



Prader-Willi Syndrome Association (NZ) Incorporated

Annual Performance Report

for the year ended 31 Dec

2024



PWSA New Zealand

Legal Name of Entity

Prader-Willi Syndrome Association (NZ) Incorporated

Entity Type and Legal Basis

Incorporated Society & Registered Charity

Registration Number

CC46009

Postal Address

30 Golf Road, Paraparaumu Beach, Paraparaumu 5032

Contact



021791391 | 0800 4 PWS HELP



enquiries@pws.org.nz



www.pws.org.nz



www.facebook.com/PraderWilliSyndromeAssociationNZ

Contents

Legal and Contact Information.....	1
Statement from the Chair	3
About PWSA(NZ)	4
Management Report.....	8
Approval of the Performance Report.....	13
Statement of Service Performance.....	14
Statement of Financial Performance.....	15
Statement of Financial Position.....	16
Statement of Cash Flows.....	17
Statement of Accounting Policies.....	18
Notes to the Performance Report.....	19
Independent Review Report.....	26

Statement from the Chair

On behalf of the Committee, I am pleased to present the 2024 Annual Performance Report for the Prader-Willi Syndrome Association (NZ) Incorporated.

People affected by PWS face unique challenges which can be compounded by limited knowledge in our health and disability systems about the syndrome and how to support better outcomes. PWSA has continued in our mission to enhance the lives of people living with PWS but there is still much work to be done to improve the supports, services and healthcare available for people living with PWS. This is one reason why we were pleased to be able to support Bjørn Christensen to attend IPWSO's International PWS Caregivers' Conference held in May 2024 to assist us in addressing some of the issues in residential care services. We appreciate Bjørn's passion and dedication to providing quality support for people living with PWS and are pleased to have the ongoing opportunity to benefit from Bjørn's experience, knowledge and ideas.

During 2024 we were significantly involved in the organising of the 6th Asia Pacific PWS Conference in Sydney. It was somewhat disappointing that there was limited professional attendance from New Zealand, and extending our national PWS professional expertise remains a major focus for PWSA. I would like to thank all the speakers from New Zealand who attended, and we were especially grateful to be able to call upon Dr John Ford, PWS behaviour specialist, and we thank him for his ongoing support for the Association.

Another focus during 2024 was transition from school. We held our first event to concentrate on this important topic which was very well received by those who attended. I would like to thank all our volunteer speakers for their time and effort presenting for us.

Finally, I would like to thank our staff and PWSA Committee for their continued commitment to the Association, with special thanks to Rachel McLellan for the extensive voluntary hours she has contributed to managing our accounts, and to Julie-anne Quinney for her valuable contribution to the planning and running of the transition event. With Julie-anne's wealth of experience in residential service management and as a transition coordinator at Spectrum Care, we are very lucky to have her on our Committee.

From this year's AGM I will be stepping down as Chair of the Committee, but I hope to be able to continue contributing to the work of the Association as a Committee Officer, and I would encourage anyone else considering a governance role in PWSA to come and talk to any of our Committee about how you can be involved.

Ngā mihi nui - Thank you

Kahu Simmonds,

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

The PWSA(NZ) is governed by a Committee, which currently comprises 9 officers and aims to meet every two months. Two Committee Officers are also part-time paid contractors – the CEO and the Training Manager. All other Committee Officers are volunteers who have been nominated and elected to the Committee.

The PWSA(NZ) does not have a physical office, and its staff work remotely. Our day-to-day operations and whānau support are managed by the CEO/Operations Manager and the Training Manager. We were very pleased to recruit a Young Families Support Coordinator to the team in June 2024.

Our Staff Team



Jo Davies

CEO / Operations Manager, Committee Officer

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 Administration Manager in 2011 and my role has continued to grow since then.



Cindy Adams-Vining

Training Manager, Committee Officer

I chose to be a board member to help run our organisation for the benefit of all individuals and families living with PWS in NZ. I feel strongly about stepping up to take responsibility rather than waiting for things to happen. I believe being a parent of someone with PWS for 34 years represents a lot of knowledge (and more questions).



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 am looking forward to meeting new families in our community.

Committee Officers



Kahu Simmonds
Chairperson

Kahu lives in Christchurch and joined the board in 2016. He has a young daughter living with PWS and he works as a barrister and solicitor.



Rachel McLellan
Treasurer

I live in Otago and decided to join the board in 2022 when a new treasurer was needed.

I have an accounting background and an adult son living with PWS, so I also thought it would be nice to reconnect with families.



Hayley Arnott

I live in Tauranga and have an 9-year-old daughter who lives with PWS. I work part time as a speech-language therapist for the Ministry of Education. I joined the board in 2018 and enjoy being part of making things happen for and within our unique community.



James Robinson
ALPWS Representative

James lives in Auckland and joined the board at our 2023 AGM. James joined to represent adults living with PWS.



Julie-anne Quinney

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



Jeanette Mabin

I live in Northland and joined the board at our AGM in 2023. I train literacy, language and numeracy in the workplace and am also a hypnotherapist. I have a young son with PWS and joined the board to be part of supporting the wider PWS community.



Grant Rogers

Grant lives in Auckland and joined the board in 2005. He has an adult daughter living with PWS and is our longest serving committee member.

Would you like to join our Committee?

PWSA(NZ) is seeking nominations for Committee officers. Please contact us if interested.

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 2024 we were grateful to receive grant funding from IPWSO and Friends of IPWSO(USA) toward our Transition Symposium in Auckland. 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. In 2024, we have just started to sell PWSA merchandise with a marginal markup 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. In 2024 we fundraised for Prader-Willi Research Foundation Australia by hosting a movie screening about PWS.



Reliance on Volunteers, Donated Goods or Services

PWSA(NZ) relies on volunteers to form the governing Committee of our Association, and 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

During 2024 we held less in-person support events than we did in the previous year (which had been a bit of a 'catch-up' year to reconnect after Covid lockdowns), but we focused our attention on transition to adulthood and held our first successful Transition Symposium. 2024 was also the year of the 6th Asia Pacific PWS Conference held in Sydney.

We were also very pleased to welcome Rebecca to the team in 2024 in our new Young Families Support Coordinator role.

Advocacy

In 2024 I submitted a formal response to the Law Commission's 2nd Issues Paper on their review of adult decision-making capacity law.

The response mainly focused on Q.6 and the proposed single test for assessing decision-making capacity which would not be a reliable measure for assessing capacity to make safe decisions about food in PWS. The Law Commission admit that some people have vulnerabilities that can lead to adverse consequences (such as compulsion to act in a certain way) but suggest that safeguarding legislation would be beneficial in these circumstances and placed this area out of scope of the decision-making review. Our submission argued that safeguarding and decision-making capacity should not be viewed in isolation and that gaps in

understanding based on the interpretation of just one area of legislation have the potential to create considerable risk. The Law Commission's final report to the Minister of Justice is expected in 2025.

In response to issues around late diagnosis of scoliosis and the advice sometimes provided to patients, I sent a letter to New Zealand's orthopaedic, endocrine and paediatric groups advocating for a review of scoliosis screening practice for patients with PWS. Unfortunately, we have not received a response, but we will follow this up and continue to monitor practice. We would appreciate families informing us if their child is not screened appropriately or if you have any concerns.

I submitted 3 applications to Pharmac for medicines - two for the approval of new medicines, pitolisant and guanfacine, and another application for GHT to be funded for adults with PWS to ensure that this remains on Pharmac's radar. Although Pharmac are able to fund medicines not funded by Medsafe if they are approved by other international regulatory bodies, they decided not to progress the pitolisant and guanfacine applications because they are unapproved. However, we have good news that Takeda Pharmaceuticals have since sponsored an application to Medsafe for guanfacine and we hope to hear news on this soon.

During May, we participated as always in international PWS Awareness Month and managed to significantly increase our reach once again through our social media campaign.



As part of the RDNZ collective, we also supported Rare Disorders Month in March to raise awareness of rare disorders and celebrate our rare community.

In August I attended RDNZ's biennial Support Group Lead Hui in Wellington. It was fantastic to celebrate the long-awaited Rare Disorders Health Strategy being published in July, but unfortunately the Ministry of Health have placed implementation on hold, and we are still waiting for government commitment to the strategy. We have encouraged members to [sign the petition](#) demanding action. The strategy didn't contain everything we wanted (patient registries / data collection, coding systems, a centre of expertise), but it is an important first step in recognising the unique challenges of living with a rare disorder in New Zealand.

We have also been developing relationships with key stakeholders to encourage the national development of clinical expertise and practice. We have built an important new relationship with PWRFA (Prader-Willi Research Foundation Australia) and have connected Professor Paul Hofman to the Australian PWS Centre of Expertise, with the aim of connecting more of our national specialists in future. We have also discussed the obstacles some parents have faced with their child being able to start GHT by 6 months with Prof Hofman and this will be raised at the next annual paediatric endocrinology meeting.

We are focused on gathering national expertise with a view to forming a PWSA clinical advisory group, and this may also assist with future advocacy projects such as the establishment of adult PWS clinics.

With the number of new drugs currently in phase 2 or 3 trial stages for PWS or pending approval overseas, I have also been making efforts to forge links with the relevant pharmaceutical companies. We got close to having a trial site for a phase 3 hyperphagia treatment in New Zealand but unfortunately a decision was made not

to progress this. We will continue working on our medicines access action plan.

In 2024, Hayley Arnott (committee officer) and I closed our Education Survey and are reviewing the collated data to inform our strategy going forward. We intend to submit a proposal to the Ministry of Education requesting a guarantee of funding for pupils with PWS to ensure their health and safety needs are met.

Last year saw significant sudden changes made to Disability Support Services and funding guidelines. I sought feedback from families and attended 2 meetings with Whaikaha (now MSD) to discuss these changes and seek further clarification around the new, temporary funding rules.

Our advocacy work in 2024 also included advocating for individuals and families as requested or needed.

Education

The three yearly Asia Pacific PWS Conference was held in August 2024 at Rydges Sydney Central and was attended in-person by myself, Cindy Adams-Vining, Hayley Arnott, Dr John Ford, a provider representative, and a family member. 13 others registered for the livestream sessions.



We were part of the organising committee for APPWS2024 and were pleased to present such a great line-up of speakers, including plenary speakers Dr Deepan Singh and Prof Tony Holland. Cindy, Hayley and John Ford also kindly gave their time to present at the conference. A detailed conference summary report has been shared with members.

The conference was also an important opportunity for networking with others working in the PWS field.



Part of our work to facilitate the sharing of information and advice about PWS involves upskilling key people so that they can then share their learning with others. Last year, in conjunction with an IPWSO travel scholarship, we were pleased to be able to support Bjørn Christensen, Service Delivery Lead at Community Connections, to attend IPWSO's PWS Professional Providers and Caregivers Conference in Berlin.

Bjørn is very keen to develop PWS specialism, discuss common issues, and work with others to evolve best practice. He returned from the conference having gained lots of knowledge and enthused with lots of ideas. He provided us with a lengthy report and we look forward to working with Bjørn in future projects sharing experience and expertise. Bjørn is also keen to connect residential providers in New Zealand to discuss issues, share experiences, ideas and strategies. Our hope is that in the future, New Zealand will have more specialist residential services for PWS, but in the meantime, it is important for future proofing that we develop and widen our national expertise.



During May Awareness Month, we shared a film screening of 'The Life You're Given' where filmmakers, Jay and Susan, were able to join us afterwards to answer questions. The film screening was very well attended and raised awareness and understanding of PWS for those unfamiliar with the syndrome. Families were also able to connect, share experiences and ask questions.

Our screening also raised funds for PWS research.



5 in-person PWS training workshops were delivered during the year. Cindy trained staff from residential support service providers: Spectrum Care, Community Connections, and Hohepa; I ran a school workshop in the Wellington region, and we provided PWS training at our transition event. Cindy also delivered 10 training sessions via Zoom for Complex Staffing Solutions. Some of these were full training workshops and others were shorter sessions of around an hour to provide support around issues that were arising. This is a new way of working that proved very useful for the provider and helped to facilitate important staff discussions.

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

In October 2024 we held our first transition event – a 2 day symposium at The Mount Richmond Hotel in Auckland. One day was for families and the other day was designed for agencies and service providers such as NASCS, supported employment agencies, residential providers etc. The provider day covered topics such as an overview of PWS, the impact of the transition period, the importance of good health and mental wellness during transition, and tips on accessing the community. 11 staff were registered from residential services (CSS, Community Connections, Spectrum Care) and support agencies (Enrich Plus and Care on Call). The parent day covered similar topics with more of a focus on what transition is and how to prepare for it, and this day was attended by 13 parents.

We are grateful to committee member Julie-anne Quinney (Transition Coordinator at Spectrum Care) who voluntarily provided essential input to the planning and running of this event. We would also like to thank all our invited guest speakers for giving up their time to present for us: lawyer Nan Jensen, psychologist Dr John Ford, endocrinologist Prof Paul Hofman, psychiatrist Dr Diana Andrea Barron, and Transition and Disability Information Advisors, Marian Galvin and Robyn Hoffman.

We were a little disappointed in the attendance numbers for this event but have noticed a reduced uptake of our training services last year and presume this might be linked to government funding freezes for providers. However, we were very fortunate and grateful to receive a project grant from IPWSO and Friends of IPWSO(USA) which meant the event was run without incurring expenses.

“It was really interesting and informative. What a complex syndrome. Guest speakers were great.”

“Enjoyed it. Always great when people presenting have lived experiences.”

“The most useful information and the challenge of support people working with PWS.”

“Everything was really informative and very helpful.”

“Lots of info and pamphlets which will be a great help.”

Various information resources were posted out during the year on request to families, hospitals and support providers, largely New Parent Packs, Teacher Packs and cookbooks. I have also supplied packs of resources to rare disorders events and to GP Conference events.

Two new videos were produced last year, with more in the pipeline, and work is ongoing to prepare a new transition to adulthood resource, and on the completion of our new information pack for supporting adults living with PWS.

I have continued to keep in touch with our subscribed database via regular emails, newsletters and social media, to share information about recommended webinars, conference presentations and new resources such as PWSAI's 'Practical Portions'.

Support

Our transition event not only provided information, but the opportunity for parents to connect, share experiences and learn from each other. These experiences are important to families.

***“Enjoyed the session, a lot covered.
Great to network with others.”***

***“Great meeting in person with
presenters and other parents.***

Informal discussions so useful.”

***“Really relevant material. Helpful
content and presented in an
authentic and empathetic manner.”***



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 include: accessing supports, illness, medicines and treatments, dietary advice, challenging behaviour, school funding, residential services, transition, mental health, court and legal issues.

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.

In 2024 we were very pleased to welcome Rebecca Payne to the staff team as our Young Families Support Coordinator. Rebecca has taken on this role in a voluntary capacity and has been doing a great job 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. Rebecca also hosted a meet and greet Zoom session to support and connect families of newly diagnosed children.

On a final note...

Finally, I would like to say a huge 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 Cindy for her dedication to the Association, for giving up a lot of her own time to support families in crisis and always being available to support me when I need it.

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 2024.

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: **Kahu Simmonds**
Position: Chair of the Committee
Date: 27 June 2025



Signed

Name: **Rachel McLellan**
Position: Treasurer
Date: 27 June 2025



Statement of Service Performance

Description of 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 and Quantification of Outputs	Actuals 2024	Actuals 2023 Unreviewed
Submissions made or public speaking on behalf of the PWS community.	7	4
Number of ALPWS advocacy & leadership peer group meetings.	1 (zoom)	2 (+ zooms)
Number of people reached through PWS awareness month via social media.	~ 13,000	~ 8000
Number of people reached through website Jul-Dec (page views/file downloads).	16,123 / 1061	not measured
Number of general information & support newsletters produced during the year.	7	6
Number of people receiving our general information & support newsletters.	303-352	296-352
Number of information packs distributed on request. (<i>new parent packs, school packs, information pamphlets, posters, booklets etc.</i>)	25 requests 49 resources + training notes	50 requests 152 resources + training notes
Number of training sessions provided for staff supporting people living with PWS.	15	13
Number of support enquiries received via phone, email, online contact.	62	24
Number of attendees living with PWS at PWSA in-person support events.	0	48
Number of relatives of people living with PWS at PWSA in-person support events.	15	not measured
Number of in-person support meetings with people living with PWS or families.	19	not measured
Number of in-person national support events or national meetings hosted.	1 (+3 via zoom)	2

Additional Information on Output Measures

We started using Google Analytics in mid-July and did not collect website data before this. 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. Our database contains 667 active contacts with emails distributed to targeted groups.

Statement of Financial Performance

For the year ended 31 December 2024

Revenue and Other Income	Note	2024	2023 Unreviewed & Restated
Grants and Funding	1	64,595	52,620
Donations and Fundraising	1	10,662	2,688
Training	1	2,840	4,424
Other Revenue	1	1,069	217
Interest Revenue	1	2,036	1,626
		<hr/>	<hr/>
Total Revenue		81,202	61,575
		<hr/>	<hr/>
Less: Expenses			
Volunteer and Contractor Related Costs	2, 6	(67,597)	(52,111)
Costs Related to Providing Goods or Services	2	(9,787)	(32,904)
Administrative Expenses	2	(6,970)	(11,177)
		<hr/>	<hr/>
Total Expenses		(84,354)	(96,192)
		<hr/>	<hr/>
Surplus / (Deficit) for the Year		(3,152)	(34,617)
		=====	=====

This Performance Report is to be read in conjunction with the accompanying Notes.

Statement of Financial Position

For the year ended 31 December 2024

CURRENT ASSETS	Note	2024	2023 Unreviewed & Restated
Bank Accounts and Cash	3	17,921	18,346
Term Deposits	3	35,415	33,378
Accounts Receivable	3	15,545	15,582
Other Receivables	3	-	615
		<hr/>	<hr/>
TOTAL ASSETS		68,881	67,921
		<hr/>	<hr/>
CURRENT LIABILITIES			
Creditors and Accrued Expenses	3	2,963	663
GST Payable	3	4,736	2,924
		<hr/>	<hr/>
TOTAL LIABILITIES		7,699	3,587
		<hr/>	<hr/>
NET ASSETS		61,182	64,334
		=====	=====
ACCUMULATED FUNDS			
Accumulated Surplus at the beginning of the year		64,334	98,951
Surplus / (Deficit) for the year		(3,152)	(34,617)
		<hr/>	<hr/>
		61,182	64,334
		=====	=====

This Performance Report is to be read in conjunction with the accompanying Notes.

Statement of Cash Flows

For the year ended 31 December 2024

Cash Flows from Operating Activities	2024	2023 Unreviewed & Restated
Cash was received from:		
Donations, fundraising and other similar receipts	74,738	54,903
Receipts from providing goods or services	4,459	4,074
Net GST (paid) / received	1,811	(1,287)
 Cash was applied to:		
Payments to suppliers	(23,528)	(49,838)
Payments to contractors	(57,905)	(50,150)
 Net Cash Flows from Operating Activities	 (425)	 (42,298)
 Cash Flows from Investing and Financing Activities		
Net Cash Flows from Investing and Financing Activities	-	-
 Net Increase / (Decrease) in Cash	 (425)	 (42,298)
 Opening Cash	 18,346	 60,644
Closing Cash	17,921	18,346
 This is represented by:		
Bank Accounts and Cash	17,921	18,346
	=====	=====

This Performance Report is to be read in conjunction with the accompanying Notes.

Statement of Accounting Policies

For the year ended 31 December 2024

Basis of Preparation of the Performance Report

PWSA(NZ) has elected to apply PBE SFR-A (NFP) Public Benefit Entity Simple Format Reporting – Accrual (Not For Profit) on the basis that it does not have public accountability and has total annual expenses of equal to or less than \$2,000,000. All transactions in the Performance Report are reported using the accrual basis of accounting. The Performance Report is prepared under the assumption that PWSA(NZ) will continue to operate in 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 independently reviewed every 2 years. The last independent audit of our accounts was undertaken in 2022 and biennial reviews are taking place from 2024.

Tier 2 PBE Accounting Standards Applied (if any)

PWSA(NZ) has not adopted any Tier 2 PBE Accounting Standards in the preparation of these accounts.

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 2024

Note 1: Analysis of Revenue

		2024	2023
Revenue Item	Analysis	\$	\$
Grants & Funding	Contract for Services with Whaikaha / MSD (DIAS)	54,920	52,620
	IPWSO Grant – Caregiver Conference	1,039	0
	IPWSO Grant – Transition Event	7,063	0
	APPWS24 Conference Subs for Committee Members / Speakers	1,573	0
	Total	64,595	52,620

		2024	2023
Revenue Item	Analysis	\$	\$
Donations & Fundraising	Donations / Koha from the Public or Members	10,174	2,688
	Sale of PWS Awareness Bracelets	488	0
	Total	10,662	2,688

		2024	2023
Revenue Item	Analysis	\$	\$
Training	Charges for Provision of Training Services	2,840	4,424
	Total	2,840	4,424

		2024	2023
Revenue Item	Analysis	\$	\$
Other Revenue	Sales – Cookbooks, Awareness Merchandise	1,069	217
	Total	1,069	217

		2024	2023
Revenue Item	Analysis	\$	\$
Interest Revenue	Term Deposit Interest	2,036	1,626
	Total	2,036	1,626

Note 2: Analysis of Expenses

		2024	2023
Expense Item	Analysis	\$	\$
Volunteer & Contractor Related Costs	Committee Meetings / AGM – travel & flights	0	2,164
	Committee Meetings / AGM – venue & catering	0	528
	Contractor Payments – Training Manager	3,930	6,410
	Contractor Payments – CEO / Operations (JD)	53,975	38,275
	Contractor Payments – CEO (Charlotte Roos)	0	3,325
	Conference APPWS24 Sydney	4,978	0
	IPWSO Caregiver Conference Berlin	4,424	0
	Training Expenses	290	1,398
	Travel - national	0	11
	Total	67,597	52,111

		2024	2023
Expense Item	Analysis	\$	\$
Costs Related to Providing Goods or Services	Event – ALPWS support	0	15,598
	Event – National camp	1,944	14,802
	Event – Adult Transition Symposium	6,043	0
	Resource Development	1,800	2,504
	Total	9,787	32,904

		2024	2023
Expense Item	Analysis	\$	\$
Administrative Costs	Affiliation Fees – IPWSO	368	367
	Audit/review Fee	2,500	4,200
	General Expenses	1,115	3,402
	Postage, Couriers, Printing & Stationery	314	438
	Subscriptions, Bank Fees, Online Conferencing	2,015	1,878
	Telephone & Internet	658	892
	Total	6,970	11,177

Note 3: Analysis of Assets and Liabilities

		2024	2023
Asset Item	Analysis	\$	\$
Bank Accounts & Cash	PWSA(NZ) ASB Fastnet Business Account	17,921	18,346
	Total	17,921	18,346

		2024	2023
Asset Item	Analysis	\$	\$
Investments	ASB Term Deposit Account	30,000	30,000
	ASB Term Deposit Interest	5,415	3,378
	Total	35,415	33,378

		2024	2023
Asset Item	Analysis	\$	\$
Accounts Receivable	Accounts Receivable	15,545	15,582
	Other Receivables	0	615
	Total	15,545	16,197

		2024	2023
Liability Item	Analysis	\$	\$
Creditors & Accrued Expenses	Accounts Payable	2,963	254
	Donations for Research to Transfer to FPWR	0	409
	Total	2,963	663

		2024	2023
Liability Item	Analysis	\$	\$
GST Payable	GST Payable	4,736	2,924
	Total	4,736	2,924

Note 4: Property, Plant and Equipment

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

Note 5: Investments, Commitments and Contingencies

PWSA(NZ) has an investment in a 6-month term deposit.

PWSA(NZ) has no commitments as at 31 December 2024. (2023 – nil)

PWSA(NZ) has no contingent liabilities or guarantees as at 31 December 2024. (2023 – nil)

Note 6: 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.

		2024	2023	2024	2023
		\$	\$	\$	\$
Description of Related Party Relationship	Description of Transaction (in cash or in kind)	Value of Transactions	Value of Transactions	Amount Outstanding	Amount Outstanding
J. Davies, CEO, Operations Manager, Committee Officer	Invoices to PWSA for time on management and operations	\$53,975	\$38,275		
C. Adams-Vining, Training Manager, Committee Officer	Invoices to PWSA for time on ALPWS support and training	\$3,930	\$6,410		
R. McLellan, Treasurer and Committee Officer	Provided accounting services at no charge				
C. Roos, previous CEO	Invoices to PWSA for administration time		\$3,325		
J. Davies, CEO, Operations Manager, Committee Officer	Reimbs for home internet, travel/expenses to APPWS conference & transition symposium	\$1,852	\$582		
C. Adams-Vining, Training Manager, Committee Officer	Reimbs for home internet, travel/expenses to APPWS conference & transition symposium	\$1,787	\$656		
R. McLellan, Treasurer and Committee Officer	Reimbs travel for flights – 2023 cmte mtg / 2024 transition symposium	\$287	\$507		
K. Simmonds, Chairperson and Committee Officer	Reimbs for flights to cmte mtg		\$417		
H. Sankey, Secretary and Committee Officer	Reimbs for flights to cmte mtg		\$387		
H. Arnott, Committee Officer	Reimbs for travel and expenses to 2023 cmte mtg / 2024 APPWS conference	\$1,288	\$17		
J. Mabin, Committee Officer	Reimbs for fuel to cmte mtg		\$93		
J. Davies, CEO, Operations Manager, Committee Officer	Legal advice in preparation for coronary inquest.		\$2,121		

Note 7: 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 8: Ability to Continue Operating

The entity will continue to operate for the foreseeable future.

Note 9: Correction of Errors

During the review, it was discovered that there were errors in the FY2023 figures in the financial statements. In the FY2023 Statement of Financial Performance, Total Expenses were understated by \$44. This was comprised of an understatement of \$45 in the Subscriptions & Bank Fees expense account and an overstatement of \$1 in the Event – National Camp expense account, both within Administrative Expenses. To correct this, Costs Related to Providing Goods or Services has been decreased by \$1 in the Event – National Camp expense account, and Administrative Expenses has been increased by \$45 in the Subscriptions, Bank Fees & Online Conferencing expense account for the FY2023 figures within the FY2024 Statement of Financial Performance. This has resulted in a corresponding increase in the FY2023 Total Expenses of \$44.

In the FY2024 Statement of Financial Position, the FY2023 closing Accumulated Surplus balance of \$63,390 did not match the FY2024 opening Accumulated Surplus balance of \$64,334, with the FY2023 closing balance understated by \$944. This was due to the FY2023 Other Receivables balance being understated by \$615 in the FY2023 Statement of Financial Position, and both the FY2023 Creditors and Accrued Expenses balance and GST Payable balance being overstated by \$323 and \$6 respectively. To correct this error, the FY2023 balance of Other Receivables has been increased by \$615, the FY2023 balance of Creditors and Accrued Expenses has been decreased by \$323, and the FY2023 balance of GST Payable has been decreased by \$6. This has resulted in a corresponding increase in the FY2023 closing Accumulated Surplus of \$944.

In the FY2023 Statement of Cash Flows, Interest Receipts of \$1,626 for interest accrued on a term deposit were recorded in error. As the interest was not actually received, and was reinvested into the term deposit, no cash was received. To correct this, the Interest Receipts line item has been removed in the FY2023 figures within the FY2024 Statement of Cash Flows. Additionally, the FY2023 figures in the Opening Cash and Closing Cash balances in the FY2023 Statement of Cash Flows incorrectly included the Term Deposits balance in the Statement of Cash Flows, and thus the Opening Cash balance was overstated by \$31,752, and the Closing Cash balance was overstated by \$33,378. To correct this, the FY2023 Opening Cash and Closing Cash balances in the FY2024 Statement of Cash Flows have been decreased by \$31,752 and \$33,378 respectively.

PRADER-WILLI SYNDROME AWARENESS MONTH

Veronica has just started school this term. Her mum wasn't sure how she would manage the change of people and environment, but she loves her teacher and teacher aide, and is confident on the school playground with the big kids!



Veronica

PRADER-WILLI SYNDROME AWARENESS MONTH

PWS
PRADER-WILLI SYNDROME
RAKIROIRO ATE JERU
COMMUNITY
SPOTLIGHT ON...



Luella

Luella is 17 years old and really enjoyed a recent family holiday to Sanico. Luella enjoys swimming lessons and she continues to keep fit by walking the boardwalk near Mount Maunganui and the walk down to Karate Falls.

PRADER-WILLI SYNDROME AWARENESS MONTH

My name is Kyra and I am 6 months old today! Happy Mothers Day to my mum! I have recently discovered ice (food). Breakfast is my favourite time of the day. My favourite foods are mashed banana and yoghurt, and mashed butternut pumpkin.

Kyra



**PRADER-WILLI SYNDROME
ASSOCIATION NEW ZEALAND**
ADVOCACY • EDUCATION • SUPPORT

PRADER-WILLI SYNDROME AWARENESS MONTH

Bradley is 39 years old and he LOVES playing rugby! He works full time in a commercial laundrette, operating commercial washers and dryers. He is very proud to be earning a living wage and looking after clothes worn by people working in Antarctica.



Bradley

PRADER-WILLI SYNDROME AWARENESS MONTH

PWS
PRADER-WILLI SYNDROME
RAKIROIRO ATE JERU
COMMUNITY
SPOTLIGHT ON...



Clara

Clara is now 11 months old and is the youngest in her family of 4. Her parents say, "In June last year, we had our gift. Clara is a beautiful, smart, and very loving baby girl. We face challenges, but we have the greatest love in the world!"

PRADER-WILLI SYNDROME AWARENESS MONTH

Josie is 8 years old and her hobbies include doing puzzles, reading, cuddling her two fluffy cats, and going for walks with her family. Josie is currently preparing to sit her grade 1 ballet exam and she says that ballet is "sooo fun!"



Josie

PRADER-WILLI SYNDROME AWARENESS MONTH

Tommy has just turned 5 and is about to start school! Tommy loves reading books, telling stories, and music, especially musicals like The Lion King, Moana, Phantom of the Opera, and Frozen. He attends RDA, swimming lessons, and has recently started rugby practice!



Tommy

PRADER-WILLI SYNDROME AWARENESS MONTH

PWS
PRADER-WILLI SYNDROME
RAKIROIRO ATE JERU
COMMUNITY
SPOTLIGHT ON...



Emily

Emily is 12 and is lucky to be supported by a fantastic team at Mairi School. When her Mum was away recently, her school understood how hard that was and awarded her a certificate at assembly for, "Being positive and strong whilst adjusting to changes in her routine." Well done Emily!

PRADER-WILLI SYNDROME AWARENESS MONTH

Harry is 7 months old and he's quite obsessed with flipping over, but hasn't figured out how to flip back yet! He really enjoys discovering solids and he loves splashing in the bath. Harry is a lovely, happy wee baby and it seems the only thing to upset him is getting dressed!



Harry

PWS
PRADER-WILLI SYNDROME
RAKIROIRO ATE JERU
COMMUNITY
SPOTLIGHT ON...

At daycare, Harry enjoys playing with bubbles in the sandpit, and making friends.

INDEPENDENT ASSURANCE PRACTITIONER'S REVIEW REPORT

To the Committee Members of Prader-Willi Syndrome Association (NZ) Incorporated

Report on the Performance Report

Qualified Conclusion

We have reviewed the accompanying performance report of Prader-Willi Syndrome Association (NZ) Incorporated ("the Association") on pages 14 to 24, which comprise the entity information and statement of service performance, the statement of financial performance and statement of cash flows for the year ended 31 December 2024, the statement of financial position as at 31 December 2024, and the statement of accounting policies and other explanatory information. The performance report has been prepared based in accordance with the Public Benefit Entity Simple Format Reporting – Accrual (Not-for-Profit) ('PBE SFR-A (NFP)').

Basis of Qualified Conclusion

Opening balances on Statement of Financial Position as at 1 January 2023

We were appointed as assurance practitioners of the Association's performance report for the year ended 31 December 2024 after 1 January 2023. The Association's performance report, including the statement of service performance, for the year ended 31 December 2023 was not reviewed or audited and accordingly there is no assurance expressed in respect of the comparative information presented in the performance report, including the statement of service performance and the opening balances of the Association's statement of financial position as at 1 January 2023. Since opening balances enter into the determination of the Association's financial performance and its cash flows for the year ended 31 December 2024, we were unable to obtain sufficient appropriate evidence to determine whether adjustments might have been necessary in respect of the financial performance for the year reported in the statement of financial performance or the cashflows for the year reported in the statement of cashflows.

Statement of Service Performance for the period ended 31 December 2024

The Association has included a description and quantification of the Association's Outputs including the number of support enquiries received via phone, email, online contact and number of in-person support meetings with individuals in the statement of service performance. We were unable to obtain sufficient appropriate evidence to corroborate these Outputs disclosed in the statement of service performance.

The Responsibility of the Committee Members for the Performance Report

The Committee Members are responsible for the preparation and fair presentation of the performance report in accordance with the Public Benefit Entity Simple Format Reporting – Accrual (Not-for-Profit) ('PBE SFR-A (NFP)'), and for such internal control as the Committee Members determine is necessary to enable the preparation of the performance report that are free from material misstatement, whether due to fraud or error.

Assurance Practitioner's Responsibility

Our responsibility is to express a conclusion on the performance report. We conducted our review of the statement of financial performance, statement of financial position, statement of cash flows, statement of accounting policies and notes to the performance report in accordance with International Standard on Review Engagements (New Zealand) (ISRE (NZ)) 2400 (Revised), *Review of Historical Financial Statements Performed by an Assurance Practitioner who is not the Auditor of the Entity*, and the review of the entity information and statement of service performance in accordance with the International Standard on Assurance Engagements (New Zealand) ISAE (NZ) 3000 (Revised) *Assurance Engagements Other than Audits or Reviews of Historical Financial Information*. Those standards require us to conclude whether anything has come to our attention that causes us to believe that the performance report, taken as a whole, is not prepared in all material respects in accordance with the Public Benefit Entity Simple Format Reporting – Accrual (Not-For-Profit). Those standards also require that we comply with ethical requirements.

A review of the performance report in accordance with ISRE (NZ) 2400 (Revised) and ISAE (NZ) 3000 (Revised) is a limited assurance engagement. We perform procedures, primarily consisting of making enquiries of management and others within the Association, as appropriate, and applying analytical procedures, and evaluate the evidence obtained. The procedures selected depend on our judgement, including the areas identified where a material misstatement is likely to arise and includes performing procedures to obtain evidence and evaluating whether the reported outcomes and outputs, and quantification of the outputs to the extent practicable, are relevant, reliable, comparable and understandable.

The procedures performed in a review are substantially less than those performed in an audit conducted in accordance with International Standards on Auditing (New Zealand) and ISAE (NZ) 3000 (Revised). Accordingly, we do not express an audit opinion on the performance report.

Other than in our capacity as assurance practitioner we have no relationship with, or interests in, the Association.

Conclusion

Based on our review, other than the items noted above in our *Basis for Qualified Conclusion*, nothing has come to our attention that causes us to believe that the Association's performance report does not present fairly, in all material respects, the financial position of the Association at 31 December 2024, and its financial performance for the year then ended, in accordance with the Public Benefit Entity Simple Format Reporting – Accrual (Not-for-Profit) ('PBE SFR-A (NFP)').



BAKER TILLY STAPLES RODWAY AUCKLAND

Auckland, New Zealand

27 June 2025