



**Parenteral Nutrition Down Under Inc.**

# **Annual Report**

## **2022 - 2023**

**Year Ending 30<sup>th</sup> June 2023**

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# President's Report

## Annual General Meeting – 13<sup>th</sup> September 2023

As PNDU celebrates 14 years of supporting, researching and informing consumers, carers and providers of Parenteral Nutrition for Intestinal Failure across Australia and New Zealand, it was wonderful to see an increase in PNDU activities during 2022 – 2023 following several years of Covid 19 restrictions. The president's report is a wonderful opportunity to look back on the past 12 months and what we were able to achieve.

I am very grateful to have the support of a dedicated Management Committee (All Volunteers). Thank you, Miranda, Gillian, Naomi, Julia and social media volunteer Renee, without whom PNDU couldn't deliver the various support activities for our members, with their help PNDU continues to be a well-respected patient support group, not only in Australia and New Zealand, but also internationally.

This year we were also reminded of how fragile life on HPN is with the sad passing of long time HPNers and PNDU members Fay Boyd who gave 10 years of dedicated service to the management committee and Rosie Crosland who was dependent on HPN for 31 years. PNDU is like an extended family, who truly understand what life is like living with Home Parenteral Nutrition (HPN). PNDU is very grateful for the support provided by Fay and Rosie and are also extremely saddened by their loss.

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 – Chris Walker (HPN Carer) Naomi Daly (HPNer)

Committee Members – Julia Rollings (HPN Carer) Ebony Callaghan (HPNer)

Volunteers – Renee – Katie – Gil

### **PNDU Gatherings**

The PNDU annual social gathering is held alongside the AuSPEN events each year, it was wonderful to be able to meet up in person again for the first time since 2019. The social gathering is an opportunity to meet other HPNers, family and carers who truly understand what life is like living with Intestinal Failure and Parenteral Nutrition. A time to make new friends and share your lived experiences in a relaxed friendly environment.

The 2022 social gathering was held at the Hub in Docklands, Melbourne and was attended by 18 people which included 8 HPNers. PNDU provided travel sponsorships to help Felicia (HPNer) join us from New

Zealand and Syena (HPNer) and family travel from the ACT; PNDU Treasurer Naomi (HPNer) travelled from Sydney and we were joined by 5 local HPNers Laura, Meags, Daniel, Deklyn and Philip.

Everyone mingled with each other and engaged in conversations and our little ones played excitedly as the afternoon passed all too quickly. The value of being able to meet other HPNers in person and share the lived experience can never be underestimated.

Saturday 4th March marked the return of stand-alone in-person social gatherings. Miranda organised the venue, Redfern Park, in Redfern, with access to the Community room if the weather was nasty. Luckily it was a lovely autumnal day, sunny, with tables set up under the shade of a few large trees. In all, 19 people – 8 HPNers plus husbands, parents and a grandmother - and 2 dogs attended.

It was wonderful to catch up with long time PNDU members Lisa and her mum Anne while I was in Auckland for the NZ NIFRS Education and Network Day. Anne and Lisa graciously hosted PNDU founder Emeritus Professor Gil Hardy and myself for afternoon tea.

PNDU very much look forward to hosting another wonderful PNDU annual gathering on 12<sup>th</sup> November 2023 in Auckland New Zealand.

## **HPN Awareness Week 9<sup>th</sup> – 15<sup>th</sup> October 2022**

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

The week started with the release of the PNDU AW2022 Video, another awesome video production to share on social media. Thank you, Miranda and team, for producing this invaluable PNDU resource. To view the AW2022 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 industry friends Baxter Healthcare and Fresenius Kabi opened the doors of their HPN compounding facilities for guided tours, a wonderful opportunity to see how our HPN is manufactured. The pharmacy tours were a big hit with PNDU members attending every Baxter facility across Australia and New Zealand and the Fresenius Kabi Facility in Sydney. 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.

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 awareness week fun.

A very big thank you to everyone who participated in awareness week activities, sharing your photos and stories, to 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 AW2022. Thank you for your support.

Preparations for HPN Awareness Week 15<sup>th</sup> – 21<sup>st</sup> October 2023 (incorporating World HAN Day) – are again 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 to the wider community. PNDU attended Parliamentary events celebrating Rare Disease Day and 10 Years of Rare Disease Advocacy, along with attending the 2022 Rare Disease Summit, continuing to support the National Plan for Rare Diseases. It has been a very humbling experience to represent PNDU at these events for the past 10 years.

## **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 2022 AuSPEN annual scientific meeting was held in Melbourne. 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 Auckland in November 2023. 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**

The AuSPEN Home Parenteral Nutrition (HPN) Consumer Workshop is designed for consumers and carers as a unique opportunity to learn more about HPN from expert clinicians working in the field. The workshop is organised by Suzie Daniels (AuSPEN) with the assistance of PNDU.

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 2022 HPN Consumer Workshop didn't disappoint with updates from AuSPEN and PNDU President's, Sharon Carey and Chris Walker. The Four presentations from specialised HPN Clinicians were very informative and well received by our members. PNDU would like to thank Dr Darcy Holt, Dr Darren Wong, Dr Zoe McCallum, Dr Claire Burton and the AuSPEN 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 looks forward to working closely with AuSPEN on future workshops.

### **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.

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

### **Intravenous Nursing New Zealand (IVNNZ): -**

Unfortunately, the IVNNZ conference in Christchurch NZ in November 2022 coincided with the AuSPEN Conference in Melbourne and I wasn't able to attend the IVNNZ event in person. I was very grateful for the invitation to present the patient/carer perspective via a prerecorded presentation at IVNNZ conference in November 2022. PNDU appreciate the opportunity to engage with IVNNZ and look forward to future events.

### **National Patient Organisation Network: -**

The National Patient Organisation Network, Australia 2023 conference was held in Sydney May 15<sup>th</sup> – 16<sup>th</sup>. The 2023 conference theme was: 'Breaking the Cycle'

For Patient Organisations this means: Breaking the cycle of consultations and roadmaps that go nowhere, primarily because there is rarely funding for implementation. Breaking the cycle of consultations that take a top-down approach: We want to encourage debate and not silence it. Breaking the cycle of our most vulnerable populations being left behind. Breaking the cycle of funding that is not sustainable for Patient Organisations.

Video recordings of addresses and panel discussions are available on the NPON website,

[AUSTRALIA – CCDR \(npon.org\)](https://npon.org)

As a founding member of NPON PNDU appreciate the network opportunities and connections provided by attending the NPON 2023 Conference.

### **New Zealand National Intestinal Failure and Rehabilitation Service NZNIFRS.**

On behalf of PNDU I would like to thank Rebecca Coggins and Ian Bissett for the invitation to attend the NZ NIFRS Education and Network Day in Auckland, an amazing event and a credit to the NIFRS Team. The presentations from all speakers were very informative and the event provided a great opportunity for PNDU to connect with clinicians in New Zealand who specialise in the field of Intestinal Failure. I was kept very busy by the numerous attendees who visited the PNDU stand during the day. It was wonderful to see so much interest in PNDU and what we do. I happily shared a wealth of information and PNDU printed resources for the clinicians to pass on to their HPNers. PNDU welcomes all Kiwi HPNers, their family, carers and clinicians who wish to become members of PNDU to visit our website

### **PNDU Membership**

PNDU Membership continued to grow with over 360 members, representing more than 160 HPNers Across AUS/NZ

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

**Dripline Newsletter:** - since the first edition of Dripline in June 2012, 44 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](mailto: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

## 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 during the 2022 – 23 financial year.

Fresenius Kabi Australia Pty Limited

# Financial Statement 2022 - 23

<b>PNDU Accounts</b>	<b>Balances EOFY 2023</b>	<b>Balances EOFY 2022</b>
<b>New Zealand PayPal Account</b>	<b>\$259.09</b>	<b>\$259.09</b>
Credit	\$0.00	\$0.00
Debit	\$0.00	\$0.00
<b>Australian PayPal Account</b>		
<b>Payments received</b>		
Personal Donations	\$625.00	\$1,010.00
Company Donations	\$0.00	\$0.00
Sales/Merchandise	\$55.00	\$0.00

**Withdrawals and debits**

Travel Sponsorship	\$616.00	\$0.00
Awareness Week Artwork	\$100.00	\$0.00
Refund of Artwork Fee	\$100.00	\$0.00
PayPal Fees	\$20.53	\$30.26

**EOFY 2021-2022****EOFY Balance 2022 - 2023****\$6,078.53****\$6,035.06****Westpac Cash Reserve Account**

Reserved for PNDU expenses		
Travel Sponsorship (Annual Gathering)	\$0.00	\$3000.00
Venue Hire (Annual Gatherings AUS/NZ)	\$0.00	\$1000.00
2023 – 2024 PNDU Insurances	\$0.00	\$3000.00
Interest	\$0.63	\$0.63

**EOFY 2021-2022****EOFY Balance 2022 - 2023****\$7070.25****\$7069.62****Westpac Community Solutions  
(Cheque Account)****Payments Received (Credits)**

Personal Donations	\$5,875.40	\$2,280.00
Company Donations	\$3,000.00	\$15,020.61
Sales (PNDU Merchandise)	\$0.00	\$0.00

**Other Income (Credits)**

PNDU MC Travel expenses (Refunds)	\$400.00	\$501.99
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**Credits EOFY  
2021-2022****Total Credits 2022 - 2023****\$9,275.40****\$17,910.73****Withdrawals and Debits****PNDU Inc. Expenses**

Public Liability Insurance	\$1022.25	\$934.31
Professional Indemnity Insurance	\$998.36	\$987.36
A12 Statement (Dept Fair Trading)	\$50.22	\$48.21
Office Supplies	\$883.27	\$299.04
PNDU Website	\$676.49	\$0.00
Postage	\$651.93	\$506.23

**Travel and expenses to attend  
Conferences, meetings and Events**

Australia	\$6,444.47	\$1279.89
New Zealand	\$1,512.17	\$505.00
PNDU Annual gathering	\$503.75	\$0.00
Travel Sponsorship	\$1800.00	\$0.00
Membership (RVA)	\$55.00	\$55.00

**Education and Information**



Awareness Week Video	\$2000.00	\$2200.00
Dripline Newsletter	\$1,566.00	\$720.00
In Memorial	\$137.95	\$88.95
Flyers - Leaflets - Cards	\$0.00	\$103.00
Awareness Week (printed resources)	\$1373.00	\$537.00
Other Expenses (Miscellaneous)	\$50.00	\$50.07
<b>Total Debits 2022 -2023</b>	<b>\$19,724.86</b>	<b>\$8,314.06</b>

**Balance EOFY****2021-2022**

<b>EOFY Cheque Account Balance 2022 -2023</b>	<b>\$28,747.76</b>	<b>\$39,197.22</b>
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**Total PNDU Funds 2022 -2023 EOFY****\$41,896.54 AUD****EOFY 2021-2022****\$52,301.90****\$259.09 NZD****\$259.09****Balance Sheet 30 June 2023****ACCUMULATED FUNDS**

AUS Balance brought forward 2021-22	\$52,301.90
Excess of Expenditure over income	-\$10,405.36
Balance of Australian funds 30 June 2023	\$41,896.54
NZ Balance brought forward 2021-22	\$259.09
Excess in Income over Expenditure	\$0.00
Balance of N/ Zealand funds 30 June 2023	\$259.09

**Represented by Current Assets**

Cash at Bank- Westpac Cash Reserve	\$7,070.25
Cash at Bank- Westpac Cheque Account	\$28,747.76
Balance AUS PayPal	\$6,078.53
<b>Total Balance of AUS Assets</b>	<b>\$41,896.54</b>
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> 2023

G A Searles 5<sup>th</sup> September 2023

**Prepared by****Chris Walker PNDU President****Naomi Daly PNDU Treasurer****09 September 2023**