

## **Parenteral Nutrition Down Under Inc.**

# Annual Report 2024 - 2025

**Year Ending 30<sup>th</sup> June 2025** 

www.pndu.org contactpndu@gmail.com 128 Rainbow Street Randwick NSW 2031 AUSTRALIA



# **President's Report**

### **Annual General Meeting – 10th September 2025**

Marking the end of my 6th year as PNDU president, 2025 has been one of the busiest years since I joined the PNDU Management Committee in 2013. "The PNDU Management Committee" is a small group of dedicated volunteers, and with their support PNDU continues to achieve its mission of supporting, researching and informing consumers, carers and providers of Parenteral Nutrition for Intestinal Failure across Australia and New Zealand. As PNDU celebrates its 16<sup>th</sup> year, I take this time to say thank you to the PNDU MC, Miranda, Gillian, Julia, Sarah and volunteer Renee, without whom PNDU wouldn't be able to continue providing support for our members and remain a well-respected patient support and advocacy group, not only in Australia and New Zealand, but also around the globe, internationally.

As PNDU membership continues to grow, PNDU continues to engage with HPN Health Care professionals at conferences, workshops and on committees, with a vision of improving the overall Quality of Life for all HPNers Down Under, our little group can deliver a range of advocacy, support and social activities for our members.

The president's report is a wonderful opportunity to look back on the past 12 months of PNDU activities and what we were able to achieve.

#### **PNDU Management Committee**

President - Chris Walker, (HPN Carer)

Vice President/Dripline Editor – Gillian Anderson (HPNer)

Secretary/Public Officer – Miranda Einstein (HPN Carer)

Treasurer - Chris Walker (HPN Carer)

Committee Members – Julia Rollings (HPN Carer) Sarah Joyce (Stepped down due to ill health)

Volunteers - Renee - Katie - Gil - Mariann

PNDU MC meetings are held every 6-8 weeks via Microsoft Teams.

#### **PNDU SNUG Camp 2024**

PNDU is grateful to the Steve Waugh Foundation for providing the recent SNUG (Special Needs Unlimited Group) camp for our HPN families to enjoy.

The SNUG Retreats Programs are organised by the Special Needs Unlimited Group from the University of Newcastle with the support of the Steve Waugh Foundation.

PNDU held their inaugural SNUG Camp in 2017 with future camps to be organised every 2-3 years', Covid interrupted these plans but with Covid restrictions eased.

On November 15, 2024, Six PNDU families with seven fabulous HPN warriors, varying from toddler through to mid-teen, along with their siblings, gathered at a beautiful bush setting on the banks of Lake Macquarie, NSW. A seventh family, unfortunately, had to pull out at the last minute due to illness. Families travelled from Queensland, Victoria, NSW and the ACT but distance was soon forgotten as kids quickly made new friends and parents unpacked SOOO much medical luggage. Volunteer helpers, led by SNUG organiser Liz, were there to greet us and show us to our rooms. Each family had their own room with an ensuite in one of two dormitories, with a large, shared space in each to socialise and a kitchen for snacks, beverages, and fridges to store TPN and meds.

PNDU is grateful to SNUG and the Steve Waugh Foundation for making this wonderful opportunity possible for our children and their families.

Full story can be found pndu.org Resources Dripline 50th edition January 2025

#### **PNDU Social Gatherings**

A wonderful opportunity to meet other HPNers, family and carers who truly understand what life is like living with Chronic Intestinal Failure and Home Parenteral Nutrition. A time to make new friends and share your lived experiences in a relaxed friendly environment.

The PNDU annual social gathering is held each year alongside the AuSPEN Conference. The 2024 social gathering was held at the West End Croquet Club, in Brisbane, Queensland. The Social gathering was hosted by PNDU president Chris and Secretary Miranda, who welcomed 10 of our members. The weather was spectacular, providing the perfect backdrop for a lively afternoon of croquet games and conversations. Attendees included members from Queensland, New South Wales, Victoria, South Australia, and even New Zealand, making it a truly diverse and memorable gathering. These informal moments of connection allow members to share personal stories, HPN-life tips, offer support, and enjoy each other's company in a truly relaxed and welcoming setting.

PNDU look forward to hosting the annual social gathering on 9<sup>th</sup> November 2025 in Sydney NSW.

#### HPN Awareness Week 13th - 19th October 2024

The value of being able to meet other HPNers in person and share the lived experience can never be underestimated.

PNDU hosted another social gathering as part of HPN awareness week on the 16<sup>th</sup> of October 2024 at Flinders Medical centre in Adelaide.

It truly was an amazing day at Flinders Medical Centre, Adelaide. PNDU co-hosted the first HPN Awareness Week event at FMC. The day included a virtual tour of Baxter compounding facilities. Over 40 people attended, with an overwhelming outpouring of respect from the 13 FMC HPNers who attended

the event as they said farewell to Dr Holt, who has left an amazing legacy in the way he has managed the South Australian HPN community.

Home Parenteral Nutrition (HPN) Awareness Week (AW) is the biggest event on the PNDU calendar and PNDU's major fundraising event of the year.

#### 2024 Theme was - HPN "LIFE: - It's in the Bag"

HPN Awareness Week started with the release of the PNDU Video, another wonderful production from Miranda and her team. The video is on the PNDU website pndu.org

Or click this link HPN Awareness Week 2024

This year we wanted to lift the covers and show everyone "what's in the Bag" HPN is life giving intravenous nutrition, which enables people with intestinal failure to life their life outside of the hospital. Parenteral Nutrition is a chance to feel the sunshine, a toe dip in the sea and a chance to spend time with your mates. HPN – LIFE: - It's in the Bag.

Encouraging everyone to wear their Awareness week stickers, share PNDU resources and start conversations about what life is really like living with a drip. It's always wonderful to see our members out and about enjoying life the best way they can.

PNDU provides a wide range of resources, ideas and opportunities for our members, friends, hospitals and industry to become involved in AW activities. We are always delighted when we receive positive feedback and photos from the ever-growing number of people joining in the awareness week fun.

HPN Awareness Week is a wonderful opportunity for PNDU to raise awareness and a better understanding with the wider community, of what it is like "Living with a Drip" (HPN).

Baxter Healthcare once again opened the doors of their HPN compounding facilities for guided tours. The pharmacy tours are always a big hit. PNDU members attended every Baxter facility across Australia and New Zealand. The open days also provide the opportunity for HPNers to share their stories of HPN life with pharmacy staff in doing so, this brings about a greater awareness of what it is like living with a chronic illness.

A very big thank you to everyone who participated in awareness week activities, sharing your photos and stories. PNDU are grateful for the support of our industry friends Fresenius Kabi, Baxter Healthcare, Biomed and Takeda Australia, along with the 20 Hospitals Across AUS & NZ who received PNDU resources and became involved in AW2024. Thank you for your support.

Preparations for HPN Awareness Week 28th September – 4th October 2024 – are again well underway.

#### **PNDU Representation**

PNDU continue to represent our members at conference's, workshops, forums, events and on various committees. PNDU is very grateful for the invitations and opportunities we receive, to represent our members across Australia and New Zealand and would like to thank the organisers of these events for including PNDU and the increasing value being placed on the patient/carer voice and perspective.

#### Rare Voices Australia (RVA)

PNDU is very proud to be an RVA Partner Organisation and wish to thank RVA for providing the opportunity to raise awareness of Chronic Intestinal failure requiring Home Parenteral Nutrition. PNDU were invited to attended Parliament House in Canberra, celebrating Rare Disease Day.

PNDU participate in the Rare Disease Disability Project

PNDU are contributing to the RVA RARE Education Portal developing an informative page on Chronic Intestinal failure with links to PNDU

#### Rare Disorders New Zealand (RDNZ)

**Rare Disorders NZ** represents more than 140 rare disease support groups (including PNDU) and is part of the global rare disease community, aiming to amplify the collective voice of rare disorders in New Zealand.

#### Australasian Society of Parenteral and Enteral Nutrition (AuSPEN)

#### **AuSPEN Conference**

The 2024 AuSPEN annual scientific meeting was held in Brisbane QLD. This annual clinical conference provides PNDU with the wonderful opportunity to engage with HPN clinicians and industry friends from across Australia and New Zealand.

PNDU would like to thank AuSPEN for this wonderful opportunity and look forward to attending the AuSPEN conference in Sydney NSW, November 2025.

#### The AuSPEN HPN Model of Care (MOC) & HPN Registry project

It is wonderful to be invited to join the AuSPEN Governance Steering Committee and to be able to contribute to the AuSPEN working groups developing a HPN Registry and HPN Model of Care. To develop guidance documents to support the delivery of HPN services that are of high quality within Australasia.

2024 saw the roll out of the HPN registry across Australia and the commencement of the HPN Model of Care (MOC) working group, with 4 consumer representatives from PNDU actively involved in the MOC project. 2025 completed the first 12 months of Data collection for the registry and the circulation of a Draft HPN Model of care for feedback as the MOC project nears completion.

A very big thank you to AuSPEN for your support of PNDU.

#### Australian Patient Advocacy Alliance: - APAA

As a member of the Australian Patient Advocacy Alliance (APAA), PNDU were invited to attend the APAA25 Summit in Canberra. 12<sup>th</sup> February 2025. The summit was well attended with 80 APAA members, representing Patient Organisations from across Australia. The Summit provided the opportunity to work collaboratively together and identify advocacy priorities that best meet the needs of people living with chronic and complex disease.

#### Gastroenterological Nurses College of Australia (GENCA)

PNDU were invited to join the GENCA conference in Adelaide 16 – 19 May 2025 Providing an excellent opportunity to exhibit PNDU resources and engage with Clinicians and industry representatives from across Australia.

PNDU member Rob presented a heartfelt Patient lived experience of his own life story, reinforcing the value of the patient's voice at these events.

Thank you to GENCA for the invitation to this amazing event and the follow up networking opportunities it has provided.

#### New Zealand National Intestinal Failure & rehabilitation Service NZ NIFRS

PNDU were invited to attend the NZ NIFRS Education & Network Day in Auckland in March 2025. Another wonderful opportunity for PNDU to display our patient support groups resources and engage with clinicians and industry in New Zealand.

A PNDU – NZ NIFRS co project webinar Travelling with HPN was presented in August 2025.

#### **PNDU Membership**

PNDU Membership continued to grow with over 400 members, representing more than 160 HPNers Across AUS/NZ

PNDU maintains a website <a href="www.pndu.org">www.pndu.org</a> generously donated and designed by Orange Line, a valuable source of HPN related information, hints and tips to help make life on HPN a little easier. PNDU welcomes new members – consumers and carers, clinicians, industry representatives and others generally interested in parenteral nutrition for intestinal failure.

To access all areas of the PNDU website and the full range of member resources, including access to the closed email and facebook forums. Please consider becoming a PNDU member https://pndu.org/membership/

#### PNDU Inc.

Parenteral Nutrition Down Under Inc. (PNDU) is a self-funded, not-for-profit support group for consumers and carers in Australia and New Zealand on Home Parenteral Nutrition (HPN).

Our mission is to support, research and inform consumers, carers and providers of parenteral nutrition for intestinal failure, across Australia and New Zealand.

Parenteral Nutrition Down Under (PNDU) is registered under the Associations Incorporation Act 2009 (NSW Fair Trading).

Certificate of Incorporation as an Association INC1501052 (23 July 2015)

Parenteral Nutrition Down Under Inc. (PNDU Inc.) ABN 49 742 201 085 has been registered by the Australian Charities and Not-for-profits Commission (ACNC) since 1<sup>st</sup> July 2016

PNDU Inc. is endorsed for charity tax concessions and is endorsed as a Deductible Gift Recipient (DGR) by the Australian Taxation Office.

PNDU holds a charitable fundraising license in NSW CFN/24388

#### **PNDU Resources**

To help make life on HPN a little easier, PNDU provides a range of resources, "Free of Charge" for our members, all PNDU resources are listed on the PNDU website <a href="https://pndu.org/resources/">https://pndu.org/resources/</a>

**Dripline Newsletter**: - since the first edition of Dripline in June 2012, 52 editions of our quarterly newsletter have been released, we are very grateful for the hard work and dedication of our editor Gillian, who ensures each edition is packed full of interesting articles about members lives on HPN, PNDU activities and relevant HPN related topics. A valuable PNDU resource with over 500 subscribers. To stay up to date with all things HPN related, subscribe to the Dripline newsletter <a href="https://pndu.org/resources/dripline-newsletter/">https://pndu.org/resources/dripline-newsletter/</a>

**On-line chat forums**: - PNDU maintains 2 online chat forums, a closed email group and a closed facebook page, exclusively for Aussie and Kiwi HPNers and Carers. A wonderful way to connect and share stories with other HPNers and Carers across Australia and New Zealand.

**Travel Booklet**: - PNDU provides free to Aussie and Kiwi HPNers, carers and clinicians a Travel Information Booklet with lots of relevant information for Kiwi and Aussie HPNers and carers (and their hospitals) to assist planning and organising a safe holiday on HPN.

**Restaurant Card, Toilet Card**: - (Members only) Both are free to PNDU member HPNers, carers and HPN clinicians (for their HPN patients) in Australia and New Zealand. IMPORTANT: these cards are not legally binding, but are a visual aid to assist in possibly difficult or awkward situations for those living with Intestinal Failure and HPN. To obtain one or both cards, please contact us at <a href="mailto:contactpndu@gmail.com">contactpndu@gmail.com</a>

**PNDU Merchandise:** - PNDU provide a range of merchandise, T-Shirts 'I Live with a Drip' PNDU supporter T-Shirts and Caps 'I support people living with a drip" along with stickers and charity cards, all PNDU merchandise is cost price + postage, to view the range of PNDU Merchandise visit <a href="https://pndu.org/resources/merchandise/">https://pndu.org/resources/merchandise/</a>

Instagram: - Follow PNDU activities and events on Instagram – @pndownunder

#### **Thank You**

I very much appreciate the ongoing support of PNDU's Industry friends, Baxter, Fresenius Kabi, Takeda and Biomed, along with the support of clinicians, hospitals, AuSPEN, NZNIFRS, IVNNZ, AVAS, AVATAR, all of our amazing PNDU Management Committee and PNDU members (HPNers, Carers, family and friends) who all in some way or another, contribute to making PNDU what it is today, a caring HPN community Down Under, who understand what life is like 'living with a drip.'

I look forward to another wonderful year ahead, as PNDU continues to support, research and inform consumers, carers and providers of Parenteral Nutrition for Intestinal Failure across Australia and New Zealand

Kind regards

**Chris Walker** 

**PNDU President** 

#### **Finances and Donations**

As a self-funded not for profit organisation (registered charity), run entirely by volunteers, PNDU relies on donations from members, family, friends and the wider community. PNDU would like to thank you for making a donation to Parenteral Nutrition Down Under Inc. (PNDU). Donations like yours enable PNDU to continue our work of supporting those living with Home Parenteral Nutrition for Chronic Intestinal Failure, and their families in Australia and New Zealand.

PNDU acknowledges and very much appreciates the ongoing support of the following organisations and industry friends, for your generous donations/grants during the 2024 – 25 financial year.

Fresenius Kabi Australia Pty Limited, Baxter Healthcare Pty Ltd, Takeda Pharmaceuticals Australia Pty Ltd.

## Financial Statement 2024 - 25

PNDU Accounts		Balances EOFY 2025	Balances EOFY 2024
New Zealand PayPal Account		\$259.09	\$259.09
Credit	\$0.00		\$0.00
Debit	\$0.00		\$0.00
Australian PayPal Account Payments received			
Personal Donations	\$495.00		\$770.46
Company Donations	\$0.00		\$0.00
Sales/Merchandise	\$0.00		\$55.00
Withdrawals and debits			
PayPal Fees	\$15.30		\$23.56
Transfer to Westpac	\$0.00		\$6000.00
EOFY Balance 2024 - 2025		¢1200 12	EOFY 2023-2024
EOFY Balance 2024 - 2025		\$1360.13	\$880.43
Westpac Cash Reserve Account Reserved for PNDU expenses			
Travel Sponsorship (Annual Gathering)	\$0.00		\$2,000.00
PNDU Future Research Projects	\$0.00		\$10,000.00
Interest	\$128.48		\$0.63
	•		EOFY 2023-2024
EOFY Balance 2024 - 2025		\$19,199.36	\$19,070.88
Westpac Community Solutions (Cheque Account) Payments Received (Credits)			
Personal Donations Company Donations Sales (PNDU Merchandise)	\$1,000.00 \$15,000.00 \$25.00		\$1,850.00 \$21,000.00 \$230.00

			9
Other Income (Credits)	¢517.11		¢0.00
PNDU MC Travel expenses (Refunds)	\$517.11		\$0.00
PNDU Travel Support	\$0.00 \$0.00		\$300.00
Transfer from PayPal	\$0.00		\$6,000.00
			Credits EOFY 2023-2024
Total Credits 2024 - 2025	\$16,542.11		\$29,380.00
Withdrawals and Debits			
Transfers to Cash Reserve			
Travel Sponsorship Annual Gathering	\$0.00		\$2,000.00
PNDU Future Research Projects	\$0.00		\$10,000.00
PNDU Inc. Expenses	,		, -,
Public Liability Insurance	\$1,118.70		\$1028.03
Professional Indemnity Insurance	\$1,038.74		\$1,009.36
A12 Statement (Dept Fair Trading)	\$56.24		\$54.24
Office Supplies	\$729.34		\$417.87
PNDU Website	\$340.95		\$77.44
Postage	\$666.76		\$623.10
Travel and expenses to attend			
Conferences, meetings and Events			
Australia	\$6,044.58		\$5,381.15
New Zealand	\$2,054.47		\$5,963.24
PNDU Social Gatherings	\$3,577.43		\$233.75
Travel Sponsorship	\$3,851.68		\$0.00
Membership (RVA)	\$55.96		\$55.00
Education and Information			
Awareness Week Video	\$0.00		\$2,180.00
Dripline Newsletter	\$1,587.04		\$1,806.00
In Memorial	\$0.00		\$210.93
Flyers - Leaflets - Cards	\$0.00		\$717.53
Awareness Week (printed resources)	\$2170.96		\$3,884.00
Other Expenses (Miscellaneous)	\$0.00		\$24.19
Total Debits 2024 -2025	\$23,292.85	Total Debits 23-24	\$35,665.83
10101. 2021. 2022	<i>\$23,232.03</i>	10101 50510 25 21	Balance EOFY
			2023-2024
EOFY Cheque Account Balance 2024 -2025		\$15,711.19	\$22,461.93
			EOFY 2023-2024
Total PNDU Funds 2024 -2025 EOFY		\$36,270.68 AUD \$259.09 NZD	\$42,413.24 \$259.09
Balance Sheet 30 June 2025 ACCUMULATED FUNDS			
AUS Balance brought forward 2023-24	\$42,413.24		
Excess of Expenditure over income	-\$6,142.56		
Balance of Australian funds 30 June 2025	\$36,270.68		
NZ Balance brought forward 2022-23	\$259.09		
-			

Excess in Income over Expenditure	\$0.00
Balance of N/ Zealand funds 30 June 2024	\$259.09
Represented by Current Assets	
Cash at Bank- Westpac Cash Reserve	\$19,199.36
Cash at Bank- Westpac Cheque Account	\$15,711.19
Balance AUS PayPal	\$1,360.13
<b>Total Balance of AUS Assets</b>	\$36,270.68
Balance NZ PayPal	\$259.09

PNDU books have been audited by Grahame Searles CPA, and found to give a true and fair view of the financial operations of Parenteral Nutrition Down Under Inc. for the twelve months ending June 30<sup>th</sup>, 2025

G A Searles 7<sup>th</sup> September 2025

#### **Prepared by**

Chris Walker PNDU President/PNDU Treasurer

10 September 2025