



SUPPORTING PEOPLE WITH PRADER-WILLI SYNDROME AND THEIR FAMILIES

Prader-Willi Syndrome Association (NZ) Incorporated

Patron: His Excellency the Right Honourable Sir Anand Satyanand GNZM, QSO, Governor-General of New Zealand
President: Esko Wiltshire, MD, FRACP

Prader-Willi Syndrome Association (NZ) Inc Annual Report



Year Ending December 2010

Funding from the NZ Lottery Grants Board helps fund this Association

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Consultants: Peter SW Davies, PhD, Director, Children's Nutrition Research Centre, Royal Children's Hospital, Brisbane; John Ford, Psychologist, Tautoko Services, Nelson; Clare Wall PhD, Nutritionist, Auckland Medical School

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1. Chairperson's Report

The year has been an interesting one for the Association with the continuation of our work in all of our traditional areas of activity which involves advocating for members and representing their interests in our society in many different ways. This translates into our continuing battle for wider use of Growth Hormone, assisting education applications for teacher aide and funding services, providing caregiver and teacher training, together with a general advisory service and pastoral care service as and when required.

In addition your Board has been involved in detailed planning for the Association's future following Linda Thornton's retirement from the National Director role, which has culminated in a restructure to a management form that will take us into, and through, the next phase of our development.

The model for the running of the New Zealand Association that has been adopted by your Board is one that provides opportunity for members to contribute in many different ways and in many different areas of our Association's interests.

The new management structure includes the appointment of a Chief Executive Officer, the appointment of an Administration Manager, and a series of Team Leaders who have each been assigned age related groups to provide a more pastoral approach to our members in an endeavor to become more relevant to their individual needs on a day to day basis.

Team Leaders and/or committees have been assigned projects and areas of responsibility which include Education, Growth Hormone, Training, Fund Raising, and Residential Care. Clear objectives are being set so that outcomes can be measured in a meaningful way.

Activities are being planned this year for various age groups and we are looking forward to the Australasian conference next March in Sydney, for which planning has started on both sides of the Tasman.

I wish to thank Linda Thornton for her many years of service to the Association as National Director, and to welcome the new Chief Executive Officer and management team. I look forward to working with all members, board members, and the new management team in the coming year so that the objectives we have set for our Association are met.

I would like to thank the board for its support of me as Chairman during the last year and to express my gratitude to all of our consultants for the work they put in on a voluntary basis. I hope the year ahead will be an exciting and positive one for all.

Gerald Williams
Chairperson
YE December 2010

2. National Director's Report

This will be my last report as National Director due to a change in the Association's structure. The Association's major service is to those people with Prader-Willi Syndrome, their families, and the caregivers, teachers, and other professionals who support them. I am very grateful to all who have given me my own 'training' and understanding of the syndrome and who have allowed me to help them in return.

On the whole, this year pretty much followed last year's workload, but with more international participation.

Education and training

Residential and teachers' staff training continues to play the major role in our service delivery.

Training was done in the following areas:

February

- Christchurch, Halswell Residential College, Educational & Residential Workshop
- Porirua East Primary school support visit
- Sydney workshop for professionals, parents, educationalists
- Adelaide (ditto)
- Brisbane (ditto)

March

- Auckland Teachers' workshop
- Porirua Holy Family School support visit

April

- Team Leaders' Meeting, Wellington

May

- Upper Hutt School support visit
- International PWS Conference (Taiwan)

June

- NASC meeting as advocate for family (Wellington)
- Palmerston North, residential workshop

July

- Auckland, staff training (2 workshops)

September

- Timaru – workshop & parent meeting
- Ashburton – workshop & parent meeting
- Christchurch – workshop & parents meeting

October

- School support visit– Elsdon (Wellington area)

November

- Auckland – 2 workshops, parent visit, supported living visit

December

- Advocate for NASC family visit & residential transfer (Wellington)

Workshops are run as half days or full days, with the option of trainees attending morning or afternoons where the geographical and staffing situations are tight – this is generally only in the Auckland area.

In August, I took leave to travel to South Africa to hold several training workshops there for professionals, parents and teachers. The area of residential homes for those with PWS is very limited.

- Total number of workshops run (excluding Australia) 10
- Total number of workshops run (including Australia & South Africa): 23

- Total number of school visits: 4
- Total number of advocate family supports: 2

Family support

This year saw more support to families in the form of advocacy for NASC assessments, both for residential care and for family care. There seemed to be higher stress levels in families, perhaps this is following the younger-to-mid-age group as they enter teenage and early 20s. After discussion with some of the board, it was decided to help alleviate some of the holiday pressure for families by having a Summer Camp for a week at the Kaitoke YMCA camp at the foothills of the Rimutaka Ranges, Wellington for school-aged children. With help from Cindy Adams-Vining and Jo Davies, this was run in January 2011.

Although we decided on a limited participation level of 12 school-age children, we did not reach this figure without opening participation to our older adults in residential care. In the earlier years of our Association, we held many successful summer camps, but it would appear today that these are not especially well-attended as in the past, with a noticeable division between younger children and the older group, and parents choosing to participate according to age groups. This is a world-wide phenomenon and has been experienced in all countries, as a result of a new generation of children coming on. This isn't noticed in those with PWS however who are usually very happy to mix together.

Conferences

The 7th IPWSO conference was held in Taiwan in May this year, with a contingent of five of our parents attending. I am quite sure this was of great benefit to our younger parents and will help them participate in the running of future conferences. Our 2nd South Pacific & Asian Conference will be hosted by Australia in 2012 and it is expected that New Zealand will have some participation in this.

Growth Hormone Treatment

There has been no further move on PHARMAC's behalf to broaden the access to GHT, although access for adults generally, has been taken into consideration. This means that eventually those with PWS reaching adulthood can apply for GHT under this 'adult' criterion.

Publicity

Our website continued to be updated during the year, and most of our new parents come via email through the website.

Publication of our Australasian newsletter, "PWS Downunder" which is distributed in Australia and New Zealand with courtesy copies to USA, South Africa, UK, was published 3 times over the year.

IPWSO

I remain on the Board of IPWSO as Secretary and will be continuing to work for IPWSO as a consultant. I believe this international work will continue benefit countries throughout the world. The next international conference will be held in Cambridge, UK, 17-21 July, 2013.

Consultants

Our Association's consultants, John Ford, Rosie Furniss, Clare Wall, Peter Davies, and Paul Hofman, have provided essential help over the years, and I hope will continue to do so. My personal thanks to all our very willing and helpful advisors for their support over the years, to me in particular, but to all those with PWS and their families.

Financial support

Grateful thanks to our major sponsor, the NZ Lottery Board who has supported us for some 20 years with funding for staffing, to Pfizer who have supported us over the years with the publication of educational material and conference sponsorship, and our grateful thanks to the Trusts Charitable Foundation this year for their support to the Summer Camp 2011.

Changes in Association's structure

At the October board meeting, it was agreed that I would undertake to focus on Training & Education during 2011 (at the end of which, I had planned to retire), and that the position of National Director would be disseminated among 5 people, with a CEO, Administration officer, and three Team Leaders. I look forward to my new role and that of supporting the transition of leadership. My very grateful thanks go to my colleague, Cindy Adams-Vining who has been my willing co-worker for some 15 years and undoubtedly helped in the successful growth of this Association.

Linda Thornton
National Director
31 January 2010

3. Team Leaders' Reports

Report by Cindy Adams-Vining

Team Leader – Adults 18+

- Attended International conference in Taiwan
- Facilitated day out at Butterfly Creek in Auckland
- Partially assisted organizing and attended camp Kaitoki.
- Assisted with or ran training sessions throughout NZ including. (Including Auckland, Christchurch, Ashburton, Levin & Nelson).
- Visited with some families while in these regions.
- Phone and email contacts with some families (not all are from the older group).
- Manned the 0800# for much of the year.

In my role as an Evaluation Team member for SAMS (Standards & Monitoring Services) I visit a lot of facilities and houses for people with disabilities throughout the country so I often get unplanned opportunities to see some of our people with PWS and their families, this is a little bonus for our Assoc.

Contacts:

Most contacts have been through the training sessions or organized events. Emails contacts are intermittent – especially with the older families. I find that we do not have email contacts for many of these families or they are not current. It is my intention to update all phone, emails and addresses. This will take time, mostly on the phone at night.

Residential Options:

NZ now has three specific PWS residences that will provide a good network for professional carers' with a strong knowledge and skills base developing along with our Best Practice Guidelines. The Thorne Rd house in Auckland (where 4 ladies with PWS live) is to feature in the next 'PWS Downunder' newsletter.

Planned Halswell Reunion:

This was postponed until this year (2011) but in light of the disaster in Christchurch. I think this should be put on hold indefinitely and we should look at some other way of getting our people together.

Butterfly Creek

As the team leader for older people with PWS I originally planned a day together in Auckland at Butterfly Creek, but decided to open it to all families who wanted to attend. It was a great day with over 20 people there including parents, siblings, and caregivers. It has been a long time (maybe up to 3 years) since some of our members have seen each other. Butterfly Creek gave us group discounts and allowed us to eat our own lunches there. The venue was perfect with plenty of interaction with animals and each other. I think it was a very successful day and probably led on to many of these people coming to camp in Kaitoki.

Camp Report:

Firstly I would like to thank Jo for her tremendous effort in making this camp happen and to the generosity of the TTCF Trust. Although it was disappointing that the camp didn't seem to attract high numbers, this did open it up for some of our older members to attend which, I think those who attended will agree made it very successful in many ways.

We had 19 people attend the camp. 12 of these have PWS, three are professional carers' and four are parents. The age of the campers ranged from 8 to 35yrs. The camp ran for 5 days (5 nights) from

Sunday 16th – Friday 21st January at Camp Kaitoki just north of Wellington. Thanks to funding from TTCF Trust and the NZ PWSA the cost of the camp was covered for all attending.

The camp assigned 2 support staff to our group for the entire camp. These two ladies were exceptionally helpful and supportive of our group and were a fundamental part of the camp's success.

Our group enjoyed many activities including kayaking, orienteering, abseiling, campfire cooking, visit to animal farm, horse riding, swimming and also joined in games & campfire with the whole camp in the evenings (a highlight for our kids and the other campers).

The great things about the camp:

- The chance for our kids (all ages) to meet each other again or for the first time – building valuable friendships.
- Parents get together
- Having the opportunity to join mainstream kids at times was a bonus.
- Care-givers and parents all said the camp enabled them to see a different side of the person their look after, They were surprised at the level of ability, social skills and willingness to accept each others' "difficulties"
- The older kids had the opportunity to be "grown up" and looked out for the young ones.
- Younger kids got to experience "fitting in".
- Younger parents got to see some positive aspects for PWS in the older person.
- Seeing our kids do things way beyond our expectations.
- The camp even provided and unexpected training opportunity where staff from the new house in Levin came to meet with staff from Thorn Rd (Spectrum) for a day. A promising start to a good working relationship.
- Our kids & adults had the chance to experience some things they have never done before.

Not so great things:

- Five nights was too long.
- It was sometimes difficult to manage some campers behaviours because we didn't know them well enough.
- No swimming pool available due to water shortages. - we got around this problem by arranging an outing to the H₂O pools in Upper Hutt – very much enjoyed by all.
- Didn't attract the young kids as originally planned.
- Time of year made it difficult for families to send their kids and for those helping.

Recommendations for future Camps:

Almost unanimous agreement that they would like to get together again like this.

At that camp I would recommend:

- This be for a shorter period (2 -3 nights).
- Parent for someone responsible for each child, (whole family would be ideal).
- Hold the next camp nearer the Auckland area – hopefully accessible to airport.
- Instigate the option of using a YMCA camp again as they now "have the recipe".

The whole formula is very much like the camps we used to hold, they were the best way to make and keep contact even though we have wonderful modern technology and "easy access" there is nothing that can replace face to face contact and seeing your child shine in a safe and encouraging place.

Report by Karen O'Reilly
Team Leader - Children (0-12years)

Introduction

The six months since my last report have passed swiftly, with the Christmas/New Year period offering its usual interruptions. I am continuing to work on keeping in touch with the young families, and offering the support they need. Whilst a young families weekend was proposed both last year, and this year, it seems as though budgetary constraints will make this impossible unless funding can be sourced externally, so further thought to alternative ways of keeping in touch will be required.

Young Families

I have kept in touch with the younger families via email and through newsletters. With a number of the families, I have had one-on-one contact via phone, email and in person, in response to their queries about health, schooling etc.

A new family has been identified in Christchurch – their daughter, Charlotte, is now 5 months old, and has PWS. Thankfully, the family have survived the February 22 earthquake with some property damage but otherwise OK. Charlotte did require hospitalisation in the weeks immediately following the quake after contracting a gastro bug but she is recovering well. I have talked through support and care options with the family to ensure that they are receiving all of the assistance they require in each area (early intervention, paediatrics, medical, subsidies and benefits, growth hormone etc).

I have also been in ongoing contact with another 'new' family who have a one year old son with PWS. This family currently live in Australia but are considering relocating home to NZ (primarily to be closer to their family and support networks). We have discussed at length what entitlements they may receive when they come home and what they need to do to get these organised (including obtaining medical records, referrals etc).

Services Provided

1. Information

- Newsletters for young families in December 2010 and March 2011
- General emails and phone calls in response to queries (including the two new families)
- Advance notice of Asia-Pacific Conference in Sydney 2012.
- I have started compiling a 'Beginners Guide' for parents - this speaks less about the Syndrome itself (on which there is already a wealth of information) and more about support services, resources, entitlements, developmental tips etc (ie the network of information that slowly filters through to us over time). Hopefully this can be developed into a comprehensive document that will be useful for all families.

2. Growth Hormone

Discussions with new families in relation to what they need to do to access this treatment once Charlotte turns 18 months old. Most of the other young families are now on the treatment and reporting good success. It is pleasing to note that several of our slightly older children have recently gained funded access to this treatment.

3. Young Families Get-Together/s

Originally scheduled for November 2010, this was rescheduled for 2011 and preliminary planning (and a draft budget) was completed. Unfortunately, the Association's limited financial resources this year mean that this event is unlikely to happen unless specific funding can be secured for it. Many of the families have expressed enthusiasm for the weekend and are keen to attend. We are seeking the funding to enable the weekend to eventuate.

In the meantime, I have been looking at organising a regional get together in Auckland, and one in Wellington over the next few months. I am anxious to consider how we can best support our families in Christchurch – not so much because of the earthquake, but more so because the two Charlottes

(aged 5 months and 5 years) are both new diagnoses and it would be good for them to meet other families.

4. Education

The recent Government review of special education seems to have produced no tangible result other than [empty?] promises that more funding will be available to our children with special needs. I was advised recently by the MOE that unless a child is consistently performing at a level three or more years below their chronological age (in every area tested) they will not even be considered for ORRS funding.

This may be a real issue for many of our PWS children who struggle at school to the extent they need extra help, but don't struggle enough to qualify for it. For example, my son is behind in some areas but 'normal' for reading and comprehension which effectively means no assistance is available despite some significant problems coping with other aspects of the school curriculum. I'm not sure yet where we go to on this.

I have started compiling a list of resources and teaching techniques etc that will be useful for teachers to use and for parents to also use at home.

4. Treasurers Report

I have pleasure in presenting the audited 2010 Financial Statements of the Prader-Willi Syndrome Association (NZ) Inc.

The closing balance (net assets) as at 31 December 2010 was **\$46,662**. This consisted of:

\$10,493	in cheque account	
\$39,357	in term deposits	
\$670	in fixed assets	
Total		\$50,520
Less liabilities		\$3,858
		<u>\$ 46,662</u>

The Net Assets (equity) at 31 Dec 10 was 31.44 % less than for the 2009 FY. This was caused by less income and interest (\$6,051) and greater expenditure (\$13,510). The increase in expenditure was due to gratuities paid to three team leaders (\$7,500); an extra Board meeting, and the cost of sending four extra Board members to the Taiwan PWS Conference.

The Association starts 2011 in reasonable financial shape.

Nick Thornton

Treasurer

YE 31st December 2010

5. Financials

Prader-Willi Syndrome Association Financial Reports For the Year Ended 31st December 2010

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Prader-Willi Syndrome Association
Statement of Financial Performance
For the Year ended 31st December 2010

<i>2009</i>		<i>2010</i>
<i>\$</i>		<i>\$</i>
	Revenue	
10,000	Grant - Lotto Salary	-
2,000	Sponsorship - Pfizer	2,058
2,570	Grant - J R McKenzie Trust	-
-	Grant - Trust Charity Fund	4,950
4,344	Sales & Courses	1,763
943	Donations	238
44,982	Ministry of Health Contract	44,982
-	Half Share 2008 Conference Profit	7,250
1,324	Subscriptions	595
66,163		61,836
66,163		61,836
	Sundry Income	
6,159	Interest Received	4,435
6,159		4,435
72,322		66,271
	Less Expenses	
51,109	Operating Expenses	57,467
22,554	Administration Expenses	29,876
497	Non-Cash Expenses	327
74,160		87,670
(1,838)	Net Loss for the Year	(21,399)

Prader-Willi Syndrome Association
Statement of Financial Position
As at 31st December 2010

<u>2009</u>		<u>2010</u>	
\$		\$	\$
	Current Assets		
11,759	Westpac Bank - Cheque Account	9,361	
<u>-</u>	Accrued Interest	<u>1,132</u>	
11,759			10,493
	Non Current Assets		
997	Fixed Assets as per Schedule	670	
23,463	Westpac Term Deposit - 0002	15,721	
22,618	Westpac Term Deposit - 0008	23,636	
11,835	Westpac Term Deposit - 0011	-	
<u>15,791</u>	Westpac Term Deposit - 0014	<u>-</u>	
74,704			<u>40,027</u>
86,463	TOTAL ASSETS		50,520
	Current Liabilities		
2,610	GST Due for payment	2,713	
<u>1,292</u>	Accounts Payable	<u>1,145</u>	
3,902		3,858	
	Term Liabilities		
14,500	Conference Reserve		-
18,402	TOTAL LIABILITIES		3,858
<u>\$68,061</u>	NET ASSETS		<u>\$46,662</u>
	Represented by;		
<u>\$68,061</u>	EQUITY as per Capital Account		<u>\$46,662</u>

Prader-Willi Syndrome Association
Depreciation Schedule
For the Year ended 31st December 2010

Asset	Cost Price	Book Value 01/01/2010	Additions Disposals	Gain/Loss on Disposal	Capital Profit	--- Depreciation --- Mth Rate	Accum Deprec 31/12/2010	Book Value 31/12/2010
PLANT & EQUIPMENT								
Filing Cabinet	250	5				12 20.0% DV	1	246
Binding Machine	450	15				12 20.0% DV	3	438
Filing Cabinet	462	87				12 20.0% DV	17	392
HP T230A Computer	3,200	59				12 48.0% DV	28	3,169
Toshiba Notebook	2,685	285				12 33.3% DV	95	2,495
PB Imedia Computer	2,311	245				12 33.3% DV	82	2,148
Myob Software	355	38				12 33.3% DV	13	330
Photocopier	695	74				12 33.3% DV	25	646
Projector	1,777	189				12 33.3% DV	63	1,651
TOTAL	12,185	997					327	11,515

Prader-Willi Syndrome Association
Schedule of Expenses
For the Year ended 31st December 2010

<i>2009</i>		<i>2010</i>
<i>\$</i>		<i>\$</i>
	Operating Expenses	
269	Accident Compensation Levy	236
2,520	Publications	-
44,468	Wages & Salaries	52,804
<u>3,852</u>	Workshop Expenses	<u>4,427</u>
<u>51,109</u>		<u>57,467</u>
	Administration Expenses	
1,001	Audit Fees	911
8	Bank Charges	133
2,133	Computer Expenses	711
835	Conference Expenses	600
5,009	Regional Meetings	2,934
2,510	AGM/Board Meetings	6,085
1,182	General Expenses	2,029
553	Postage & Mail	166
501	Printing	287
2,448	Stationery	2,547
141	Subscriptions	186
2,705	Telephone	2,686
<u>3,528</u>	Travelling Expenses	<u>10,601</u>
<u>22,554</u>		<u>29,876</u>
	Non-Cash Expenses	
<u>497</u>	Depreciation as per Schedule	<u>327</u>
<u>497</u>		<u>327</u>

Prader-Willi Syndrome Association
Statement of Movements in Equity
For the Year ended 31st December 2010

<i>2009</i>		<i>2010</i>
<i>\$</i>		<i>\$</i>
69,899	Equity at Start of Period	68,061
	Surplus & Revaluations	
<u>(1,838)</u>	Net Profit (Loss) for the period	<u>(21,399)</u>
<u>(1,838)</u>	Total recognised revenues & expenses	<u>(21,399)</u>
	Other Movements	
<u>\$68,061</u>	Equity at End of Period	<u>\$46,662</u>

Prader-Willi Syndrome Association
Notes to the Financial Statements
For the Year Ended 31 December 2010

1. STATEMENT OF ACCOUNTING POLICIES:

1.1 Measurement System

This is a special purpose report prepared under the requirements of the Incorporated Societies Act 1908. Unless otherwise stated, these accounts have been prepared on an historical cost basis. Accrual accounting is used to match expenses and revenues.

1.2 Particular Accounting Policies

1.2.1. Accounts Receivable

Accounts receivable are stated at expected realisable value.

1.2.2. Fixed Assets

All fixed assets are initially recorded at cost.

1.2.3. G.S.T.

These accounts have been prepared on a G.S.T. exclusive basis, except for accounts receivable and accounts payable which are G.S.T. inclusive.

1.2.4 Taxation

All business income of the association has been applied in a manner so as to be non taxable as per CW42 of the Income Tax Act 2004

1.3 Changes In Accounting Policies

There have been no significant changes in accounting policies. Accounting Policies have been applied on bases consistent with those used in previous years.

2. NOTES TO FINANCIAL STATEMENTS:

2.1 Entity

Prader Willi Syndrome Association provides support and assistance to sufferers and families of Prader Willi Syndrome and also runs an education programme. The Association is registered as a charity under the Charities Act 2005

Audit Report

Prader-Willi Syndrome Association (NZ) Incorporated

To the Readers of the financial report of Prader-Willi Syndrome Association (NZ) Incorporated. We have audited the financial report on pages 1-6. The financial report provides information about the past financial performance of the Society and its financial position as at 31 December 2010. This information is stated in accordance with the accounting policies set out on pages 6

Core Groups Responsibilities

The Core Group is responsible for the preparation of a financial report which gives fairly reflects the financial position of the Society as at 31 December 2010 and of the results of operations and cash flows for the year ended 31 December 2010.

Auditors' Responsibilities

It is our responsibility to express an independent opinion on the financial report presented by the Board and report our opinion to you.

Basis of Opinion

An audit includes examining, on a test basis, evidence relevant to the amounts and disclosures in the financial report. It also includes assessing:-

- the significant estimates and judgements made by the Board in the preparation of the financial report, and
- whether the accounting policies are appropriate to the Society's circumstances, consistently applied and adequately disclosed.

We conducted our audit in accordance with generally accepted auditing standards in New Zealand. We planned and performed our audit so as to obtain all the information and explanations which we considered necessary in order to provide us with sufficient evidence to give reasonable assurance that the financial report is free from material misstatements, whether caused by fraud or error. In forming our opinion we also evaluated the overall adequacy of the presentation of information in the financial report. Other than in our capacity as auditors we have no relationship with or interests in the Society.

Unqualified Opinion

We have obtained all the information and explanations we have required.

In our opinion:-

- In our opinion the financial reports on pages 1 to 6 fairly reflects the financial position of Prader-Willi Syndrome Association (NZ) Incorporated as at 31 December 2010 and the results of its operations and cash flows for the 12 months ended on that date.

Our Audit was completed on 9 March 2011 and our unqualified opinion is expressed as at that date.



AMY KERR & ASSOCIATES LIMITED
Chartered Accountants
Masterton