Prader-Willi Syndrome Association (NZ)

Annual Performance Report

Year ending December 2023

PWS PRADER-WILLI SYNDROME
ASSOCIATION NEW ZEALAND
ADVOCACY · EDUCATION · SUPPORT

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

9 Otupoa Way, Paraparaumu, 5032

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Statement from the Committee

The Committee is pleased to present the 2023 Annual Performance Report for the Prader-Willi Syndrome Association (NZ) Incorporated.

Our purpose is to enhance the lives of New Zealanders living with Prader-Willi syndrome by providing advocacy, education and support. Prader-Willi syndrome is a rare and complex genetic condition affecting around 1 in 15,000 to 25,000 newborns. People affected by PWS face unique challenges due to limited knowledge in our health and disability systems about the syndrome and how to support better outcomes.

The past year involved plenty of mahi on our purpose, which included collaborations with Rare Disorders NZ on health strategy, continuing with our education pillar by sharing information materials and providing trainings to residential support service providers and schools, and by providing one-to-one support to families and people living with PWS when they call for it.

We held our biennial national camp at Lake Taupō which was well attended and is always a valuable opportunity to connect with others travelling a similar journey in a mutually supportive environment. Thanks to the Lottery Board for contributing to those costs. We also held a Leadership and Social weekend in Auckland for adults living with PWS which was an enormous success. PWS significantly impacts the lives of adults living with PWS and can result in a feeling of isolation in the wider community. It was therefore so important for those attending (adults living with PWS and their support person) to re-connect with peers, share, learn and have fun.

Our Committee were also able to meet in-person during the year and work on our strategic planning. Using a SWOT analysis we identified an area for strengthening as new directions for supported living options for PWS. We discussed concerns around wait times for residential places, system navigation, prevention of and response to crisis, and issues around use of restrictive practice. We were pleased to be able to support Bjørn Christensen to attend IPWSO's International Caregivers' Conference this year to assist us in addressing these issues, and by expanding our relationships and networks, we also aim to maximise our training potential.

The Committee acknowledges that New Zealand lacks expertise in many areas of support (such as mental health and behaviour support), so we are actively supporting attendance at conferences as well as accessing the expertise of international specialists where possible.

While we made some great strides, the year was one of our toughest years to date as we sadly lost further members of our community too soon, including the dearly-loved children of PWSA staff, Hannah Adams-Vining and Jacob Davies. Sadly, Jacob's death could most likely have been avoided had his support workers at the time known more about PWS.

Our focus in the next year is to maintain emphasis and build on education for families and organisations that support people with PWS. This will be through a transition symposium and a support providers network forum.

Ngā mihi nui - Thank you

Committee of the PWS Association NZ

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 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 around PWS.

Our Strategy

Advocacy

To advocate on issues that affect people living with PWS or their families.

To provide advocacy services to individuals and families as needed.

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

Education

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

To provide PWS training courses, workshops, and conference opportunities.

Support

To support families via hosted events, facilitated connection, and on request.

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

To support PWS research, and the development of clinical expertise.

Our Structure

The PWSA(NZ) is governed by a committee, which currently comprises 10 officers and aims to meet every two months. Two committee members are also part-time paid contractors – the CEO and the Training Manager. All other committee members 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, the Training Manager, and we are pleased to have just welcomed a Young Families Support Coordinator to the team in June 2024.

Our Staff Team

Jo Davies

CEO / Operations and Projects 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 8-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.

Helen Sankey, Secretary

I live in Christchurch and joined the board in 2016. I work as a pharmacist and have a teenage daughter living with PWS. I joined the board with the aim of helping others and passing on knowledge gained over the years.

Our Main Sources of Cash and Resources

Our main source of income is through our DIAS contract with Whaikaha for providing Disability Information and Advisory Services. Our current contract expires 30 June 2026. We also submit grant applications for specific projects, such as family support weekends. In 2023 we were fortunate to receive partial funding from Te Puna Tahua | Lottery Grants Board toward our national camp in Taupō. As a registered charity, PWSA(NZ) also receives a small amount of donations.

Our Main Methods of Fundraising

PWSA(NZ) has a Givealittle page which our members can use for collecting donations, or to create their own fundraising pages for events they might participate in, 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 that may be needed, such as ribbons, wristbands, posters and Tshirts.

Sometimes we organise our own fundraising events, such as sponsored walks in the past, and a movie screening that took place recently.

PWSA(NZ) also facilitates fundraising for PWS research through a 2nd Givealittle page because being able to contribute to finding future treatments is important to families.

Our 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. Our small staff team are stretched to fill multiple roles, so volunteers are much appreciated.

Management Report

During 2023, I formally took on the CEO role in addition to Operations and Projects Manager.

It was another busy year for PWSA in which we held two well attended support weekends, published a new resource, increased the number of training workshops delivered, advocated on several issues, and initiated a number of new projects.

Advocacy

I submitted 2 formal responses to public consultations: one by Pharmac on testosterone formulations, and one by the Law Commission on their current review of adult decision-making capacity law.
I have also followed this up by making international enquiries around guidelines and law in place overseas that influence ability to apply restrictive practices or decision-making supports enabling food security.
There is more work to be done in this area following the release of the Law Commission's 2nd Issues Paper. We also need to ensure that safety systems can easily be activated to support people living with PWS wherever they choose to live, work, or participate in the community.
In 2023, PWSA was asked to write to the restrictive practices board of a residential support services provider - an example of the need for national guidelines that include the safety support needs of PWS.

In response to concerns around late diagnosis of scoliosis and the advice sometimes provided to patients, I sought advice from a leading expert, Dr Harold van Bosse, and have since sent a letter to New Zealand's orthopaedic, endocrine and paediatric groups advocating for a review of scoliosis screening practice for patients with PWS.

New Zealand's first Rare Disorders Month took place in March, which we supported as part of the RDNZ collective to raise awareness of the unique challenges faced by people living with rare disorders in New Zealand.

In May, Cindy and I attended RDNZ's Parliament launch of their Insights Report by BERL *"Pathways towards better health outcomes"*. The event was attended by key stakeholders: MPs, officials from the Ministry of Health, Whaikaha and Pharmac, health professionals, academics and pharmaceutical companies. I was invited to speak and shared personal family experience of unmet needs and told my son's story up until that point, of how a lack of supports from the education, social, health and mental health systems had resulted in dire negative consequences. I also reflected on the common challenges experienced by many people living with PWS due to a lack of evidence based and coordinated standards of care with appropriate supports.

During May, we also participated as always in international PWS Awareness Month, but managed to significantly increase our reach through a new infographic campaign and a new social media account on Instagram.

During the year I have attended various meetings, including with Whaikaha, IPWSO, RDNZ, and other national support group leads. Most importantly, I have provided input via RDNZ to the development and draft stages of a Rare Disorders Health Strategy by the Ministry of Health, key points being a centre of expertise, equitable access to specialist services, national care standards and clinical pathways for PWS linked to patient health records, enabling new medicines to more easily become available, and the availability of pharmacogenomic testing.

Later in the year, we started work on planning the 2024 Asia Pacific PWS Conference with PWS Australia and Prader-Willi Research Foundation Australia. This conference is taking place in Sydney, August 2024. It has been good to establish a valuable new relationship with PWRFA.

Towards the end of the year, Hayley Arnott (committee officer) and I also started work on developing an action plan to improve educational supports for pupils with PWS, especially around health and safety needs. We began by constructing a survey for families to build an accurate picture of the adequacy of current supports available.

The advocacy work of the PWSA also includes advocating for individuals as requested or needed. Last year this involved advocating with agencies such as NASC services and seeking expert advice when needed.

Education

Our Statement of Service Performance report (p.14) records that many free information resources were posted out during the year on request to families, schools, hospitals and support providers. I have also supplied large packs of information resources to rare disorders events and to the North & South Island GP Conference and Medical Exhibitions.

A new health and safety poster was made available that included some updated advice.

I also began work on another new resource – an information pack on supporting adults living with PWS, which is yet to be completed.

I endeavour to keep our website resources up to date and people frequently tell us that they were able to find what they were looking for and download resources.

Cindy delivered 5 in-person trainings during the year to residential support service providers. These were for staff at One2One, Spectrum Care, Community Connections, and 2 branches of IDEA Services. Cindy also delivered 8 training workshops via Zoom – for Creative Abilities, Community Living Trust, Complex Staffing Solutions, and 3 trainings for schools. PWS training is essential for support staff, so we are very pleased to see this growth in the number of trainings, with providers increasingly making use of our website booking page, as well as continuing to book directly with Cindy.

I have continued to keep in touch with our subscribed database via regular emails, newsletters and social media to share information about important new advice, resources, recommended webinars and conference presentations.

Support

After postponing our 2022 camp due to covid, we were able to hold our national camp in March and returned to Lake Taupō once again. Our camp is a fantastic opportunity for people living with PWS of all ages, their families and support workers, to connect, share experiences and learn from each other. Our feedback survey indicated that the camp was enjoyed by all.

> ***"Camps are highly invaluable to us as a family. It is our only way to connect to other families who are going through the same things as ourselves, and it is something we always look forward to and try to attend."***

> ***"The main benefits were networking with people who understand, talking through issues and seeing how others dealt with them."***

> ***"I really enjoy these camps and this one was especially good. Meeting up with other parents and caregivers and listening to their stories is really great."***

We had 78 people register for our 2023 camp and 70 people who were able to attend. We are grateful to the Lottery Grants Board for their contribution of $5000 toward the camp costs. Total camp costs were just under $17,000 before grant funding and after family contributions. Therefore, with costs expected to rise in future, the Association will need to secure additional funding and consider increasing family contribution amounts.

The camp provided an opportunity for another adults living with PWS meeting (ALPWS Leadership), attended by 17 people. The group decided that they would like a representative group to meet more often *(pictured here)*, and new goals were set which included offering peer support and increasing leadership opportunities, with a spokesperson at PWSA committee meetings.

James Robinson was nominated by the group for the spokesperson role and we were pleased to see him elected to our Committee at our 2023 Annual General Meeting.

Our ALPWS group were able to meet again last year at our second Leadership and Social Weekend for adults living with PWS. This took place in Auckland during November and was attended by 21 adults living with PWS. The weekend was facilitated by Cindy, assisted by her husband by Mike, and lots of fun was had by all. Cindy supported the group in developing self-advocacy skills through role-play and advisory panel activities. Some of the activities were recorded by a videographer and we are working on editing the footage from this weekend to create useful material for advocacy, awareness raising, and to use in training sessions.

The overall cost of the ALPWS Leadership and Social Weekend was around $16,000 excluding videographer costs, and after contributions. We would not usually be able to run two such costly events in one year, but it was important to have a bit of a 'catch-up' after covid postponements. However, as above, the Association will need to look more widely at future fundraising opportunities and plan carefully for years ahead.

"All activities were a great experience. Being a part of the ALWPWS was definitely a learning experience for myself and the person I supported."

"The ice breaker games were fantastic. I will use some of these ideas in group situations"

"A fantastic opportunity to meet people and get to know the community."

In addition to hosting events, the PWSA provides support services in other ways. We have continued to receive support enquiries through our website, our freephone helpline, and via email or messenger contact. Support enquiries have related to diet, medications, living situations, school issues, residential support services, and general information. Occasionally these enquiries involve reaching out to an expert for some specialist clinical advice.

Each year we also receive contact from families with newly diagnosed children and I have connected them to other families with young children. Hayley Arnott has been helping with welcoming young families to our support network and I am very pleased that Rebecca Payne has also just volunteered to help support new families and is taking on a Young Families Support Coordinator role.

Many families tell us that they prefer to connect with families whose children are at a similar age or stage, so in 2023 I set up 3 new age-based Facebook groups for parents of 0-5yrs, 6-12yrs, and 13+ years. These are beginning to be well used, particularly the group for younger families. I have also encouraged the forming of a sibling support group, run by and for siblings, and hope to see this established soon.

On a final note…

One of the highlights of 2023 occurred at the end of the year when Pharmac gave a prioritisation ranking to the funding of growth hormone therapy for adults living with PWS, following a funding recommendation by Pharmac's Endocrinology Specialist Advisory Committee. It now sits on Pharmac's Options for Investment List, and I have asked for further information about the priority ranking, but this is apparently commercially sensitive information that cannot be shared. Pharmac are also unable to provide a timeframe for funding because this is dependent on many factors, including the funds available to Pharmac. I will continue to apply pressure for funding to be approved, and Rare Disorders New Zealand (RDNZ) have been supporting us in this.

I think it is important to recognise all those who have worked on the approval and funding of growth hormone for PWS and the gradual widening of access over the last 2 decades. Linda Thornton and Karen O'Reilly were instrumental in achieving the removal of the 3rd height percentile criterion which had prevented access to treatment for most children with PWS. Sarah McLarin and I worked on later submissions for earlier treatment, the removal of the remaining growth criteria, and requesting treatment extension into adulthood. Many parents also wrote letters, shared their stories and submitted responses to Pharmac. We also need to thank Rare Disorders New Zealand for attending meetings with us, supporting us with our submissions, and raising the funding of GHT in their regular medicines access meetings with Pharmac.

Combined advocacy has strengthened our voice and achieved results. We just need to continue working together for one final push!

Unfortunately, 2023 has also been the most difficult year for the staff team at PWSA because Cindy and I both lost a child who had lived with PWS, Hannah and Jacob, who are both featured on this report's title page.

Cindy's daughter Hannah was 34 years old and very well-known and liked amongst New Zealand's PWS community. Her insightful and wise presence was greatly missed at the adult's weekend in November.

Jacob was only 20 years old when he died suddenly and unexpectedly. His life was tragically cut short as a direct result of poor care received by a service provider whose staff had no training, experience or understanding of PWS. Sadly, where Jacob was living was not of his or our family's choosing, and despite our concerns, we had no say in where he was placed. The events that unfolded highlight the necessity for compulsory training of anyone who is working in a support role for persons living with PWS, and for provider training to be repeated regularly due to high staff turnover. A requirement for compulsory training is something that I have personally set a goal to achieve in Jacob's memory.

There are service providers in New Zealand who work closely with us and do contact us frequently to book either full 'Introduction to PWS' training or refresher courses for their staff. We continue to share information resources, but the gathering of staff for training is one of the only ways to ensure that important health and safety information has been disseminated and understood.

Cindy and I would like to thank everyone who has reached out and supported us during this difficult period.

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 whose strength and ability to carry on supporting others has been inspirational.

Jo Davies

CEO, Operations and Projects

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 ending December 2023.

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

Signed		Signed	
Name:	**Kahu Simmonds**	Name:	**Rachel McLellan**
Position:	Chair of the Committee	Position:	Treasurer
Date:	21st June 2024	Date:	21st June 2024

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 will have had opportunity to have their voice listened to.**
- **More people will have awareness of PWS and a wider understanding of the support needs associated with PWS.**

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 PWS in residential services will be well supported to live safe, healthy lives, participating in their local community.**

Support

- **Individuals living with PWS 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.**
- **Any fundraising efforts for PWS research will have been supported.**
- **Clinical practice, expertise, or access to trials & treatments may be improved through collaborations and exchange of ideas.**

Description and Quantification of Outputs	Actuals 2023	Actuals 2022
Submissions made or public speaking on behalf of the PWS community.	4	2
Number of ALPWS advocacy & leadership peer group meetings.	2 (+ zooms)	
Number of people reached through PWS awareness month via social media.	~ 8000	
Number of general information & support newsletters produced during the year.	6	8
Number of people receiving our general information & support newsletters.	296-352	
Number of information packs distributed on request. *(new parent packs, school packs, information pamphlets, posters, booklets etc.)*	50 requests 152 resources + training notes	48 requests
Number of training sessions provided for staff supporting people living with PWS.	13	5
Number of support enquiries received via phone or email contact.	24	
Number of attendees living with PWS at PWSA(NZ) in-person support events.	48	6
Number of in-person national support events or meetings hosted.	2	1

Additional Information on Output Measures

Our website is a main source of up-to-date information that is easily found and well used, but we do not collect data on website views or downloads. We also do not collect data from our private Facebook group that parents often use to ask questions, seek advice, share ideas and experiences, including data from the 3 new age-based groups. Our database contains 656 active contacts but emails and general newsletters are distributed to targeted groups.
We are continuing to refine qualitative measures of our outputs.

> *“I was looking up medical research for PWS and found your website. It is extremely helpful information. I wanted to thank you for your excellent work.”* (Email received Nov 2023)

Statement of Financial Performance

For the year ended 31 December 2023

Revenue and Other Income	**Note**	**2023**	**2022**
Grants & Funding	1	52,620	55,195
Subscriptions & Donations		2,688	3,287
Sales & Courses		4,424	980
Other revenue		217	355
Interest revenue		1,626	683
Total Revenue		61,575	60,500
Less: Expenses			
Contractor costs	2	(48,010)	(41,455)
Administrative expenses		(48,138)	(22,765)
Total Expenses		(96,148)	(64,220)
Surplus / (Deficit) for the Year		(34,573)	(3,720)
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Statement of Financial Position

For the year ended 31 December 2023

CURRENT ASSETS	Note	2023	2022
Cash at Bank	3	18,346	60,644
Short Term Deposits		33,378	31,752
Accounts Receivable		15,582	14,459
Other Receivables			615
		________	________
TOTAL ASSETS		67,306	107,470
		________	________
CURRENT LIABILITIES			
Creditors and accrued expenses	3	986	13,769
GST Payable		2,930	3,716
		________	________
TOTAL LIABILITIES		3,916	17,485
		________	________
NET ASSETS		63,390	89,985
		============	============
ACCUMULATED FUNDS			
Accumulated surplus at the beginning of the year		97,963	93,705
Surplus / (Deficit) for the year		(34,573)	(3,720)
		________	________
		63,390	89,985
		=============	=============

Statement of Cash Flows

For the year ended 31 December 2023

Cash flow from Operating Activities	**2023**	**2022**
Cash was received from:		
Donations, fundraising and other similar receipts	54,903	60,045
Receipts from providing goods or services	4,074	1,335
Interest receipts	1,626	
Net GST (paid) / received	(1,287)	(1,305)
Cash was applied to:		
Payments to suppliers	(49,838)	(18,073)
Payments to contractors	(50,150)	(40,108)
Net Cash from Operating Activities	(40,672)	1,894
Cash Flow from Financing Activities		
Cash was applied to:		
Transfers (to) / from short term deposits	-	-
Net Cash from Financing Activities	-	-
Net Increase / (Decrease) in Cash	(40,672)	1,894
Opening Cash	92,396	58,750
Closing Cash	51,724	60,644

** (Refer to note in Statement of Accounting Policies - Bank Accounts and Cash)*

This is represented by:

Cash and cash equivalents	51,724	60,644
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Statement of Accounting Policies

For the year ended 31 December 2023

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.

* It is noted that prior to 2023, the PWSA(NZ) short term deposit and interest has not been recorded on the Statement of Cash Flows. This has been corrected and hence, the opening cash figure in 2023 differs from the closing cash figure in 2022 by the Short Term Deposit Balance as at 31 December 2022.

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 will take 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 2023

Note 1: Analysis of Revenue

		2023	2022
Revenue Item	**Analysis**	**$**	**$**
Fundraising			
	Total	**0**	**0**

		2023	2022
Revenue Item	**Analysis**	**$**	**$**
Donations and other similar revenue	Donations / koha from the public or members	2,688	3,287
	Total	**2,688**	**3,287**

		2023	2022
Revenue Item	**Analysis**	**$**	**$**
Fees, subscriptions and other revenue from members			
	Total	**0**	**0**

		2023	2022
Revenue Item	**Analysis**	**$**	**$**
Revenue from providing goods or services	Contract for services with Whaikaha (DIAS)	52,620	50,195
	Lotteries Grant Board (for family support camp)	0	5,000
	Charges for provision of training services	4,424	980
	Sales – cookbooks, awareness merchandise	217	355
	Total	**57,261**	**56,530**

		2023	2022
Revenue Item	**Analysis**	**$**	**$**
Interest, dividends and other investment revenue	Term Deposit interest	1,626	683
	Total	**1,626**	**683**

Note 2: Analysis of Expenses

		2023	2022
Expense Item	**Analysis**	**$**	**$**
Expenses related to public fundraising			
	Total	**0**	**0**

		2023	2022
Expense Item	**Analysis**	**$**	**$**
Volunteer and employee related costs	Committee meeting / AGM – travel & flights	2,164	0
	Committee meeting / AGM – venue & catering	528	0
	Contractor payments – Training Manager	6,410	1,800
	Contractor payments – Operations & Projects	38,275	32,380
	Contractor payments – CEO (Charlotte Roos)	3,325	7,275
	Training expenses	1,398	1,170
	Travel national	11	0
	Total	**52,111**	**42,625**

		2023	2022
Expense Item	**Analysis**	**$**	**$**
Costs related to providing goods or services	Audit Fee	4,200	3,105
	Event – ALPWS Support	15,598	
	Event – National Camp	14,803	
	Event – Young Families Support		7,204
	General Expenses	3,402	280
	Postage, Couriers, Printing & Stationery	438	7,700
	Resource Development	2,504	
	Subscriptions & Bank Fees	1,833	2,075
	Telephone & Internet	892	886
	Total	**43,670**	**21,250**

		2023	2022
Expense Item	**Analysis**	**$**	**$**
Grants and donations made			
	Total	**0**	**0**

		2023	2022
Expense Item	**Analysis**	**$**	**$**
Other expenses	Affiliation fees – IPWSO	367	345
	Total	**367**	**345**

Note 3: Analysis of Assets and Liabilities

		2023	2022
Asset Item	**Analysis**	**$**	**$**
Bank accounts and cash	PWSA(NZ) ASB fastnet business account	18,346	60,644
	Total	**18,346**	**60,644**

		2023	2022
Asset Item	**Analysis**	**$**	**$**
Debtors and prepayments	Accounts receivable	15,582	14,459
	Other receivables		615
	Total	**15,582**	**15,074**

		2023	2022
Asset Item	**Analysis**	**$**	**$**
Inventory			
	Total		

		2023	2022
Asset Item	**Analysis**	**$**	**$**
Investments	ASB Term Deposit account	30,000	30,000
	ASB Term Deposit interest	3,378	1,752
	Total	**33,378**	**31,752**

		2023	2022
Liability Item	**Analysis**	**$**	**$**
Creditors and accrued expenses	Accounts payable	202	10,528
	GST payable	2,930	3,716
	Total	**3,132**	**14,244**

		2023	2022
Liability Item	**Analysis**	**$**	**$**
Employee costs payable			
	Total	**0**	**0**

		2023	2022
Liability Item	**Analysis**	**$**	**$**
Unused donations and grants with conditions	Donations for research to transfer to FPWR	784	3,241
	Total	**784**	**3,241**

Note 4: Property, Plant and Equipment

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

Note 6: Commitments and Contingencies

There are no commitments as at 31 December 2023. (Last year – nil)

There are no contingent liabilities or guarantees as at 31 December 2023 (Last year – nil.)

Note 9: 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.

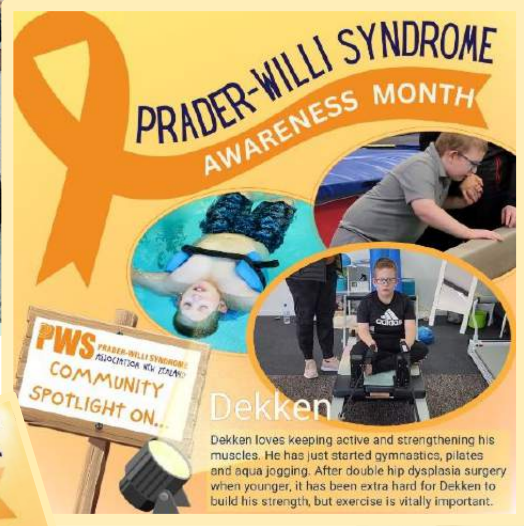
		2023	2022	2023	2022
		$	$	$	$
Description of Related Party Relationship	**Description of Transaction (in cash or in kind)**	**Value of Transactions**	**Value of Transactions**	**Amount Outstanding**	**Amount Outstanding**
J. Davies, CEO, Operations and Projects Manager, Committee Officer	Invoices to PWSA for time on management and operations	$38,275	$30,240		$2,140
C. Adams-Vining, Training Manager, Committee Officer	Invoices to PWSA for time on ALPWS support and training	$6,410	$1,800		
R. McLellan, Treasurer and Committee Officer	Provided accounting services at no charge				
C. Roos, previous CEO	Invoices to PWSA for administration time	$3,325	$7,275		
C. Roos, previous CEO	Reimbursements for expenses incurred		$261		
J. Davies, CEO, Operations and Projects Manager, Committee Officer	Reimbursements for travel, home internet, expenses	$582	$943		$73
C. Adams-Vining, Training Manager, Committee Officer	Reimbursements for flights to cmte mtg, home internet, expenses	$656	$1,268		
R. McLellan, Treasurer and Committee Officer	Reimbursements for flights to cmte mtg	$507			
K. Simmonds, Chairperson and Committee Officer	Reimbursements for flights to cmte mtg	$417			
H. Sankey, Secretary and Committee Officer	Reimbursements for flights to cmte mtg	$387			
H. Arnott, Committee Officer	Reimbursements for parking for cmte mtg	$17			
J. Mabin, Committee Officer	Reimbursements for fuel to cmte mtg	$93			
J. Davies, CEO, Operations and Projects Manager, Committee Officer	Legal advice in preparation for coronary inquest.	$2,121			

Note 10: 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. (Last year – nil)

Note 11: Ability to Continue Operating

The entity will continue to operate for the foreseeable future.



Dekken loves keeping active and strengthening his muscles. He has just started gymnastics, pilates and aqua jogging. After double hip dysplasia surgery when younger, it has been extra hard for Dekken to build his strength, but exercise is vitally important.

Emily is challenged by PWS every day in many ways. The hardest for her being anxiety, not understanding people if they talk too fast, and fatigue due to low muscle tone.

But 12 year old Emily powers through due to her extreme curiosity, sociability and slapstick sense of humour. Nice work Emily!

My name is Xzavier and I'm 8 years old. I love playing the exercise games on my Nintendo switch, going for walks with my baby brother, doing puzzles and drawing pictures for all the people I love. I also love cuddling in the quilt my Nana Jo made me for PWS awareness month. My goal this year is to be able to go to my new school full time.