



PNDU
Parenteral Nutrition Down Under

**Parenteral Nutrition Down Under
Inc.**

**Annual Report
2019 - 2020**

Year Ending 30th June 2020

www.pndu.org
contactpndu@gmail.com

128 Rainbow Street
Randwick NSW 2031
AUSTRALIA

President's Report

Annual General Meeting – 17th August 2020

The 2019 – 2020 year saw a changing of the guard for PNDU as we farewelled our inaugural president, Karen, who stepped down after 10 years involvement with PNDU, Karen will always be sadly missed by the Management Committee (MC). A member of the MC, having held the position of PNDU treasurer since 2014, I nervously stepped up to the role of president, knowing I had some big shoes to fill and the responsibility to lead PNDU into the future. No-one could have predicted how the world would change during the second half of the year with the COVID 19 pandemic, social distancing, isolation and a move to a virtual world working from home without any face to face contact, despite all the challenges, PNDU has continued to support our members.

PNDU has grown into a well-respected patient support group, not only in Australia and New Zealand, where our membership continues to grow each year, but also internationally. Accepted by hospitals, industry, clinical groups and most of all Home Parenteral Nutrition (HPN) consumers and carers, through the wonderful contacts, associations and friendships built over the past 11 years. 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).

In order for PNDU to continue to be recognised as the “Go – To” Organisation for HPNers Down-Under, PNDU relies on the dedication of our Management Committee (All Volunteers), without whom PNDU couldn't continue to be proactive, providing support, raising awareness, sharing the patients voice to the wider community, and representing all HPNers across Australia and New Zealand. This year we welcomed Belinda and Ryan to the MC at the AGM, with Naomi volunteering early in 2020. I am very grateful for the support of all PNDU MC and volunteers. MC meeting are held every 6-8 weeks via Skype.

PNDU Management Committee

President – Chris, (HPN Carer)

Vice President/Dripline Editor – Gillian (HPNer)

Secretary/Public Officer – Miranda (HPN Carer)

Treasurer – Belinda (HPN Carer)

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

Volunteers – Renee (HPNer) – Naomi (HPNer) – Katie (HPN Carer)

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 220 representing a possible 125 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 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/>. 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

Dripline Newsletter:- since the first edition of Dripline in June 2012, 32 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 electronically circulated to the wider community, 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

Hints and Tips: - Amongst a whole host of very helpful HPN information contained on the PNDU website, are handy hints, tips and fact sheets including the following 2 very valuable resources. "Preparing your HPN Child for School", and Tips Sheet: 'Accessing the Australian NDIS'.

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/>

Share the PNDU love and help raise awareness of HPN at the same time: Please email us at contactpndu@gmail.com to place your order, confirm postage costs, and organise payment and delivery.

Medical Play Toys: - PNDU have supplied more than 30 Medical Play Toys, "Free of Charge' to our HPN children under 10 years of age, specially designed with Central Lines, Mic-Key buttons, Stoma bags etc. to help encourage our little ones to engage in medical play time with their new PNDU playmates. This wonderful resource has proved to be very helpful for parents and children, a visual aid to help explain the complex nature of Intestinal Failure and Parenteral Nutrition.

Unfortunately, our local manufacturer, Just Like You Dolls, closed early in 2020. PNDU is currently researching other manufacturers, in order to continue to provide this wonderful resource to our member children.

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 the second half of the year, PNDU always welcomes the opportunity to share the patient/carers 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/carers voice and perspective.

Rare Voices Australia (RVA)

PNDU is very proud to be an RVA Partner Organisation and to have the opportunity to contribute to the Fair for Rare campaign, Rare Disease Summits and the development of the National Strategic Action Plan for Rare Diseases. Adding our small patient voice for those living with Chronic Intestinal failure requiring Parenteral Nutrition, to the unified voice of all Australians living with a rare disease.

During a very busy HPN Awareness Week, (October 2019) PNDU was invited by Rare Voices Australia (RVA) to attend Parliament House in Canberra for the release of the McKell Institute Report, *Disability & Rare Disease: Towards Person Centred Care for Australians with Rare Diseases*. Jordan and Logan (HPNers) feature as a case study in the report and also featured in a national press release the same day, giving great exposure for PNDU during AW19. Importantly, the McKell Report has helped inform the development of the National Plan for Rare Diseases.

<https://mckellinstitute.org.au/research/reports/disability-rare-disease/>

Coinciding with Rare Disease Day events, (February 2020) PNDU was invited by Rare Voices Australia (RVA) to attend Parliament House in Canberra for the launch of the National Strategic Action Plan for Rare Diseases. Launched by the Health Minister Hon. Greg Hunt, the action plan has Bipartisan support from the Australian Government and most importantly The Action Plan has been developed by the rare disease sector, for the rare disease sector, to provide the best possible health and wellbeing outcomes for Australians living with a Rare Disease. (Dripline 31 February 2020).

Rare Disorders New Zealand (RDNZ)

Coinciding with Rare Disease Day events, (February 2020) PNDU was invited by Rare Disorders New Zealand (RDNZ) to attend Parliament House in Wellington New Zealand for the launch of the “Fair for Rare” campaign in NZ. Gil Hardy represented PNDU at the Fair for Rare event. **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. (Rare is Everywhere – Dripline 31 February 2020)

Australasian Society of Parenteral and Enteral Nutrition (AuSPEN)

AuSPEN Conference

November 2019 PNDU MC members Fay and Chris travelled to Adelaide SA for the AuSPEN annual scientific meeting. PNDU would like to thank AuSPEN for the opportunity to once again exhibit free of charge, at the AuSPEN ASM held at the National Wine Centre in Adelaide on November 25th – 26th 2019. This annual clinical conference provides PNDU with the wonderful opportunity to engage with HPN clinicians and industry friends from across Australia and New Zealand.

The PNDU Poster, a summary of the PNDU retraining survey, was accepted for display at the conference. I had the opportunity to discuss the poster and survey with clinicians during the lunchtime breakout session on Sunday the 24th.

AuSPEN HPN Consumer Workshop

The AuSPEN HPN Consumer Workshop allows HPNers and their family/carers to hear presentations on a range of HPN related topics, directly from clinicians and provides the opportunity to ask questions with regard to these topics. The HPN Consumer Workshop was held on Saturday 23rd November at the Adelaide Health and Sciences Building. The event was attended by 9 PNDU members who travelled from interstate and 9 local HPNers and carers, a very successful turnout for this event.

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 workshop organisers Suzie Daniels and Margie O’Callaghan, for organising and hosting the 5th annual AuSPEN HPN Consumer Workshop, alongside the 2019 AuSPEN ASM, believed to be the only consumer workshop of its kind, hosted by a professional society, anywhere in the world.

Emma Osland (AuSPEN) presented an update on the AuSPEN HPN Model of Care (MOC) and Health Outcomes. 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.

Intravenous Nursing New Zealand (IVNNZ): - Unfortunately the COVID 19 travel restrictions forced the postponement of the IVNNZ conference planned for Christchurch NZ in March, 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. I look forward to presenting online via zoom, when the conference is rescheduled in November 2020.

New Zealand National Intestinal Failure Service (NZ NIFS): - Unfortunately the COVID 19 travel restrictions forced the cancelation of the NZ NIFS conference planned for Wellington NZ in April 2020. PNDU look forward to once again exhibiting at the NZ NIFS conference, when the world returns to normal.

As PNDU membership continues to grow in New Zealand, PNDU are very grateful for the opportunities provided by Intravenous Nursing NZ (IVNNZ), NZ National Intestinal Failure Service (NZNIFS), and the growing relationships with NZ hospitals and clinicians.

International Alliance of Patient Organisations (IAPO – Patient Alliance for Chronic Intestinal Failure and Home Artificial Nutrition (PACIFHAN): - PNDU continue representation in PACIFHAN and it was wonderful to see all member countries participating and sharing patient stories during HAN Awareness Day 15th October 2019, 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.

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 13th – 19th October 2019

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 AW2019 Video. A wonderful light hearted look at HPN Degustation. Thank you, Miranda, Dave and team, for producing and starring in this invaluable PNDU resource. The AW2019 Video was shared with PNDU members and the wider community, recording over 750 views on YouTube. To view the AW2019 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 excited, encouraged and 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 23 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 AW2019, Fresenius Kabi/Slade Health, Baxter Healthcare (AUS/NZ) and Biomed who generously hosted guided tours of their HPN Compounding Pharmacies and Takeda/Shire Australia for your support.

Preparations for HPN Awareness Week 11th – 17th October 2020 (incorporating World HAN Day) – are again underway. AW2020 activities will be affected by COVID 19 restrictions, we will keep you updated on how to become involved in AW2020 over the coming months.

PNDU Gatherings

PNDU hosted the annual social gathering at the Minor Works Building (MWB) in Adelaide on Friday 22 November, 2019. The annual social gathering is held in conjunction with the AuSPEN ASM. PNDU provided 3 travel sponsorships valued at \$600 each, to help PNDU members attend the social gathering and AuSPEN HPN Consumer Workshop. The gathering was attended by 9 PNDU members who travelled from interstate and 4 locals.

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.

I would like to personally thank everyone who was able to attend the annual gathering and make this a very special day on the PNDU calendar. I look forward to another wonderful PNDU annual gathering when the COVID 19 pandemic is over, details of the next gathering will be published in Dripline and on the PNDU forums.

Unfortunately, the planned Gatherings in Christchurch and Wellington New Zealand, had to be cancelled due to COVID 19, PNDU very much look forward to hosting a gathering for our Kiwi members as soon as we are able to travel again.

Research

PNDU's latest member survey on retraining in HPN procedures was presented as a poster at the AVAS and AuSPEN conferences in 2019, and is now a peer reviewed and Published Paper, our first PNDU member survey to be accepted for publication in a medical journal.

“Retraining of Home Parenteral Users in Australia and New Zealand: a consumer audit” by Winterbourn et al, was published in the October 2019 issue of Vascular Access (DOI <https://doi.org/10.33235/va.5.2.29-37>). also featuring in the global publication IVTEAM update on New Year's Day (2020).

In Memoriam

With Heartfelt sadness PNDU joined with family and friends to say goodbye to 4 members of the PNDU family, James (HPNer), Lara (HPNer), Aidan (HPNer) and Tanya (Carer). Our sincere condolences to all

family and friends who's loved ones have passed away. May we all find comfort as we remember their love, strength and courage.

A very special thank you to everyone who made generous donations to PNDU, in memory of their dearly departed loved ones.

Thank You

We look forward to announcing the winners of the PNDU Awards 2020, a wonderful way to recognise and say thank you, to the people (PNDU members, clinicians and industry employees) who do amazing work within the HPN community, to help make our life on HPN a little easier. Winners will be announced at the AGM and published in Dripline.

I very much appreciate the support of the PNDU MC, volunteers Industry friends, hospitals, clinicians, and all of our amazing 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 the ongoing support of the following organisations and industry friends, for your generous donations/grants.

The Book Depository

https://www.bookdepository.com/?a_aid=parenteralnutrition&a_bid=4064d519

IPANEMA (NZ charity - Charities Commission Registration CC21178)

Baxter Healthcare Pty Ltd

Takeda Pharmaceuticals Australia Pty Ltd

Fresenius Kabi Australia Pty Limited

Biomed NZ

Financial Statement 2019-20

PNDU Accounts		Balances EOFY 2020	Balances EOFY 2019
New Zealand PayPal Account			
Credit	\$280.00	\$259.09	\$282.87
Debit	\$303.78		\$54.16
Australian PayPal Account			
Payments received			
Personal Donations	\$2240.00		\$3820.60
Company Donations	\$53.99		\$198.45
Sales/Merchandise	\$121.70		\$68.05
Withdrawals and debits			
Transfer to Westpac	\$1700.00		\$3800.00
PayPal Fees	\$128.37		\$115.02
Purchases (In Memoriam)	\$55.00		
EOFY Balance 2019 - 2020		\$845.17	EOFY 2018-2019 \$257.85
Westpac Cash Reserve Account			
Reserved for PNDU expenses			
Travel Sponsorship (Annual Gathering)	\$1000.00		\$1000.00
Venue Hire (Annual Gathering)	\$500.00		\$500.00
2019 – 2020 PNDU Insurances	\$2000.00		\$2000.00
Interest	\$3.80		\$8.82
EOFY Balance 2019 - 2020		\$3566.99	EOFY 2018-2019 \$3554.37
Westpac Community Solutions			
(Cheque Account)			
Payments Received (Credits)			
Personal Donations	\$6785.00		\$2630.00
Company Donations	\$18000.00		\$11150.67
Sales (PNDU Merchandise)			\$466.57
Interest	\$8.63		\$8.34
Transfer from AUS PayPal	\$1700.00		\$3800.00
Other Income (Credits)			
PNDU MC Travel expenses (Refunds)	\$524.75		\$1481.42
Miscellaneous (Refunds)			\$21.52
Total Credits 2019 - 2020	\$27018.38		Credits EOFY 2018-2019 \$19558.52

Withdrawals and Debits**PNDU Inc. Expenses**

Public Liability Insurance	\$934.31	\$774.05
Professional Indemnity Insurance	\$987.36	\$953.37
Constitution Amendment	\$52.21	
A12 Statement (Dept Fair Trading)	\$47.19	\$46.18
Office Supplies	\$265.16	\$111.68
PNDU Website	\$163.90	
Postage	\$803.16	\$1004.24

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

Australia	\$4956.35	\$3420.18
New Zealand	\$789.37	\$3269.30
PNDU Annual gathering	\$2026.99	\$1622.19
Membership (RVA)	\$55.00	\$50.00

Merchandise

Caps		\$1397.00
T Shirts		\$1760.94

Education and Information

Awareness Week Video	\$2000.00	\$1980.00
Medical Play Toys	\$231.60	1182.80
Dripline Newsletter	\$1412.00	\$1363.20
Travel Booklet		\$302.50
PNDU Survey (Retraining)	\$236.00	\$143.00
Flyers - Leaflets - Cards	\$30.00	\$396.00
Awareness Week (printed resources)	\$1529.78	\$1177.00
PNDU Awards		\$9.76
Other Expenses (Miscellaneous)	\$300.01	\$550.77

Total Debits 2019 -2020

\$16,820.99

\$20,069.97

Balance EOFY**2018-2019****\$11285.73****EOFY Cheque Account Balance 2019 -2020****\$20,971.67****EOFY 2018-2019****\$14,595.32****Total PNDU Funds 2019 -2020 EOFY****\$25,383.83 AUD****\$259.09 NZD****Balance Sheet 30 June 2020****ACCUMULATED FUNDS**

AUS Balance brought forward 2018-19	\$14,595.32
Excess in Income over Expenditure	\$10,788.51
Balance of Australian funds 30 June 2020	\$25,383.83
NZ Balance brought forward 2018-19	\$282.87
Excess in Income over Expenditure	-\$23.78
Balance of N/ Zealand funds 30 June 2020	\$259.09

Represented by Current Assets

Cash at Bank- Westpac Cash Reserve	\$3,566.99
Cash at Bank- Westpac Cheque Account	\$20,971.67
Balance AUS PayPal	\$845.17
Total Balance of AUS Assets	\$25,383.83
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 2020

G A Searles 8th August 2020

**Prepared by
Chris Walker
PNDU President**

17 August 2020