



PNDU
Parenteral Nutrition Down Under

Parenteral Nutrition Down Under Inc.

Annual Report

2021 - 2022

Year Ending 30th June 2022

www.pndu.org
contactpndu@gmail.com

128 Rainbow Street
Randwick NSW 2031
AUSTRALIA

President's Report

Annual General Meeting – 26th August 2022

Another year over and time to reflect on PNDU activities during 2021 – 2022. PNDU celebrates 13 years of supporting, researching and informing consumers, carers and providers of Parenteral Nutrition for Intestinal Failure across Australia and New Zealand. Despite the many challenges and difficulties PNDU has faced during the past year, with Covid 19 Isolation, lockdowns and restrictions on face-to-face meetings. PNDU has continued to support HPNers down under via the wonderful world of technology. On behalf of PNDU I would like to thank all of the organisations who provided the opportunity to join their online conferences, Webinars, education/training sessions and meetings, maintaining good connections helps PNDU support our HPN members.

PNDU membership has continued to grow and we very much look forward to meeting our new members as travel restrictions ease and PNDU gatherings can once again be held across Australia and New Zealand.

PNDU relies on the dedication of our Management Committee (All Volunteers), Miranda, Gillian, Naomi, Ryan and social media volunteer Renee, with the support of their hard work and dedication PNDU continues to be proactive in representing all HPNers across Australia and New Zealand. Through the wonderful, connections, associations, and friendships built over the past 12 years, 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.

This year PNDU farewelled 2 MC members, our long-standing member Fay, who stood down due to ill health after 10 years of dedicated service and the passing of a very inspirational woman, and PNDU treasurer, Tracie. 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 is very grateful for the support provided by Fay and Tracie and also extremely saddened by their loss.

PNDU look forward to welcoming new MC members Julia and Ebony, working together for a brighter future supporting our members. PNDU MC meetings are held every 6-8 weeks via Skype.

PNDU Management Committee

President – Chris Walker, (HPN Carer)

Vice President/Dripline Editor – Gillian Anderson (HPNer)

Secretary/Public Officer – Miranda Einstein (HPN Carer)

Treasurer – Tracie Bowman (HPNer) Chris Walker (HPN Carer) Naomi Daly (HPNer)

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

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 358 representing over 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, 40 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

<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 have again interrupted PNDU representation during 2021-22, 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 attended the 2021 Virtual Rare Disease Summit and look forward to attending Parliamentary events and the 2022 Rare Disease Summit, continuing to support the National Plan for Rare Diseases.

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

The 2021 AuSPEN annual scientific meeting was a virtual event due to covid. 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 2022. 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. The 2021 HPN Consumer

Workshop was held as a virtual event, with over 50 HPNers and carers attending online. 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 both in person and online in Melbourne November 2022.

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 opportunity to attend online workshops – and learning what patient-based evidence can add to PBAC submissions.

Pharmaceutical Benefits Advisory Commission (PBAC)

PNDU made another patient submission to the PBAC in support of Teduglutide (Revestive), a 2year review of the uptake use of Teduglutide, the submission received positive feedback and we wish to thank everyone who contributed to the submission. The report for the uptake use of Teduglutide (Revestive) will be released later in 2022.

Intravenous Nursing New Zealand (IVNNZ): - Unfortunately the COVID 19 travel restrictions forced the postponement of the IVNNZ conference planned for Christchurch NZ in 2020 and again in 2021. PNDU are very grateful for the invitation to present the patient/carer perspective at IVNNZ conference in November 2022.

National Patient Organisation Network: - The Standing Committee and the Centre for Community-Driven Research held the National Patient Organisation Network, Australia 2022 conference to Melbourne. The 2022 conference aims to increase awareness of the role and services provided by patient organisations, as an integral part of the health system, and their unique role as advocates. As part of this, it is important for patient organisations to understand how they are perceived by stakeholders and where their advocacy issues might sit within the many competing priorities that decision-makers are managing, and how to use their position in the community to relay important health messages. As a founding member of NPON PNDU appreciate the network opportunities and connections provided by attending the NPON 2022 Conference, although this conference was another virtual event, the connections made will benefit PNDU in the future.

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.

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: - Consumer Health Forum (CHF), Australian Vascular Access Society (AVAS), Qld Health PN Steering Committee, Agency for Clinical Innovation NSW (ACI), New Zealand National Intestinal Failure and Rehabilitation Service NZNIFRS.

HPN Awareness Week 10th – 16th October 2021

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 AW2021 Video. Another wonderful production focusing on the importance HPN connections, support makes the world of difference and a HPNers connections with health care professionals, family and friends help to improve our quality of life lived outside of hospital. Thank you, Miranda and team, for producing this invaluable PNDU resource. To view the AW2021 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 AW2021, Fresenius Kabi, Baxter Healthcare, Biomed and Takeda Australia for your support.

Baxter Healthcare provided a wonderful online event and virtual pharmacy tour, sharing videos of PNDU HPN member stories with their staff. The feedback during the online crosses to various Baxter pharmacy sites, was nothing short of amazing. PNDU thank Baxter for providing this opportunity during awareness week and look forward to in person pharmacy tours and awareness week activities in the future.

Preparations for HPN Awareness Week 9th – 15th October 2022 (incorporating World HAN Day) – are again underway. AW2022 activities may again be affected by COVID 19 restrictions, we will keep you updated on how to become involved in AW2022 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 on 20th November 2022 in Melbourne.

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 2021 - 22

PNDU Accounts		Balances EOFY 2022	Balances EOFY 2021
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	\$1,010.00		\$4249.77
Company Donations	\$0.00		\$0.00
Sales/Merchandise	\$0.00		\$75.00
Withdrawals and debits			
Transfer to Westpac	\$0.00		\$0.00
PayPal Fees	\$30.26		\$114.62

Purchases (In Memoriam)	\$0.00	\$0.00
EOFY Balance 2021 - 2022	\$5,055.32	EOFY 2020-2021 \$5,055.32

Westpac Cash Reserve Account

Reserved for PNDU expenses		
Travel Sponsorship (Annual Gathering)	\$3000.00	\$3000.00
Venue Hire (Annual Gatherings AUS/NZ)	\$1000.00	\$1000.00
2022 – 2023 PNDU Insurances	\$3000.00	\$3000.00
Interest	\$0.63	\$3.80
EOFY Balance 2021 - 2022	\$7069.62	EOFY 2020-2021 \$7068.99

Westpac Community Solutions (Cheque Account)

Payments Received (Credits)

Personal Donations	\$2,280.00	\$689.37
Company Donations	\$15,020.61	\$18225.00
Sales (PNDU Merchandise)		\$0.00
Interest	\$0.00	\$6.52
Transfer from AUS PayPal	\$0.00	\$0.00

Other Income (Credits)

PNDU MC Travel expenses (Refunds)	\$501.99	\$96.14
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Total Credits 2021 - 2022

\$17,910.73

Credits EOFY 2020-2021

\$19,172.03

Withdrawals and Debits

Transferred to Cash Reserve Account

Travel Sponsorship (Annual Gathering)	\$0.00	\$1000.00
Venue Hire (Annual Gatherings AUS/NZ)	\$0.00	\$500.00
2022 – 2023 PNDU Insurances	\$0.00	\$2000.00

PNDU Inc. Expenses

Public Liability Insurance	\$934.31	\$934.31
Professional Indemnity Insurance	\$987.36	\$987.36
Constitution Amendment	\$0.00	\$0.00
A12 Statement (Dept Fair Trading)	\$48.21	\$47.21
Office Supplies	\$299.04	\$265.16
PNDU Website	\$0.00	\$219.48
Postage	\$506.23	\$389.63

Travel and expenses to attend Conferences, meetings and Events

Australia	\$1279.89	\$295.06
New Zealand	\$505.00	\$0.00
PNDU Annual gathering	\$0.00	\$0.00

Membership (RVA)	\$55.00	9. \$55.00
Merchandise		
Caps	\$0.00	\$0.00
T Shirts	\$0.00	\$0.00
Education and Information		
Awareness Week Video	\$2200.00	\$2000.00
Medical Play Toys	\$0.00	\$0.00
Dripline Newsletter	\$720.00	\$1104.00
In Memorial	\$88.95	\$0.00
Flyers - Leaflets - Cards	\$103.00	\$0.00
Awareness Week (printed resources)	\$537.00	\$614.00
PNDU Awards	\$0.00	\$7.00
Other Expenses (Miscellaneous)	\$50.07	\$70.00
Total Debits 2021 -2022	\$8,314.06	\$10 543.15
		Balance EOFY 2020-2021
EOFY Cheque Account Balance 2021 -2022	\$39,197.22	\$29,600.55
		EOFY 2020-2021
Total PNDU Funds 2021 -2022 EOFY	\$52,301.90 AUD	\$41,724.86
	\$259.09 NZD	\$259.09
Balance Sheet 30 June 2022		
ACCUMULATED FUNDS		
AUS Balance brought forward 2020-21	\$41,724.86	
Excess in Income over Expenditure	\$10,577.04	
Balance of Australian funds 30 June 2022	\$52,301.90	
NZ Balance brought forward 2020-21	\$259.09	
Excess in Income over Expenditure	\$0.00	
Balance of N/ Zealand funds 30 June 2022	\$259.09	
Represented by Current Assets		
Cash at Bank- Westpac Cash Reserve	\$7,069.62	
Cash at Bank- Westpac Cheque Account	\$39,197.22	
Balance AUS PayPal	\$6,035.06	
Total Balance of AUS Assets	\$52,301.90	
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 2022

G A Searles 16th August 2022

Prepared by
Chris Walker
PNDU President/Treasurer

26 August 2022