



PNDU
Parenteral Nutrition Down Under

**Parenteral Nutrition Down Under
Inc.**

**Annual Report
2020 - 2021**

Year Ending 30th June 2021

www.pndu.org
contactpndu@gmail.com

128 Rainbow Street
Randwick NSW 2031
AUSTRALIA

President's Report

Annual General Meeting – 17th August 2021

Despite the challenges of covid 19, we take this opportunity to look back at the very difficult year that was 2020-21. As PNDU celebrates 12 years supporting HPNers Down Under, PNDU membership has continued to grow and with the hard work and dedication of our management committee, PNDU has grown into a well-respected patient support group, not only in Australia and New Zealand, but also internationally. Accepted by hospitals, industry, clinical groups and most of all by Home Parenteral Nutrition (HPN) consumers and carers, through the wonderful contacts, associations and friendships built over the past 12 years.

PNDU relies on the dedication of our Management Committee (All Volunteers), without whom PNDU couldn't continue to be proactive in representing all HPNers across Australia and New Zealand. This year we welcomed Tracie and Naomi to the MC, both have worked tirelessly alongside Miranda, Gillian, Fay and Ryan, to ensure PNDU has continued to support our members. I am very grateful for the support of all PNDU MC and volunteers. PNDU MC meetings are held every 6-8 weeks via Skype.

PNDU is more like an extended family, who truly understand what life is like living with Chronic Intestinal Failure (CIF) requiring Home Parenteral Nutrition (HPN).

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)

Assistant Treasurer – Tracie Bowman (HPNer)

Committee Members – Fay Boyd (HPNer), Ryan How (HPN Carer) Naomi Daly (HPNer)

Volunteers – Renee – Katie - Gil

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 1st 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 Membership

PNDU Membership continued to grow over the past year, with Total Membership of 255 representing a possible 160 HPNers Across AUS/NZ

PNDU maintains a website www.pndu.org 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 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 <https://pndu.org/resources/>

Dripline Newsletter: - since the first edition of Dripline in June 2012, 36 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 almost 500 subscribers. To stay up to date with all things HPN related, subscribe to the Dripline newsletter <https://pndu.org/resources/dripline-newsletter/>

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 contactpndu@gmail.com

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 <https://pndu.org/resources/merchandise/>

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

PNDU Representation

PNDU continue to represent our members at conference's, workshops, forums, events and on various committees. Although the COVID 19 restrictions may have interrupted PNDU representation during 2020-21, PNDU always welcomes the opportunity to share the patient/carer voice and perspective to the wider community, using whatever medium is available. 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 attend educational webinars and workshops. PNDU looks forward to attending the next Rare Disease Summit later in 2021.

Rare Disorders New Zealand (RDNZ)

PNDU continue to support the "Fair for Rare" campaign in NZ. **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

Unfortunately, the AuSPEN annual scientific meeting was cancelled due to covid in 2020. PNDU would like to thank AuSPEN for the opportunity they provide to exhibit free of charge, at the AuSPEN ASM and we look forward to attending the AuSPEN conference in Melbourne in November 2021. This annual clinical conference provides PNDU with the wonderful opportunity to engage with HPN clinicians and industry friends from across Australia and New Zealand.

AuSPEN HPN Consumer Workshop

Held alongside the AuSPEN conference, the HPN Consumer Workshop allows HPNers and their family/carers to hear presentations on a range of HPN related topics. PNDU is very grateful for the opportunity to learn from professionals working in the field of Parenteral Nutrition and would like to thank AuSPEN, and the HPN consumer workshop organisers for their ongoing commitment to hosting the AuSPEN HPN Consumer Workshop, believed to be the only consumer workshop of its kind, hosted by a professional society, anywhere in the world. PNDU members look forward to attending the workshop in November 2021.

The AuSPEN HPN Model of Care (MOC) project

It is wonderful to see the AuSPEN HPN MOC project progressing. PNDU is very grateful to have the opportunity to contribute to the MOC project and we look forward to working with AuSPEN's MOC project officer on the future development of the HPN MOC. A very big thank you to AuSPEN for your support of PNDU.

Patient Voice Initiative (PVI)

The Patient Voice Initiative is a collaboration between patients/consumers, researchers and industry working towards improving the patients voice in the Australian health system. It was wonderful to have the chance to attend the recent PVI workshop, patient-based evidence – using patient preference research – and what patient-based evidence can add to PBAC submissions.

Pharmaceutical Benefits Advisory Commission (PBAC)

PNDU made a patient submission to the PBAC in support Teduglutide (Revestive), for use in children with short bowel syndrome, the submission received positive feedback and we wish to thank everyone who contributed to the successful submission. The PBS listing for the use of Teduglutide (Revestive) will be updated to include children later in 2021.

Intravenous Nursing New Zealand (IVNNZ): - Unfortunately the COVID 19 travel restrictions forced the postponement of the IVNNZ conference planned for Christchurch NZ in 2020, PNDU are very grateful for the opportunity provided by IVNNZ to have an exhibition stand and the invitation to present the patient/carer perspective at IVNNZ conference in 2022.

New Zealand National Intestinal Failure and Rehabilitation Service (NZ NIFRS): - Unfortunately the COVID 19 travel restrictions forced the cancelation of the NZ NIFRS conference planned for Wellington NZ in 2020. NZ NIFRS hosted the Congress of the Intestinal Rehabilitation & Transplant Association (CIRTA 2021) in Auckland 29th June – 2nd July. PNDU members Karen and Shirley had the opportunity to share the patient carer perspective and congratulations to both for excellent presentations.

“Full credit to NZ NIFRS and the conference organisers for hosting this event during the covid restrictions.” - Karen

Karen’s article appears in the 36th edition of Dripline - [Final-dripline-issue-36-May-Jul-21.pdf \(pndu.org\)](#)

PNDU look forward to catching up with our wonderful friends at the next NZ NIFRS conference, when the world returns to normal.

International Alliance of Patient Organisations (IAPO – Patient Alliance for Chronic Intestinal Failure and Home Artificial Nutrition (PACIFHAN): - PNDU is a founding member of PACIFHAN.

PACIFHAN’s mission is to work together to promote the international sharing of information and resources to improve the quality of life of Home Artificial Nutrition patients.

Home Artificial Awareness (HAN) Day is celebrated worldwide on the 15th October each year.

IV Passport

“IV Passport is an initiative of Griffith University, the University of Queensland and Children’s Health Queensland. Through PNDU’s highly valued relationship with the AVATAR team (Alliance for Vascular Access Teaching & Research www.avatargroup.org.au), “

PNDU was invited to be a part of this project from its outset, giving input from the consumer perspective. This involvement was transferred to former PNDU President Karen as an individual HPNer/consumer from late 2019. Karen’s article can be found in Dripline 36 [Final-dripline-issue-36-May-Jul-21.pdf \(pndu.org\)](#) More information about IV Passport, including the secure way in which privacy is managed and data stored, as well as IV Passport set-up information, can be found on AVATAR’s website: <https://www.avatargroup.org.au/passport.html> .

Passport is currently available for downloading in Australia, New Zealand, USA and Canada: • Android: <https://play.google.com/store/apps/details...> and • Apple: <https://apps.apple.com/au/app/passport/id1555412253>.

As PNDU Representation opportunities continue to grow with the above organisations, PNDU also look forward to our ongoing involvement with the following organisations and committees: - Australian Patient Organisation Network (APON), Consumer Health Forum (CHF), Australian Vascular Access Society (AVAS), Qld Health PN Steering Committee, Agency for Clinical Innovation NSW (ACI).

HPN Awareness Week 11th – 17th October 2020

The biggest event and major fundraising activity on the PNDU calendar, Home Parenteral Nutrition (HPN) Awareness Week (AW), started with the release of the PNDU AW2020 Video. Another wonderful production focusing on the importance of handwashing, a great reminder, especially in these difficult times. Thank you, Miranda and team, for producing this invaluable PNDU resource. To view the AW2020 Video please visit the home page on the PNDU website <https://pndu.org/>

HPN Awareness Week (incorporating World HAN Day) 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).

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 very delighted when we receive positive feedback and photos from the ever-growing number of people joining in the AW fun.

A very big thank you to everyone who proudly wore their AW Stickers, shared photos and patient stories during AW. A big shout out to the 20 Hospitals Across AUS & NZ who received PNDU resources and became involved. Thank you as well, to our industry friends for your involvement and help during AW2020, Fresenius Kabi, Baxter Healthcare, Biomed and Takeda Australia for your support.

Preparations for HPN Awareness Week 10th – 16th October 2021 (incorporating World HAN Day) – are again underway. AW2021 activities will again be affected by COVID 19 restrictions, we will keep you updated on how to become involved in AW2021 over the coming months.

PNDU Gatherings

The PNDU annual social gathering is a wonderful opportunity to meet other HPNers, carers and their families, the chance to exchange stories and make lasting friendships with people who share and understand our journey, living with the rare and complex condition of Intestinal Failure requiring Parenteral Nutrition.

The annual social gathering is held each year in conjunction with the AuSPEN ASM. PNDU provide 2 travel sponsorships valued at \$600 each, to help PNDU members attend the social gathering and AuSPEN HPN Consumer Workshop.

PNDU very much look forward to hosting another wonderful PNDU annual gathering when the COVID 19 pandemic is over and we are able to travel again, details of the next gathering will be published in Dripline and on the PNDU forums.

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 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.

Baxter Healthcare Pty Ltd

Takeda Pharmaceuticals Australia Pty Ltd

Fresenius Kabi Australia Pty Limited

Financial Statement 2020 - 21

PNDU Accounts		Balances EOFY 2021	Balances EOFY 2020
New Zealand PayPal Account		\$259.09	\$259.09
Credit	\$0.00		\$280.00
Debit	\$0.00		\$303.78
Australian PayPal Account			
Payments received			
Personal Donations	\$4249.77		\$2240.00
Company Donations	\$0.00		\$53.99
Sales/Merchandise	\$75.00		\$121.70
Withdrawals and debits			
Transfer to Westpac	\$0.00		\$1700.00
PayPal Fees	\$114.62		\$73.37

Purchases (In Memoriam)	\$0.00	\$55.00
EOFY Balance 2020 - 2021	\$5,055.32	EOFY 2019-2020 \$845.17

Westpac Cash Reserve Account

Reserved for PNDU expenses		
Travel Sponsorship (Annual Gathering)	\$1000.00	\$1000.00
Venue Hire (Annual Gatherings AUS/NZ)	\$500.00	\$500.00
2022 – 2023 PNDU Insurances	\$2000.00	\$2000.00
Interest	\$3.80	\$3.80
EOFY Balance 2020 - 2021	\$7068.99	EOFY 2019-2020 \$3566.99

Westpac Community Solutions (Cheque Account)

Payments Received (Credits)

Personal Donations	\$689.37	\$6785.00
Company Donations	\$18225.00	\$18000.00
Sales (PNDU Merchandise)		\$0.00
Interest	\$6.52	\$8.63
Transfer from AUS PayPal	\$0.00	\$1700.00

Other Income (Credits)

PNDU MC Travel expenses (Refunds)	\$96.14	\$524.75
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Total Credits 2020 - 2021

\$19,172.03

Credits EOFY 2019-2020

\$27018.38

Withdrawals and Debits

Transferred to Cash Reserve Account

Travel Sponsorship (Annual Gathering)	\$1000.00	\$1000.00
Venue Hire (Annual Gatherings AUS/NZ)	\$500.00	\$500.00
2022 – 2023 PNDU Insurances	\$2000.00	\$2000.00

PNDU Inc. Expenses

Public Liability Insurance	\$934.31	\$934.31
Professional Indemnity Insurance	\$987.36	\$987.36
Constitution Amendment	\$0.00	\$52.21
A12 Statement (Dept Fair Trading)	\$47.21	\$47.19
Office Supplies	\$265.16	\$265.16
PNDU Website	\$219.48	\$163.90
Postage	\$389.63	\$803.16

Travel and expenses to attend

Conferences, meetings and Events

Australia	\$295.06	\$4956.35
New Zealand	\$0.00	\$789.37
PNDU Annual gathering	\$0.00	\$2026.99

Membership (RVA)	\$55.00	\$55.00
Merchandise		
Caps	\$0.00	\$0.00
T Shirts	\$0.00	\$0.00
Education and Information		
Awareness Week Video	\$2000.00	\$2000.00
Medical Play Toys	\$0.00	\$231.60
Dripline Newsletter	\$1104.00	\$1412.00
PNDU Survey (Retraining)	\$0.00	\$236.00
Flyers - Leaflets - Cards	\$0.00	\$30.00
Awareness Week (printed resources)	\$614.00	\$1529.78
PNDU Awards	\$7.00	\$0.00
Other Expenses (Miscellaneous)	\$70.00	\$301.01
Total Debits 2020 -2021	\$10,543.15	\$16 820.99
		Balance EOFY 2019-2020
EOFY Cheque Account Balance 2020 -2021	\$29,600.55	\$11285.73
		EOFY 2019-2020
Total PNDU Funds 2020 -2021 EOFY	\$41,724.86 AUD	\$25,383.83
	\$259.09 NZD	\$259.09
Balance Sheet 30 June 2021		
ACCUMULATED FUNDS		
AUS Balance brought forward 2019-20	\$25383.83	
Excess in Income over Expenditure	\$16,341.03	
Balance of Australian funds 30 June 2021	\$41,724.86	
NZ Balance brought forward 2019-20	\$259.09	
Excess in Income over Expenditure	\$0.00	
Balance of N/ Zealand funds 30 June 2021	\$259.09	
Represented by Current Assets		
Cash at Bank- Westpac Cash Reserve	\$7,068.99	
Cash at Bank- Westpac Cheque Account	\$29,600.55	
Balance AUS PayPal	\$5,055.32	
Total Balance of AUS Assets	\$41,724.86	
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 30th 2021

G A Searles 12th August 2021

Prepared by
Chris Walker
PNDU President/Treasurer

17 August 2021