / Te Whatu Ora agree to developing SOC for PWS and development is in progress or achieved. The integration of SOC for PWS with patient data systems is being planned for or in place.</p> <p>PWS training opportunities for psychiatrists and dietitians have been offered and are ongoing.</p>
b.) Develop professional knowledge and understanding of PWS and specialist connections through the hosting of a national PWS conference.	<ul style="list-style-type: none"> Attract keynote speakers and sponsors. Prepare and host a national PWS conference in 2027 or 2028. 	<p>A national conference would have taken place.</p> <p>The Committee will have reviewed the success of this conference and would have either decided to plan for repeat national conferences at set intervals or would have decided on an alternative conference or format for the sharing of expertise and professional connection.</p>

c.) Improve the quality of healthcare for adults living with PWS by encouraging a multidisciplinary approach to PWS healthcare.	<ul style="list-style-type: none"> ▪ Encourage Health NZ / Te Whatu Ora to establish multidisciplinary clinics for adults living with PWS. (One clinic could operate as a model for optimal healthcare.) 	<p>A multidisciplinary clinic for adults living with PWS would have been established.</p> <p>Feedback / data gathering will be in place to monitor the success of this clinic that can be used to develop multidisciplinary care further and establish further clinics.</p>
4. Ensure the longevity and capability of PWSA to achieve our purpose by increasing Association funding.	<ul style="list-style-type: none"> ▪ Diversify and seek new funding streams, i.e. for salaries, projects or regular events. ▪ Explore philanthropic partnerships. ▪ Explore patronage. 	<p>New funding streams would have been explored and applied for. Philanthropic partnerships would have been explored and potentially developed. Any benefits of patronage will have been discussed and if agreed, potential candidates identified and approached.</p>
5. Ensure support for our CE in actioning our strategic and operational planning to achieve our purpose.	<ul style="list-style-type: none"> ▪ PWSA Committee to be engaged in strategic and operational planning processes. ▪ Ensure PWSA has good succession planning in place. ▪ Review staff and volunteer roles to ensure sustainability. Adapt roles / create new roles as needed. 	<p>The PWSA Committee meets on a regular basis and regularly reviews the progress of this strategic plan. Annual operational plans are developed.</p> <p>The PWSA Committee has a succession plan that allows for smooth transition of management.</p> <p>There are clearly defined and manageable roles in place for paid staff.</p>
6. Ensure that as a small organisation with one paid staff member, PWSA can achieve its purpose through the division of tasks and creation of subcommittees.	<ul style="list-style-type: none"> ▪ Establish subcommittees for each strategic plan goal above. Subcommittees to help action goals, also enlisting volunteer support from members / the community. 	<p>PWSA subcommittees are working effectively to support the CE and achieve PWSA's purpose.</p>