



**PNDU**

Parenteral Nutrition Down Under

**Parenteral Nutrition Down Under Inc.**

# **Annual Report**

## **2019**

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AUSTRALIA

# President's Report

## Annual General Meeting – 19<sup>th</sup> August 2019

PNDU has truly come of age, turning 10 years old in January this year, and well-accepted and known by consumers and carers, clinical groups, hospitals and industry, locally and internationally as the go-to organisation 'down under' for Home Parenteral Nutrition (HPN) consumer and carer support and representation.

This President's Report is a perfect opportunity to recap the past year, ready for the year, and future, ahead. For me personally, this Report is especially significant as it marks 10½ years of involvement in PNDU (almost 8 of those as Convenor/President), and my last. It's from a place of incredible gratitude and appreciation that I step down as President and out of the Management Committee (MC) to allow PNDU's next President, Chris, to lead PNDU forward and into its next chapter. I am so proud of our little organisation and how far it has come in 10 years, and humbled to have had the privilege to lead a great MC, our members and PNDU to this place of growth and success.

PNDU's MC is its engine room. With all MC volunteers – me, Miranda, Chris, Gillian and Fay – living with Intestinal Failure (IF) and HPN either as consumers or carers, teamwork is crucial, and I'm grateful for the generous involvement, skills and contributions of all MC members. Our MC Skype meetings have continued every 6-8 weeks, and with this AGM, we welcome 2 new MC volunteers – Belinda and Ryan. A wonderful blessing to PNDU.

### **PNDU Inc.**

The big event for PNDU this past year was its 10<sup>th</sup> Birthday on 6<sup>th</sup> January 2019. We started celebrations a month early, combining it with PNDU's annual social gathering in Sydney in early December 2018. Over 30 members attended, with lots of party fun, reflections, speeches, congratulatory messages and cake cutting. See the new dedicated [PNDU turns 10! Webpage](#). The celebrations continued through to 6<sup>th</sup> January, with a media release and special 10<sup>th</sup> Birthday gifts so all 'down under' members could be involved, no matter where they live.

Total PNDU membership has almost tripled in the 2 years since our new website launch to 170 members, as has the number of current 'down under' HPNers represented in PNDU membership (up to a possible 97). While the majority of membership growth continues to be in Australia, it has been very encouraging to see membership growth starting again in New Zealand – HPNers, carers and clinicians. We are very grateful for continuing growing relationships with NZ National Intestinal Failure Service (NZNIFS), Intravenous Nursing NZ (IVNNZ), NZ hospitals and clinicians.

PNDU accounts continue to be independently audited; and our charity and tax deductible status in Australia maintained. Thank you Chris and Miranda for your ongoing work to ensure this. We also continue our association with IPANEMA in New Zealand, enabling tax deductibility for New Zealand

donations. With Chris taking over as President, we are thrilled that Belinda will be filling the Treasurer vacancy in the MC.

## Member Resources and Activities

Dripline has now been running for over 7 years, with the 28<sup>th</sup> issue recently sent to PNDU's readership of over 450, and circulated much further. A highly valued PNDU resource allowing all readers opportunity to read about members' lives with HPN; relevant medical articles; and PNDU activities and resources. Thank you once again Gillian.

We're back providing medical play toys free of charge to PNDU under 10 yrs HPNers (and at a special price to others). Terrific little local company, [JustLikeYouDolls](#), provides soft toys and anatomically correct dolls with extra medical bits and pieces just like little HPNers, which have proven invaluable for these little ones. Thank you Chris for managing this project.

Alongside PNDU's existing resources, provided free of charge to members (two closed chat forums, Travel Information Booklet, Restaurant Card, Toilet Card, and access to helpful information on the website), two new valuable resources have been developed: Fact sheet: 'Preparing your HPN Child for School', and Tips Sheet: 'Accessing the Australian NDIS'. In time for HPN Awareness Week 2018, we launched [PNDU's own public Instagram account](#), allowing everyone to follow PNDU's activities. And we now also have supporter merchandise available for cost price or less: supporter caps and stickers (launched as special 10<sup>th</sup> Birthday member gifts), as well as supporter t-shirts. A great addition to our PNDU merchandise range, allowing everyone to join in and share the PNDU love.

PNDU's annual social gathering (combined with PNDU's 10<sup>th</sup> Birthday party) in Sydney in December 2018 was held alongside AuSPEN's 2018 jam-packed HPN consumer workshop, with two PNDU travel sponsorships of \$600 each awarded. The annual workshop is a highly valuable opportunity for HPNers and carers to learn about various aspects of HPN and IF from HPN clinicians, and we are very grateful to AuSPEN for its continued efforts to run this event, with PNDU's input.

We also held the first New Zealand HPN social gathering since 2015, in Auckland in March, which while small, with some unable to attend due to illness, was a fun gathering nonetheless.

## PNDU Representation

Encouragingly, opportunities and invitations for PNDU representation at various conferences, forums, events and on committees continued to increase, and we celebrate the value being placed on the HPN consumer/carers voice and perspective.

PNDU presented at AuSPEN Conference in Sydney, Baxter Healthcare's NSW HPN Coordinator Workshop in Sydney, NZNIFS Education Day in Auckland, and Australian Vascular Access Society's conference in Sydney. Representation continued in PACIFHAN (celebrating registration in Brussels in April 2019); Rare Voices Australia; Qld PN Steering Committee; Agency for Clinical Innovation NSW; IVNNZ (by way of member magazine articles); and the Australian PBAC for the drug Revestive® (now recommended for listing on the PBS for adults with SBS-IF, and expected before the end of 2019).

New representation opportunities included in AuSPEN's development of a Quality of Care Framework (and subsequent Model of Care), AVATAR's Vascular Access Passport Project, and the inaugural Australian Patient Organisation Network (APON) conference.

## **Research and Awareness-Raising**

PNDU's pilot swimming survey was presented orally at AuSPEN's 2018 Conference, winning the President's Award (congratulations Miranda!). PNDU's latest member survey on retraining in HPN procedures was presented as a poster at AVAS conference 2019 and is our first PNDU member survey to be accepted for publication in a medical journal. Thank you [AVAS Journal](#) and to member Sharyn as well as the various clinicians who provided feedback. We're thrilled and very proud!

Preparations for PNDU's principal awareness and fundraising activity – HPN Awareness Week in October (incorporating World HAN Day) – are again underway. PNDU provides resources and opportunities for members, hospitals and industry to help increase awareness and understanding of HPN. We are greatly encouraged by the ever-increasing number of HPN hospitals getting involved (last year 16 hospitals across both countries) as well as the involvement of industry friends, Baxter, Fresenius Kabi, Biomed and Takeda, with Baxter, Biomed and Fresenius Kabi/Slade Health also hosting tours of their compounding pharmacies. And all PNDU's AW videos are now on our [website](#).

## **Thank You**

As Certificates of Appreciation (for HPN members to present to their HPN medical care team) were given as part of PNDU's 10<sup>th</sup> Birthday celebrations, PNDU Awards weren't held this year. However we look forward to again recognising and thanking those who do a great job for HPNers 'down under' through our PNDU Awards in 2020.

We appreciate and value the continued support of PNDU's industry friends, Baxter, Fresenius Kabi, Biomed and Takeda (including unconditional donations from Baxter, Fresenius Kabi and Takeda), as well as the support of local clinicians, hospitals, and clinical and research bodies AuSPEN, NZNIFS, AVAS, IVNNZ, and AVATAR.

Lastly, thank you to our MC, volunteers who assist in other capacities (Renee, Sharyn, Gil, Sharon), and to all our members who make this amazing PNDU organisation and community what it is – vibrant, caring, and effective in its mission to 'support, research and inform consumers, carers and providers of Parenteral Nutrition for Intestinal Failure'. I wish Chris, the whole MC and PNDU nothing but continued success into the future.

**Karen**  
**President**

**19 August 2019**

# Financial Statement 2018-19

PNDU Accounts		Balances EOFY 2019	Balances EOFY 2018
<b>New Zealand PayPal Account</b>			
Sales	\$54.16	\$282.87	\$228.71
<b>Australian PayPal Account</b>			
<b>Payments received</b>			
Personal Donations	\$3820.60		\$1846.00
Company Donations	\$198.45		\$25.00
Sales	\$68.05		\$267.47
<b>Withdrawals and debits</b>			
Transfer to Westpac	\$3800.00		\$2000.00
PayPal Fees	\$115.02		\$62.70
			<b>EOFY 2017-2018</b>
<b>EOFY Balance 2018 - 2019</b>		<b>\$257.85</b>	<b>\$85.87</b>
<b>Westpac Cash Reserve Account</b>			
Reserved for PNDU expenses			
Travel Sponsorship (Annual Gathering)	\$1000.00		
Venue Hire (Annual Gathering)	\$500		
2019 – 2020 PNDU Insurances	\$2000		
Interest	\$8.82		
			<b>EOFY 2017-2018</b>
<b>EOFY Balance 2018 - 2019</b>		<b>\$3563.19</b>	<b>\$3554.37</b>
<b>Westpac Community Solutions</b>			
<b>(Cheque Account)</b>			
<b>Payments Received (Credits)</b>			
Personal Donations	\$2630.00		\$1415.00
<b>Company Donations</b>			
Baxter Healthcare	\$3000.00		\$3000.00
Fresenius Kabi	\$3000.00		\$3000.00
Shire	\$5000.00		\$5000.00
Biomed (Staff Donation)	\$150.67		
Sales (PNDU Merchandise)	\$466.57		\$400.00
Interest	\$8.34		\$8.37
Transfer from AUS PayPal	\$3800.00		\$2000.00
<b>Other Income (Credits)</b>			
PNDU MC Travel expenses (Refund)	\$271.90		\$285.00
PNDU Gathering Cancellation (Refund)	\$15.18		\$123.14

IPANEMA PayPal Fees G Hardy (Refund)	\$6.34	
NIFS New Zealand Travel (Refund)	\$1209.52	
		<b>Credits</b>
		<b>EOFY 2017-2018</b>
<b>Total Credits 2018 - 2019</b>	\$19558.52	\$15231.51
<b>Withdrawals and Debits</b>		
<b>PNDU Inc. Expenses</b>		
Public Liability Insurance	\$774.05	\$698.50
Professional Indemnity Insurance	\$953.37	\$953.37
Constitution Amendment		\$54.00
A12 Statement (Dept Fair Trading)	\$46.18	\$45.18
Office Supplies	\$111.68	\$63.00
PNDU Website		\$476.47
Postage	\$1004.24	\$345.40
<b>Conferences and gatherings</b>		
AuSPEN		\$1899.63
Travel and Meetings around IVNNZ		\$1640.12
Travel and Meetings around NIFSNZ	\$3269.30	
NZ Gathering		\$133.54
PNDU Annual gathering	\$1622.19	
RVA (Rare Disease Events)	\$1127.48	\$340.00
AVAS	\$408.51	
APON	\$262.00	
(Miscellaneous PNDU Representation)		
Jodie How		\$144.00
Chris walker		\$50.01
Membership (RVA)	\$50.00	\$50.00
<b>Awareness and Promotion</b>		
Caps	\$1397.00	
T Shirts	\$1760.94	
PNDU Recipe Books		\$134.00
Education and Information		
Awareness Week Video	\$1980.00	
Medical Play Toys	\$1182.80	
Dripline Newsletter	\$1363.20	\$330.00
Travel Booklet	\$302.50	\$110.00
PNDU Survey (Retraining)	\$143.00	\$55.00
Flyers - Leaflets - Cards	\$396.00	\$476.50
Awareness Week (printed resources)	\$1177.00	\$1094.95
PNDU Awards	\$9.76	\$42.53
Other Expenses (Miscellaneous)	\$550.77	\$175.00
<b>Total Debits 2018 -2019</b>	\$20069.97	
		<b>Balance</b>
		<b>EOFY 2017-2018</b>
<b>EOFY Cheque Account Balance 2018 -2019</b>	<b>\$10774.28</b>	<b>\$11285.73</b>
		<b>EOFY 2017-2018</b>
<b>Total PNDU Funds 2018 -2019 EOFY</b>	<b>\$14595.32</b>	<b>\$14925.87</b>

Prepared by  
Chris  
Treasurer

10 August 2018