



Prader-Willi Syndrome Association (NZ) Incorporated

Annual Performance Report

for the year ended 31 December 2025



PWSA New Zealand

Legal Name of Entity

Prader-Willi Syndrome Association (NZ) Incorporated

Type of Entity

Incorporated Society & Registered Charity

Charity Registration Number

CC46009

Postal Address

30 Golf Road, Paraparaumu Beach, Paraparaumu 5032

Contact



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www.facebook.com/PraderWilliSyndromeAssociationNZ

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Statement from the Chair

On behalf of the Committee, I am pleased to present the 2025 Annual Performance Report for the Prader-Willi Syndrome Association (NZ) Incorporated.

During 2025, the Association continued to deliver on its contract of providing information and support. This is achieved through:

- Regular newsletters
- Family support camp
- Training and education
- Facebook groups
- RURU Leadership Group (adults living with PWS)
- 0800 helpline support
- Website and publications readily available

In July, the Committee participated in a strategic planning meeting where the Association's Mission Statement was reviewed and the 2025 – 2030 Strategic Plan formulated with the following goals:

1. Establish regional hubs to support and connect families and whānau, and to build relationships with regional care and support services.
2. Improve the quality of care for people living with PWS by encouraging the development of national professional and clinical expertise in PWS.
3. Improve the quality of healthcare for adults living with PWS by encouraging a multidisciplinary approach to PWS healthcare.
4. Host a PWS conference to develop professional knowledge and understanding of PWS and specialist connections.
5. Ensure the longevity and capability of PWSA to achieve our purpose by increasing funding.
6. Ensure support for our CE in actioning strategic and operational plans to achieve our purpose.
7. Ensure that as a small organisation with one paid position, PWSA can achieve its purpose through the division of tasks and creation of subcommittees.

Having this direction has improved the focus and performance of the Association, its Committee and staff. Focus groups have been established, areas of expertise needed within the Committee have been recognised and are being addressed, and goals and timelines are in place.

As a national directive, the Committee spent a lot of time and consideration developing our new Constitution. Thank you to the Committee who spent many hours and meetings developing this.

I would like to thank our staff and PWSA Committee for their continued commitment to the Association, with special thanks to Jo Davies who, as a paid staff member works well beyond the hours she is paid for. Thank you also to Rachel McLellan for the extensive voluntary hours she has contributed to managing our accounts.

Finally, I would like to thank retiring Committee members Grant Rogers and Kahu Simmonds who have both been longstanding members and contributors to the running of our Association.

Cindy Adams-Vining,

Interim Chair of the PWSA(NZ) Committee

About PWSA(NZ)

Our Vision

A world where 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 Mission

To enhance the lives of New Zealanders living with PWS, and their families / whānau by:

- providing advocacy, education and support services,
- collaborating with other organisations that have similar objectives,
- 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 Strategy

Advocacy

To lobby and advocate for access to new treatments, and on issues that detrimentally or sub-optimally impact the lives of people living with PWS, or their families and whānau.

To provide an advocacy service for individuals living with PWS, their families and whānau.

To improve the quality of care & support for persons living with PWS by fostering communities of interest and encouraging the development of clinical and professional expertise.

Education

To provide easily accessible, up-to-date information and resources about PWS.

To provide PWS training courses, workshops, and facilitate learning from conferences.

To increase awareness and understanding of PWS in the wider community.

Support

To provide support for people living with PWS and their families as needed or on request.

To provide support through facilitating a support network, connections, and hosted events.

To support our ALPWS group in developing self-advocacy and leadership skills.

Our Structure

Entity Governance Arrangements: We are governed by a Committee consisting of volunteer Officers elected or co-opted to serve on the Committee. The Committee aims to meet online every two months.

Entity Structure: Our day-to-day operations, whānau support, information and training services are managed by the CEO/Operations Manager, who is a paid contractor. We are very lucky to have a Young Families Support Coordinator working part-time in a voluntary capacity. PWSA(NZ) does not have a physical office, and its staff work remotely providing nationwide services and support.

Our Staff Team



Jo Davies

CEO / Operations

“I became involved with PWSA after my search for respite services for my son with PWS turned into organising a camp for people living with PWS! I was initially employed as an Administration Manager in 2011 and my role has continued to grow since then. Recent personal experiences of systemic failures resulting in devastating consequences for my son and our family, have strengthened my resolve to advocate for change.”



Rebecca Payne

Young Families Support Coordinator

“I appreciated having contact with another parent when my son was very little, and I remember how overwhelming learning about PWS can be. Now I would like to help other parents in the same way. I look forward to meeting new families in our community.”

Our Committee



Cindy Adams-Vining
Interim Chairperson

Cindy lives in Picton and has been actively involved with the Association since its beginning. She has lots of experience of PWS as a parent, her many years providing family support services, and as a PWS trainer for the Association.



Rachel McLellan
Treasurer

Rachel lives in Otago, has a background in accounting, and decided to join the board in 2022 when a new treasurer was needed. She also enjoys reconnecting with families. Rachel has an adult son living with PWS.



Hayley Arnott
Secretary

Hayley lives in Tauranga and has a young daughter living with PWS. She works part time as a speech and language therapist for the Ministry of Education. Hayley joined the board in 2018 and enjoys being part of making things happen for and within our unique community.



Sarah Verran

Sarah lives in Cambridge and joined the board in 2025 after attending a family support camp. Sarah brings many years of governance experience to PWSA. Sarah has an adult daughter who experiences acquired PWS-like symptoms.



Julie-anne Quinney

Julie-anne lives in Auckland and joined the board in 2019. She works for Spectrum Care as Transition Manager, and previously as a Service Manager supporting clients with PWS.



Jeanette Mabin

Jeanette lives in Northland and has a young son living with PWS. She trains literacy, language and numeracy in the workplace and is also a hypnotherapist. Jeanette joined the board in 2023 to be part of supporting the wider PWS community.

Outgoing Committee Officers



Grant Rogers

Grant joined the board in 2005 and was our longest serving board member.



Kahu Simmonds

Kahu joined the board in 2016. He became Association Chairperson, a position held until December 2025.

Our Main Sources of Cash and Resources

Our main source of income is through our DIAS (Disability Information and Advisory Service) contract with DSS at the Ministry of Social Development. Our current contract expires 30 June 2026. We also submit grant applications for specific projects, such as family support weekends. In 2025 we were grateful to receive grant funding from the Lion Foundation and Aotearoa Gaming Trust toward our Family Support Camp. PWSA(NZ) is a registered charity and receives a small amount of donations.

Our Main Methods of Fundraising

PWSA(NZ) has a Givealittle page which is used for collecting donations, and to allow the public to create fundraising pages for events, such as a sponsored marathon. International PWS Awareness Month occurs each year in May which creates an ideal opportunity for fundraising as well as raising awareness. We encourage and support any fundraising efforts by providing resources, such as ribbons, wristbands and posters. Sometimes we organise our own fundraising events. We are also starting to expand our range of PWSA merchandise for fundraising.

PWSA(NZ) also provides the option of fundraising for PWS research through a second Givealittle page because the ability to contribute to future treatments for PWS is important to families.



Reliance on Volunteers, Donated Goods, Services

PWSA(NZ) relies on volunteers to form the governing Committee of our Association and for the successful running of family support events. We are especially grateful for the role filled by our Treasurer who works many voluntary hours managing our accounts. We are also very grateful to our Young Families Support Coordinator who works on a voluntary basis. We have a very small staff team who are stretched to fill multiple roles, so volunteers are very much appreciated.

Management Report by CEO

I personally feel that the Association has worked hard to support and connect families for many years, but there is much advocacy and campaigning work to be done to improve system wide care and support for individuals living with PWS, which can be challenging for a small organisation with minimal funding and one contracted staff member to achieve.

Therefore, it was encouraging to see the Committee meet in 2025 and set a strategic direction, identifying a range of priorities that reflect both the needs of our community and opportunities for meaningful change. The commitment from the Committee to take an active role in progressing long-term goals provides confidence that together we can work toward creating a better future for people living with PWS, balanced with the ongoing delivery of core support services.

We have a strong foundation and ambitious goals to create a lasting impact. While we remain small with limited resources, the continued strength, engagement, and generosity of our community will play an important role in helping these goals take shape over time.

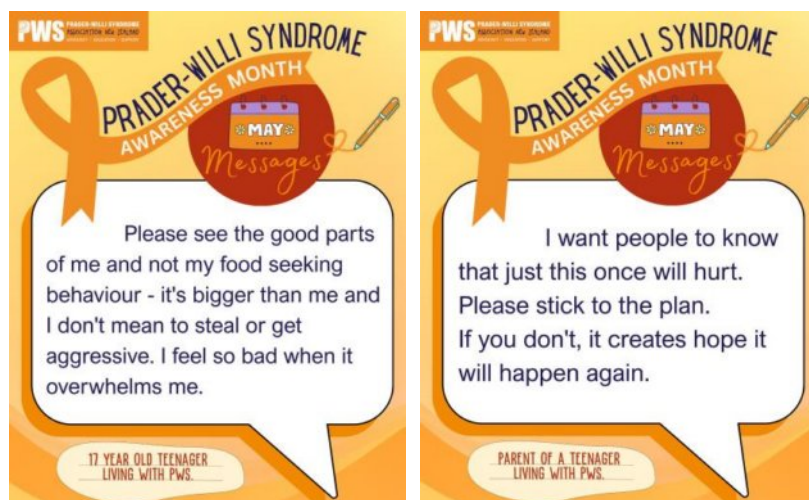
The following sections outline the progress made over the past year.

Advocacy

During 2025, I submitted responses on behalf of the PWS community to three public consultations: the DSS consultation on assessment tools, processes, and flexible funding options, informed by feedback gathered from members during family meetings; Whaikaha's consultation on its Draft Disability Strategy 2026-2030; and Pharmac's proposal to decline medications on the Options for Investment List. It was good to hear news that Pharmac decided not to proceed with the proposed changes to the OFI list, where growth hormone for adults currently sits with a confidential ranking.

I also met with the DSS taskforce regarding submitting a proposal for the development of PWS-specific residential care, which they agreed to accept and review. Unfortunately, there has been no further response from DSS on this matter and PWSA decided to approach providers directly. A proposal was submitted to a residential provider toward the end of the year and initial discussions are ongoing.

During May, we participated as always in international PWS Awareness Month and once again were able to expand our reach through a social media campaign. The theme in 2025 was 'May Messages' where people living with PWS, their family / whānau and support staff could anonymously voice a message they thought the public should know or understand about living with PWS. We were able to share many poignant messages during the month.



In November 2025, it was fantastic to hear news of inter-agency commitment, led by the Ministry of Health, to implementing the Rare Disorders Health Strategy. This was news worth celebrating because of the improvements promised by the strategy, which align with many of the healthcare needs of our community and give us greater confidence in the expectations we can have for the development of future healthcare initiatives.



We are very grateful to RDNZ for their dedication and persistence in making this happen and thank everyone in the PWS community who signed RDNZ's petition in support of this. This strategy is an important first step in recognising the unique challenges faced by our community and creating a pathway towards addressing our needs.

One of the next important steps is a support groups leads meeting with chief Health NZ officials to discuss how groups like PWSA can feed input into a Clinical Reference Group, through RDNZ.

Other advocacy work last year has included trying to bring a phase 3 clinical trial for a hyperphagia treatment to New Zealand, and then advocating for access to trial sites in Australia. Unfortunately, neither were successful and have reinforced the need to encourage the national development of clinical interest and expertise in PWS. I believe it is essential that we connect professionals working with patients with PWS if we want to achieve our goals of establishing

multi-disciplinary clinics, and improving healthcare through strategies such as syndrome specific standards of care, and access to clinical trials and new medications. I also believe that we need to be more determined than ever to raise the profile of PWS in healthcare planning as service reductions become increasingly common. A national PWS conference could play a vital role in connecting specialist clinicians and developing expertise.

Our advocacy work in 2025 also involved advocating for individuals and families where requested, including writing formal letters of support for NASCS, support teams, schools, and courts.

Education

During 2025, Cindy Adams-Vining retired from her role as PWS Training Facilitator and Coordinator. Cindy had been delivering PWS training to residential service providers across the country for many years, meeting many adults living with PWS along the way. We are very grateful to Cindy for fulfilling this role for so long, but she has not left us and is still very much involved with making things happen at PWSA as a Committee Officer, whilst also trying to enjoy retirement!

The handover of the training role provided an ideal opportunity to revise our training programme, and Cindy, Julie-anne Quinney (Committee Officer and manager at Spectrum Care) and I met to work through revisions together. We now have a brand-new, full-day training workshop which we will continue to develop as needed over time.

I am now facilitating our PWS training workshops, sometimes supported by Auckland based Julie-anne. Our plan moving forward is for PWSA to have several people able to deliver training workshops so that we can always meet demand when required.

Seven in-person PWS training workshops were delivered during the year. These were for the following service providers: MHAIDS, Spectrum Care Wellington, NZCL Christchurch, and a Wellington primary school. We also delivered three training sessions via Zoom for IHC Service Managers.

PWS training is essential for all new support staff, so we encourage providers to get in touch and discuss training needs, or to make use of our website booking page.

“Using food security to prevent disappointment is most useful.”

*“Really great explanations and examples. I’ve found the information easily ‘sticking’.
Very engaging, I have gained a lot more confidence in the subject.”*

“Gave me a lot to think about to assist with the person I support with PWS.”

“Very helpful information – would highly recommend prior to someone with PWS moving in.”

“Great 101 session – learnt heaps! Have some new things to put in place!”

“Was a very informative session and has helped me identify why the whaiora does certain things.”

“I will be able to put everything that I have learnt into practise with our patient.”

“Management strategies are particularly appropriate for this line of work.”

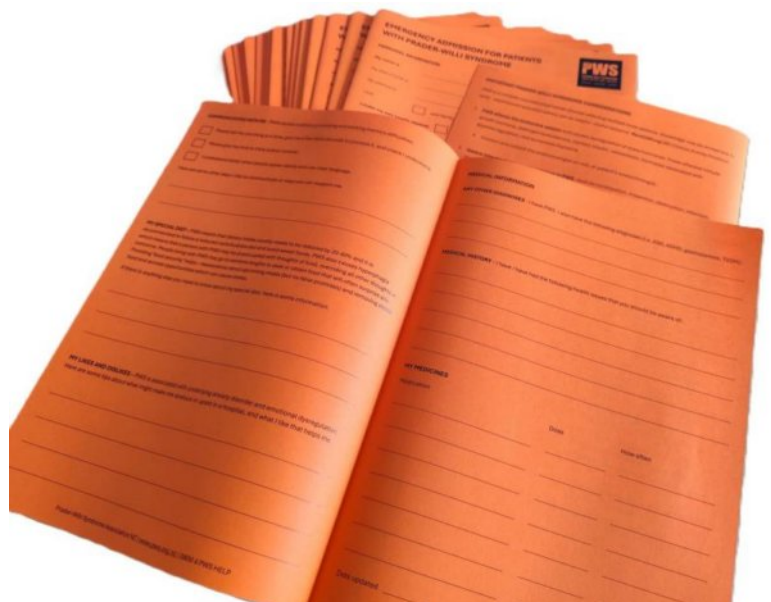
In 2025, I continued to keep in touch with our subscribed database via regular emails, four general newsletters, and through social media channels. These communication channels are used to provide general information and guideline updates, to share details of webinars, new presentations, trial participation opportunities, and the availability of new resources, such as PWSA USA’s skin picking resource, IPWSO’s Mental Health Network report, and PWSA UK’s Practical Portions.

Various information resources were supplied or posted out during the year on request to families, hospitals, and support providers. These included: awareness packs, medical alerts posters and booklets, general information pamphlets, information for schools, cookbooks, health check resources for GPs, behaviour support resources, and new parent packs.

We received a high number of requests for our new parent packs from hospitals, which suggests that previously disseminated stock is getting low and that additional copies will need to be sent to NICUs nationwide in 2026.

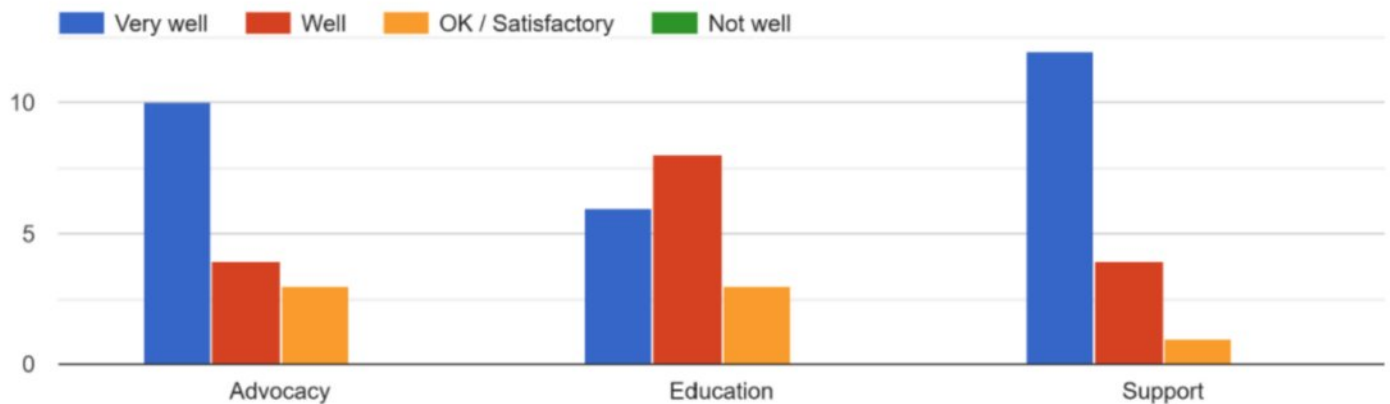
In 2025, attendance at our training workshops was high, so a large number of training packs were distributed to staff. At training events and family support meetings, we also made uncounted ‘help yourself’ copies of our pamphlets and medical alerts resources available.

We also produced a new resource in 2025 for hospital admissions, which can be used to record patient details, similar to the HDC ‘Health Passport’, but is PWS specific and includes a page of information about PWS to aid clinical evaluation. It is designed to be easy to grab in an emergency because it is printed on bright orange paper, and brief enough to be user-friendly.



Support

In 2025, as part of our general satisfaction survey, we asked family members how well they felt we were providing advocacy, education, and support services. It was encouraging, but not surprising, to see that families rated support as the area in which we were delivering most effectively.



Our much-loved biennial family support camp was held in March 2025 at MiCamp Taupo, providing opportunity for parents, people living with PWS, siblings and support staff to connect, share experiences, and learn from one another. As PWS is complex, challenging, and often poorly understood by others, these experiences are extremely important to families, and we received 96 initial registrations for our 2025 camp. We are only able to run these events with funding assistance and were very grateful for funding contributions from the Lion Foundation and Aotearoa Gaming Trust toward this camp. Our camp would also not have been possible without our volunteer team who planned and ran the camp: Hayley Arnott, Jeanette Mabin, Julieanne Quinney, Wendy Roberts, and Kahu Simmonds.





“I value spending time with the teens and young adults with PWS, seeing their strengths and weaknesses and being a bit mentally prepared for how to best deal with my child as she gets older.”

“For my child to feel part of a community that understand him and not feel different. To be able to talk to other parents who are going through the same things that I am.”

“What a wonderful weekend. A huge thank you to the organizers. We enjoyed the camp, the food, the people, the activities and the chance to talk with others living with PWS.”

In addition to hosting events, PWSA provides support services in other ways. We continue to receive support enquiries through our website, our helpline, and via email or messenger. Enquiry themes during 2025 included support following new diagnosis; dietary advice; challenging behaviour and mental health concerns; locating specialists; growth hormone treatment; medical and surgical concerns; transition and residential services; navigating funding and support systems; school funding issues, suspensions and placements; managing food-seeking behaviour and environmental controls; explaining support needs to NASCs; and advocacy support during reassessments and court cases.

Families also continue to make good use of our moderated Facebook group for all ages, as well as our groups that connect families whose children are at a similar age or stage.

Our Young Families Support Coordinator, Rebecca Payne, continues

to work in a voluntary capacity, touching base with parents of newly diagnosed or young children to ensure they are accessing the services and community supports available to them, providing any essential information or support, and connecting families with others.

During 2025, our adults living with PWS (ALPWS) group also met three times online. Topics discussed were: employment opportunities and writing a CV, hobbies, camp planning, and learning about IHC’s friendship group.

The ALPWS group also agreed to a renaming and became the RURU Leadership Group | Te Rōpū RURU. The New Zealand owl was chosen to create a connection with groups in Australia and the UK, where the owl is an acronym for ‘Our Way of Life’. Our hope is that the RURU Leadership Group is now more identifiable with their own logo.



Thank you...

I would like to conclude by expressing a special thank you to our Treasurer, Rachel McLellan, who does an amazing and time-consuming job managing our accounts in a voluntary capacity. Thank you also to the incredible volunteer team who ran our camp last year, and to Rebecca, Hayley, Julie-anne and Cindy for assisting with family support, with additional thanks to Julie-anne and Cindy for contributions to training. Finally, thank you to Cindy for her continued dedication to the Association.

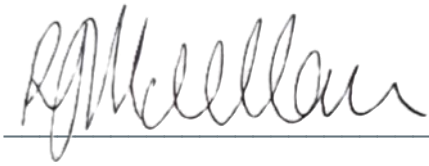
Jo Davies (CEO / Operations Manager)

Approval of the Performance Report

The Committee of the Prader-Willi Syndrome Association (NZ) Incorporated are pleased to present this approved Performance Report for the year ended 31 December 2025.

The Committee are responsible for the information contained in this financial report and have determined that the accounting policies used are appropriate for the purpose that the Performance Report is prepared.

Signed

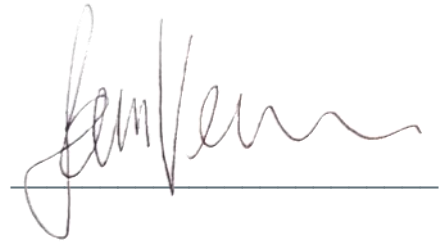


Name: **Rachel McLellan**

Position: Treasurer

Date: 10 May 2026

Signed



Name: **Sarah Verran**

Position: Chairperson

Date: 10 May 2026



Statement of Service Performance

Description of Medium to Long-Term Outcomes

Advocacy

- The impact of any new issues or changes negatively affecting people living with PWS or their families will have been raised through advocacy. Ongoing systemic issues in education, healthcare and social supports will be monitored and advocacy action will have been taken when appropriate and possible.
- Adults living with PWS and their families will have had opportunity to have their voice listened to.
- Clinical practice, expertise, or access to trials & treatments may be improved through collaborations / exchange of ideas.

Education

- Parents, wider whānau, educators, support service providers, professionals and anyone else supporting people living with PWS will have been able to access or receive up-to-date information and resources about PWS.
- Schools and residential support providers will have been able to access PWS training or workshops in line with international best practice.
- Adults living with Prader-Willi Syndrome in residential services will be able to expect quality supports that enable them to live safe, healthy lives, participating in their local community.
- More people will have awareness of PWS and a wider understanding of the support needs associated with PWS.

Support

- Individuals living with Prader-Willi Syndrome and their families will feel supported by their association and connected.
- The ALPWS leadership group would have continued to develop self-advocacy and leadership skills together.

| Description of Significant Outputs | Actuals 2025 | Actuals 2024 |
|---|--|---|
| Submissions made or public speaking on behalf of the PWS community. | 5 | 7 |
| Number of ALPWS advocacy & leadership peer group meetings. | 3 (zoom) | 1 (zoom) |
| Number of people reached through PWS awareness month via social media. | ~ 13,500 | ~ 13,000 |
| Number of people reached through website Jul-Dec (page views / file downloads). | 28,425 / 1547 | 16,123 / 1061 |
| Number of general information & support newsletters produced during the year. | 5 (+ 5 spec info) | 7 |
| Number of people receiving our general information & support newsletters. | 301 - 313 | 303-352 |
| Number of information packs distributed on request. <i>(new parent packs, school packs, information pamphlets, posters, booklets etc.)</i> | 20 requests 62 resources 90 training notes | 25 requests 49 resources + training notes |
| Number of training sessions provided for staff supporting people living with PWS. | 10 | 15 |
| Number of support enquiries received via phone, email, online contact. | 70 | 62 |
| Number of attendees living with PWS at PWSA in-person support events. | 30 | 0 |
| Number of relatives of people living with PWS at PWSA in-person support events. | 60 | 15 |
| Number of in-person support meetings with people living with PWS or families. | 6 | 19 |
| Number of in-person national support events or national meetings hosted. | 1 (+ 2 via zoom) | 1 (+3 via zoom) |

Additional Information on Output Measures

The sudden increase in website counts is because Google Analytics was not used until mid-July 2024. We do not collect data from our private Facebook groups that parents often use to ask questions, seek advice, share ideas and experiences. The number of information packs distributed in these output measures are based on requests – we have not counted resources & notes provided at trainings / workshops, packs posted out to be distributed at non-PWSA events, or 'help yourself' resources made available at our events.

Statement of Financial Performance

For the year ended 31 December 2025

| Revenue and Other Income | Note | 2025 | 2024 |
|--|------|----------|----------|
| Grants and Funding | 1 | 60,884 | 64,595 |
| Donations and Fundraising | 1 | 6,454 | 10,662 |
| Training | 1 | 5,185 | 2,840 |
| Other Revenue | 1 | 31 | 1,069 |
| Interest Revenue | 1 | 1,629 | 2,036 |
| | | <hr/> | <hr/> |
| Total Revenue | | 74,183 | 81,202 |
| | | <hr/> | <hr/> |
| Less: Expenses | | | |
| Volunteer and Contractor Related Costs | 2, 6 | (49,812) | (67,597) |
| Costs Related to Providing Goods or Services | 2 | (18,324) | (9,787) |
| Administrative Expenses | 2 | (4,785) | (6,970) |
| | | <hr/> | <hr/> |
| Total Expenses | | (72,921) | (84,354) |
| | | <hr/> | <hr/> |
| Surplus / (Deficit) for the Year | | 1,262 | (3,152) |
| | | ===== | ===== |

All figures have been rounded to the nearest dollar. This Performance Report is to be read in conjunction with the accompanying Notes.

Statement of Financial Position

For the year ended 31 December 2025

| CURRENT ASSETS | Note | 2025 | 2024 |
|--|-------------|---------------|---------------|
| Bank Accounts and Cash | 3 | 17,024 | 17,921 |
| Term Deposits | 3 | 37,044 | 35,415 |
| Accounts Receivable | 3 | 16,208 | 15,545 |
| | | _____ | _____ |
| TOTAL ASSETS | | 70,276 | 68,881 |
| | | _____ | _____ |
| CURRENT LIABILITIES | | | |
| Creditors and Accrued Expenses | 3 | 1,718 | 2,963 |
| GST Payable | 3 | 6,114 | 4,736 |
| | | _____ | _____ |
| TOTAL LIABILITIES | | 7,832 | 7,699 |
| | | _____ | _____ |
| NET ASSETS | | 62,444 | 61,182 |
| | | ===== | ===== |
| ACCUMULATED FUNDS | | | |
| Accumulated Surplus at the beginning of the year | | 61,182 | 64,334 |
| Surplus / (Deficit) for the year | | 1,262 | (3,152) |
| | | _____ | _____ |
| | | 62,444 | 61,182 |
| | | ===== | ===== |

All figures have been rounded to the nearest dollar. This Performance Report is to be read in conjunction with the accompanying Notes.

Statement of Cash Flows

For the year ended 31 December 2025

| Cash Flows from Operating Activities | 2025 | 2024 |
|---|--------------|--------------|
| Cash was received from: | | |
| Donations, fundraising and other similar receipts | 67,337 | 74,738 |
| Receipts from providing goods or services | 4,649 | 4,459 |
| Net GST (paid) / received | 1,297 | 1,811 |
| Cash was applied to: | | |
| Payments to suppliers | (28,880) | (23,528) |
| Payments to contractors | (45,300) | (57,905) |
| | _____ | _____ |
| Net Cash Flows from Operating Activities | (897) | (425) |
| | _____ | _____ |
| Cash Flows from Investing and Financing Activities | | |
| Net Cash Flows from Investing and Financing Activities | - | - |
| | _____ | _____ |
| Net Increase / (Decrease) in Cash | (897) | (425) |
| | _____ | _____ |
| Opening Cash | 17,921 | 18,346 |
| Closing Cash | 17,024 | 17,921 |
| This is represented by: | | |
| Bank Accounts and Cash | 17,024 | 17,921 |
| | ===== | ===== |

All figures have been rounded to the nearest dollar. This Performance Report is to be read in conjunction with the accompanying Notes.

Statement of Accounting Policies

For the year ended 31 December 2025

Basis of Preparation of the Performance Report

This Performance Report is prepared in accordance with the XRB's Tier 3 (NFP) Standard. The entity is eligible to apply these requirements as it does not have public accountability and has total annual expenses of less than \$5,000,000. All transactions in the Performance Report are reported using the accrual basis of accounting. This Performance Report is prepared under the assumption that the entity will continue to operate for the foreseeable future.

Goods and Services Tax (GST)

PWSA(NZ) is registered for GST. All amounts are recorded exclusive of GST, except for Debtors and Creditors (accounts receivable and accounts payable) which are stated inclusive of GST.

Income Tax

PWSA(NZ) is wholly exempt from New Zealand income tax having fully complied with all statutory conditions for these exemptions.

Bank Accounts and Cash

Bank accounts and cash in the Statement of Cash Flows comprise cash balances and bank balances (including short term deposits) with original maturities of 90 days or less.

Independent Review of Accounts

PWSA(NZ) has elected to have our accounts informally reviewed by a qualified chartered accountant with a public practicing certificate.

Changes in Accounting Policies

There have been no changes in accounting policies during the financial year.

Notes to the Performance Report

For the year ended 31 December 2025

Note 1: Analysis of Revenue

| | | 2025 | 2024 |
|------------------|--|---------------|---------------|
| Revenue Item | Analysis | \$ | \$ |
| Grants & Funding | Contract for Services with Whaikaha / MSD (DIAS) | 53,884 | 54,920 |
| | Lion Foundation – National Camp | 4,000 | 0 |
| | Aotearoa Gaming Trust – National Camp | 3,000 | 0 |
| | IPWSO Grant – Caregiver Conference | 0 | 1,039 |
| | IPWSO Grant – Transition Event | 0 | 7,063 |
| | APPWS24 Conference Subs for Speakers | 0 | 1,573 |
| | Total | 60,884 | 64,595 |

| | | 2025 | 2024 |
|-------------------------|---|--------------|---------------|
| Revenue Item | Analysis | \$ | \$ |
| Donations & Fundraising | Donations / Koha from the Public or Members | 6,454 | 10,174 |
| | Sale of PWS Awareness Bracelets | 0 | 488 |
| | Total | 6,454 | 10,662 |

| | | 2025 | 2024 |
|--------------|--|--------------|--------------|
| Revenue Item | Analysis | \$ | \$ |
| Training | Charges for Provision of Training Services | 5,185 | 2,840 |
| | Total | 5,185 | 2,840 |

| | | 2025 | 2024 |
|---------------|--|-----------|--------------|
| Revenue Item | Analysis | \$ | \$ |
| Other Revenue | Sales – Cookbooks, Awareness Merchandise | 31 | 1,069 |
| | Total | 31 | 1,069 |

| | | 2025 | 2024 |
|------------------|-----------------------|--------------|--------------|
| Revenue Item | Analysis | \$ | \$ |
| Interest Revenue | Term Deposit Interest | 1,629 | 2,036 |
| | Total | 1,629 | 2,036 |

All figures have been rounded to the nearest dollar.

Note 2: Analysis of Expenses

| | | 2025 | 2024 |
|--------------------------------------|--|---------------|---------------|
| Expense Item | Analysis | \$ | \$ |
| Volunteer & Contractor Related Costs | Committee Meetings – AGM Costs | 2697 | 0 |
| | Contractor Payments – Training Manager | 4,275 | 3,930 |
| | Contractor Payments – CEO / Operations | 42,138 | 53,975 |
| | Conference APPWS24 Sydney | 0 | 4,978 |
| | IPWSO Caregiver Conference Berlin | 0 | 4,424 |
| | Training Expenses | 702 | 290 |
| Total | | 49,812 | 67,597 |

| | | 2025 | 2024 |
|--|------------------------------------|---------------|--------------|
| Expense Item | Analysis | \$ | \$ |
| Costs Related to Providing Goods or Services | Event – National camp | 18,324 | 1,944 |
| | Event – Adult Transition Symposium | 0 | 6,043 |
| | Resource Development | 0 | 1,800 |
| Total | | 18,324 | 9,787 |

| | | 2025 | 2024 |
|----------------------|---|--------------|--------------|
| Expense Item | Analysis | \$ | \$ |
| Administrative Costs | Affiliation Fees – IPWSO | 395 | 368 |
| | Audit/review Fee | 125 | 2,500 |
| | General Expenses | 974 | 1,115 |
| | Postage, Couriers, Printing & Stationery | 676 | 314 |
| | Subscriptions, Bank Fees, Online Conferencing | 1,964 | 2,015 |
| | Telephone & Internet | 651 | 658 |
| Total | | 4,785 | 6,970 |

All figures have been rounded to the nearest dollar.

Note 3: Analysis of Assets and Liabilities

| | | 2025 | 2024 |
|----------------------|---------------------------------------|---------------|---------------|
| Asset Item | Analysis | \$ | \$ |
| Bank Accounts & Cash | PWSA(NZ) ASB Fastnet Business Account | 17,024 | 17,921 |
| | Total | 17,024 | 17,921 |

| | | 2025 | 2024 |
|-------------------|---|---------------|---------------|
| Asset Item | Analysis | \$ | \$ |
| Investments | Term Depositing – Maturing 21 June 2026 | 37,044 | 35,415 |
| | Total | 37,044 | 35,415 |

| | | 2025 | 2024 |
|---------------------|---------------------|---------------|---------------|
| Asset Item | Analysis | \$ | \$ |
| Accounts Receivable | Accounts Receivable | 16,208 | 15,545 |
| | Other Receivables | 0 | 0 |
| | Total | 16,208 | 15,545 |

| | | 2025 | 2024 |
|------------------------------|--|--------------|--------------|
| Liability Item | Analysis | \$ | \$ |
| Creditors & Accrued Expenses | Accounts Payable | 1,243 | 2,963 |
| | Donations for Research to Transfer to FPWR | 475 | 0 |
| | Total | 1,718 | 2,963 |

| | | 2025 | 2024 |
|-----------------------|-----------------|--------------|--------------|
| Liability Item | Analysis | \$ | \$ |
| GST Payable | GST Payable | 6,114 | 4,736 |
| | Total | 6,114 | 4,736 |

All figures have been rounded to the nearest dollar.

Note 4: Property, Plant and Equipment

PWSA(NZ) does not have any recorded or non-recorded significant assets.

Note 5: Commitments and Contingencies

PWSA(NZ) has no commitments as at 31 December 2025. (2024– nil)

PWSA(NZ) has no contingent liabilities or guarantees as at 31 December 2025. (2024 – nil)

Note 6: Accumulated Funds

| | |
|---|-----------|
| Opening balance from accumulated surplus: | \$61,182 |
| Add this year's surplus: | \$ 1,262 |
| Closing accumulated surplus: | \$ 62,444 |

Note 7: Goods or Services Provided in Kind to the Entity

In this reporting period, a chartered accountant provided pro bono, informal review services of the financial statements to ensure robust governance and accurate reporting. This service was provided at no cost, which saved professional fees.

All figures have been rounded to the nearest dollar.

Note 8: Related Party Transactions

During the financial year, PWSA(NZ) has made payments to members of the Committee in relation to hours worked and disbursements incurred by the members of the Committee on behalf of the Association. Committee volunteers have also provided services in kind / without payment. Persons on the Committee are deemed to be considered related parties.

| Description of Related Party Relationship | Description of Transaction (in cash or in kind) | 2025 | 2024 | 2025 | 2024 |
|---|---|-----------------------|-----------------------|--------------------|--------------------|
| | | \$ | \$ | \$ | \$ |
| | | Value of Transactions | Value of Transactions | Amount Outstanding | Amount Outstanding |
| J. Davies, CEO, Operations Manager, Committee Officer | Invoices to PWSA for time on management, operations and training | \$44,725 | \$53,975 | \$1113 | |
| C. Adams-Vining, Training Manager, Committee Officer | Invoices to PWSA for time on ALPWS support and training | \$0 | \$3,930 | | |
| J.A. Quinney Committee Officer | Invoices to PWSA for staff training | \$575 | \$0 | | |
| J Robinson, Committee Officer | Reimbs for travel to 2025 plan mtg | \$445 | \$0 | | |
| J. Davies, CEO, Operations Manager, Committee Officer | Reimbs for home internet, travel/expenses for training & events | \$416 | \$1,852 | \$26 | |
| C. Adams-Vining, Training Manager, Committee Officer | Reimbs for home internet, travel/expenses for training & events | \$619 | \$1,787 | | |
| R. McLellan, Treasurer and Committee Officer | Reimbs travel for flights – 2025 Plan mtg / 2024 transition symposium | \$220 | \$287 | | |
| K. Simmonds, Chairperson and Committee Officer | Reimbs for flights to 2025 plan mtg | \$157 | \$0 | | |
| G Rogers, Committee Officer | Reimbs for flights to 2025 plan mtg | \$174 | \$0 | | |
| H. Arnott, Committee Officer | Reimbs for travel and expenses to 2025 plan mtg / 2024 APPWS conference | \$230 | \$1,288 | | |
| J. Mabin, Committee Officer | Reimbs for travel to 2025 plan mtg | \$200 | \$0 | | |
| J.A. Quinney, Committee Officer | Reimbs for travel to 2025 plan mtg and training | \$380 | \$0 | | |
| S. Verran, Committee Officer | Reimbs for travel to 2025 plan mtg | \$352 | \$0 | | |
| R, McLellan, Treasurer and Committee Officer | Provided accounting services at no charge. | \$0 | \$0 | | |

All figures have been rounded to the nearest dollar.

Note 9: Events After the Balance Date

There were no events that have occurred after the balance date that would have a material impact on the Performance Report. (2023 – nil)

Note 10: Ability to Continue Operating

The entity will continue to operate for the foreseeable future.



Independent Review Report

Independent Review Report

To The Prader-Willi Syndrome Association (NZ) Incorporated

Report on the Financial Statements

I have reviewed the accompanying financial statements contained in the performance report of The Prader-Willi Syndrome Association (NZ) Incorporated which comprise the statement of financial position as at 31 December 2025, and the statement of financial performance and statement of cash flows for the year then ended, and the statement of accounting policies and the notes to the performance report that include other explanatory information.

Committee' Responsibility for the Financial Statements

The Committee are responsible for the preparation and fair presentation of the financial statements in accordance with the Tier 3 (NFP) Standard and for such internal controls as the Committee determine are necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

Reviewer's Responsibility

My responsibility is to reach a conclusion on the accompanying financial statements. It must be noted I am not a qualified auditor and I am not giving a qualified opinion.

My review procedures primarily consist of making enquiries of management and the treasurer based on my review of the financial information available to me in Xero and supporting documentation supplied.

My review procedures are substantially less than those performed in an audit engagement.

Other than in my capacity as reviewer, I have no relationship with, or interests in The Prader-Willi Syndrome Association (NZ) Incorporated

Conclusion

Based on my review, nothing has come to my attention that causes me to believe that the financial statements for the year ended 31 December 2025 as set out in the accompanying financial accounts do not present fairly, the financial position of The Prader-Willi Syndrome Association (NZ) Incorporated as at 31 December 2025.

Restriction on Distribution or Use

This report is made solely to the Committee The Prader-Willi Syndrome Association (NZ) Incorporated. To the fullest extent permitted, I do not accept or assume responsibility to anyone other than the Committee for the review I have done



David Hogue
Chartered Accountant
12 March 2026