DRIPLINE

PNDU
Parenteral Nutrition Down Under

This is a PNDU awards year, so read about how you can vote for a special HPN professional or company employee for their commitment to your HPN care. Get ready for HPN Awareness Week and plan to visit a compounding pharmacy tour; Save the dates for Awareness Week, and the annual Consumer Workshop and PNDU social gathering; get some ideas for helping your non-HPN children to feel special, too; be encouraged to go on holidays, setting up in different places; read an overview of the GENCA conference in Adelaide, as well as Oley's annual conference in Charleston in the US. And please HPN members, be inspired to join our MC to continue PNDU's great work!

Gillian

Dripline Editor

ISSUE 52
MAY–JUL
2025

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PNDU Needs Help!

Four Committee Members are not enough to continue running PNDU as a valuable support group for HPNers into the future.

We need you, because 'someone else' is already over-worked.

We meet on-line on Teams once every 6 weeks to discuss PNDU business -there is not much else to do apart from that...although a volunteer to be treasurer would be great!

Please write any questions (or offers to join our meetings) to Chris at contactpndu@gmail.com

Upcoming Events

1. Home Parenteral Nutrition Awareness Week (HPN AW25)

28th September – 4th October

HPN Awareness Week is the biggest event on the PNDU calendar. An opportunity for the HPN community to come together and bring about a better understanding of what life is like for almost 400 Aussies and Kiwis living with the rare condition Chronic Intestinal Failure requiring Home Parenteral Nutrition.

HPN AW25 is PNDU's major fundraising event for the year, as a registered charity all donations of $2 and over are tax deductible. To donate visit the PNDU website pndu.org.

HPN AW25 Baxter Pharmacy Tours - Save the dates in your calendar/diary

Baxter healthcare will once again open the doors of their HPN Compounding Facilities for tours; everyone is welcome, HPNers, family and carers. Why not invite your local MP to join us? The following sites have confirmed the following tour dates.

Toongabbie, Sydney - Monday 29th September

Auckland, NZ - Thursday 2nd October

Brunswick, Melbourne - Thursday 2nd October

Christchurch, NZ - Friday 3rd October

Perth, WA - Friday 3rd October

2. The Gastroenterological Society of Australia (GESA) – Australian Gastroenterology Week 2025 (AGW 2025)

PNDU has been invited to exhibit our resources at the World Congress of Gastroenterologists WCOG@ AGW 2025 meeting to be held in Melbourne, Australia from 19-22 of September 2025. The confluence of World Congress of Gastroenterology and Australian Gastroenterology Week occurs once in a generation, and this provides a unique opportunity to attend an outstanding International Gastroenterology meeting.

3. Voting for PNDU Awards, to be in by Monday 1st September (details in article)

PNDU Awards are a way of recognising the great work of members in their efforts for PNDU, as well as health professionals and industry in their dedication to providing high quality care for those living with Home Parenteral Nutrition in Australia and New Zealand.

Any PNDU member can nominate (please go to https://pndu.org/resources/ PNDU Awards page, – Click the link PNDU Award Nominations). Or contactpndu@gmail.com The winners are announced at PNDU's Annual General Meeting in mid-September.

Lifetime Membership Awards

Life Membership is a special award for any member who, as an HPN consumer, parent or carer, has given their time "over and above" for PNDU. It is the highest accolade that the group can bestow as a token of appreciation for the individual's exceptional contribution to development and growth of the group's support for people on HPN.

PNDU Professional Awards

The PNDU Professional Awards are a recognition of positive efforts by health professionals and industry to provide good quality service to HPN consumers in Australia and New Zealand. There are four categories:

Adult Parenteral Nutrition Professional of the Year: a nutrition professional who has gone above and beyond what is expected of them in their day-to-day role. This could include taking on additional duties, running a special project or charitable work related to IF and/or HPN.

Paediatric Parenteral Nutrition Professional of the Year: a paediatric nutrition professional who has gone above and beyond what is expected of them in their day-to-day role. This could include taking on additional duties, running a special project or charitable work related to IF and/or HPN.

Commitment to Patient Care – Company Employee of the Year: in recognition of an individual company employee who has shown exceptional dedication and compassion above and beyond their day-to-day role. This could include taking on additional duties, providing excellent service or charitable work in support of PNDU members.

Outstanding Achievement Award: a prestigious award to an individual/group/body who has made an outstanding contribution to IF/HPN throughout their time working within the field. This could include someone who has published key HPN-related research papers, developed a new product or educational

Lifetime Membership Award

PNDU Professional award

Helping Our Non HPN Children Feel Special

Editor's Comment: I asked for members' comments on how they cater for their children, and I'm thankful to these mums who responded with some good ideas and insights.

Brooke
Having two children on HPN, as well as a third child who isn't, is a tough journey for that child. I have taken our third child on movie or shopping dates with just the two of us. Also, my dad used to take him camping for two weeks a year so he could experience things that his brothers weren't able to. It's hard sometimes to make our non-Hpner feel special and spend the time with him to make sure he never felt as though he was being pushed aside, given how much time we must spend on taking care of his brothers.

Melanie
Emily is our HPN kid and is now 16. She's been HPN dependent for 14 years. She has two siblings above her in their late 20's and two below. Our whole family dynamic has had to revolve around her health and hospital admissions. It was hardest on the big ones who had a well-established life before Emily got sick. Matthew is closest in age to Emily, so his early childhood was hugely affected. Phoebe is now 10 and knows no difference. Mal and I have tried to have one parent with Emily if in hospital, and one home with the kids, to create the most stable environment possible. I personally don't think "special times" need to be related to siblings of chronically ill children. They should be for all... including spouses (this journey is HARD!) It's the stability and normality we all crave as hospital life is anything but that. Just knowing someone who loves you is home and available is really important. We have a pretty strong support network, so we work on the principle that it takes a village to raise children. Our most special times are with our village, ensuring all our kids are connected and valued at all times.

Caitlin
This will be great for me as my little ones get older. I have twins and at the moment it's TV while we do all our PN things. I keep him up a little bit longer after she goes to sleep so we can have more time together.

Savanna (age 11)
I like having a brother, but sometimes he has medical appointments, and it's kinda annoying that I sometimes have to tag along, even though I want to do other stuff. Sometimes I want to go out to do something at night, but only one parent can take me, because Dom is on HPN. Sometimes I want to have sleepovers with my friends, but my mum can't take me because Dom is on HPN. Say I wanted to go to their house at 7pm, but Dom is on HPN by 7pm. Us as a whole family want to do stuff at night, but only one parent can come, and they can take me, but the other parent has to stay home with Dom.

Having my brother on HPN is good at times, but bad at other times. Yes, I still do get to hang out with my family and friends so it's not too bad. I still love him a lot.

Miranda
It hasn't actually crossed my mind to do anything in particular for our non-HPN kids, but it's probably a good idea! Hmm, I probably sound like a bad parent! but honestly I'm too spent and figure they should just thank their lucky stars for their healthy bodies. The flip side of it is that they get to do lots of things which their HPN sister can't. Life's not fair either way.

Lucy
In balancing the needs of multiple kids - HPN and non HPN, the simplest of activities can be the most beneficial.

Quality time can be done in many ways; some things we do and prioritise are:
- reading together
- a game of uno, or cards or another game of choice - just being together
- cooking, craft or gaming. Share in your child's hobbies, encourage, participate and show interest and excitement. You will both benefit.
- organised outings- plan fun things for the future. Things to look forward to; an ice cream, a trip to the library, the movies or a full day activity. One- on- one outings and family outings.

- utilising other supports to be with the HPNer in a different place or room, to be able to give as close to 100% of your attention to the child your spending time with.
- putting the screen/phone away and sharing in real quality listening and conversation.

Am I good at all these things? Nope.
Am I trying? 300%
Is it okay to not get it right always? Yes.
A key learning I've had is that we don't have to be extravagant, we can work on just being present.

Lastly, self-care to us is the single most important thing you can do - without looking after you, there is no possible way to be able to continue showing up for your non HPN or HPN child.

My pointers for self-care on limited time:

- Meditation and focus on breathing.
- Stepping away and doing something for you- walking or a hobby.
- Look after your health; if you've been putting off an appointment, book it in.
- Fluid intake, water and coffee - is there any other way?

"You can't pour from an empty cup"

Save the Dates for the following free Events in November '25

HPN Consumer Workshop

PNDU is very grateful to be working with AuSPEN to deliver another HPN Consumer workshop alongside the AuSPEN Conference in Sydney, on Saturday 8th November 2025, to be held at Sydney Hilton Hotel.

The AuSPEN HPN Consumer Workshop is a unique opportunity to learn more about your HPN from expert clinicians working in the field. This event is open to all adult HPNers, their carers and adult carers of children on HPN only.

More information will be provided in Dripline and on the PNDU forums during 2025.

PNDU Annual Social Gathering

PNDU is organising our annual social gathering in Sydney, on Sunday 9th November, the day after the AuSPEN Scientific meeting & HPN Consumer workshop. It would be wonderful if our members are able to come together and be part of something special, so make note of the date now.

PNDU Gatherings are great opportunities to meet other HPNers, carers and their families and get to know each other during a relaxed afternoon. This year the gathering will take place from 12- 3:00pm at the Joseph Sargeant Centre, 60 Prospect St Erskineville, 2043. There is street parking in residential inner city, or a short walk from Erskineville station or bus stop.

Expression of Interest (EOI) to attend these events to be sent to contactpndu@gmail.com

PNDU Travel Sponsorship to attend these two events in Sydney

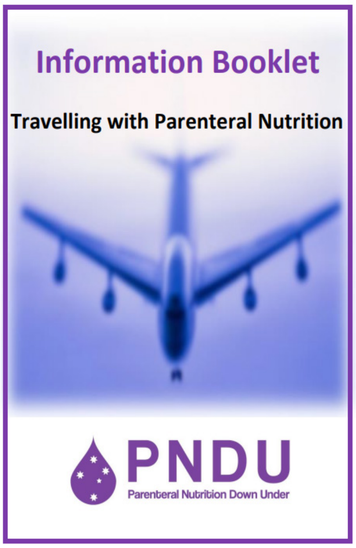
PNDU will offer four travel sponsorships, up to the value of $1000 each, to assist HPNers and Carers attend these events. Priority will be given to PNDU members who haven't before attended an AuSPEN HPN consumer workshop plus the PNDU Annual social Gathering. If you have attended past events, you can still apply again. If you're not yet a PNDU member, complete the membership form on our website today.

***(One sponsorship per family, travel must be completed and receipts forwarded to PNDU before reimbursement can be made).

To Apply for a PNDU Travel Sponsorship, please apply via email to contactpndu@gmail.com

Winners will be notified via email and announced on PNDU forums.

We look forward to meeting you all in Sydney in November.



Information Booklet

Travelling with Parenteral Nutrition

PNDU

Parenteral Nutrition Down Under

Setting up Away from Home – problem solving on holidays

By Gillian

Something that may cause anxiety for new HPNers when deciding whether or not to travel is whether there will be a suitable place to set up. Setting up (connecting to your bag of PN) becomes second nature after a while, but the ease is helped by the familiarity of repetition – doing the same thing in the same place time after time. Since ensuring sterility is absolutely essential in order to prevent line infections, deciding to stay in an unknown place can seem daunting.

Setting up recently in a motel room. No sink nearby, so prime into a bowl.

A couple of months after leaving hospital, Ray and I decided to have a couple of days away in our caravan to test the waters, so to speak. When this proved doable, we then had a week away at an apartment, also proving successful. Since then, we have stayed in many types of accommodation, in many places, in all of Australia's states, as well as around New Zealand.

During the 19 years that I have been on HPN, we have stayed at rental houses, apartments, motels, caravans, caravan park cabins, a ship's cabin, paddle wheeler cabin, as well as family member's homes, without ever getting a line infection (although I have had line infections at other times over the years). As you can imagine, there is a huge disparity in space and amenities in all of these.

The first thing to get your head around is that it won't be the same as at home; the layout of benches/table and sink will invariably be different, so you need to go about it in a different way. For example, at home, I have my sterile field on the kitchen bench, with my PN bag to the right and then the pump. This is near to my kitchen sink, so it is convenient to wash hands and then after I have my line in the pump, I can prime straight into the sink before final connection to my line. My tap is a mixer, which I can turn off with my elbow by myself.

When I am planning a holiday, I make sure that I take my own soap-on-tap and paper towels as well as the usual needs for setting up. The most usual place to set up will probably be a table or cupboard top – or even, in a motel room, the bed, in which case you might like to have a tray that can be wiped with your alcohol and used to put the dressing pack on.

When ready to set up, gather all your needs, and include a bowl to have nearby to prime into, if the sink is too far away. If there are no mixer taps, only conventional twist ones, have your travel-mate on stand-by to turn the water off for you (or if you are by yourself, use a paper towel). Although it might feel strange being so different to usual, you soon become accustomed to a different 'normal'.

Happy travels!!

***NOTE: If you use chlorhexidine to wipe down benches and use in your dressing pack, please note that isn't allowed on planes because it is highly flammable, so if you are flying, discuss what can be substituted with your hospital team.

GENCA 25 ADELAIDE

PNDU was invited to attend the Gastroenterological Nurses College of Australia National Conference, GENCA25 held between the 16th – 18th May 2025 at the Adelaide Convention Centre. The GENCA conference provided an opportunity to network and connect with clinicians specialising in the field of gastroenterology.

The GENCA organising committee generously arranged a free of charge, not for profit exhibition area for PNDU and other not for profit organisations such as AUSEE and Crohn's and Colitis. We were well positioned alongside the main sponsors and exhibitors at the conference; a high traffic area for the delegates during the breakout sessions ensured the PNDU stand was well visited each day, and I was kept busy engaging with delegates and sharing PNDU resources.

PNDU member, Rob, delivered a very inspiring and emotional presentation in relation to his own "Patient Lived Experience". A very big congratulations is extended to Rob for sharing his journey, not an easy thing to do, but always very much appreciated. The response from the GENCA delegates who heard Rob present was nothing short of amazing.

Rob's presentation was the topic of conversation for the duration of the conference, the feedback from clinicians about the value of engaging with patients and have them share their lived experiences, can never be underestimated. It is very encouraging for PNDU as a patient support group, that we are openly welcomed to these events.

It was great to catch up with the Flinders Medical Centre Intestinal Failure team, nurse Mona and Dr Sharifah, and continue our association and future planning for HPN awareness in South Australia.

Chris and Rob

GENCA CONVENTION 2025
GI DISEASES – THE PATIENT / LIVED EXPERIENCE
PRESENTER: ROB GRIERSON

Rob's presentation

Although my time in Adelaide was relatively short, I took the time to visit PNDU member Annie and mum Armanda. Annie had been quite unwell and was in club med (hospital) close to where I was staying. Catching up for a chat seemed to lift everyone's spirit and the time flew by; 3 hours later it was sadly time to say goodbye and head home.

Thank you to GENCA President, Daniel Lightowler, and the entire GENCA committee for the invitation and warm welcome I received. I look forward to our continued association and future events.

Flinders Medical Centre:
HPN Team Nurse Mona and Dr Sharifah

Visiting Annie in Club Med

The 2025 Oley Foundation Conference

By Prof Gil Hardy – an invited speaker, and a Lifetime member and co-founder of PNDU

PNDUs sister organisation, The OLEY Foundation, held their Primed and Ready to Grow Conference from June 17-20th 2025 in Charleston, S. Carolina. The gathering brought together over 600 PN and EN consumers, caregivers, clinicians, and advocates—all dedicated to improving home nutrition support in the USA.

It was a week full of connection, learning, and celebration, with breakout sessions, inspiring keynote speakers, and delegates were wowed by three nights' entertainment with ice cream and smiles.

The first day included pre-meetings of the Oley Ambassadors and the Latin American section 'Somos Comunidad', followed by the Welcome reception with a nautical/pirate "Voyage on the High Seas" theme.

The main programme started next morning, with Kidz Klub for the littlies, followed by a very motivational Keynote lecture by Canadian HPNer Trinity Lowthian, entitled: A Double-Edged Sword: Navigating the Ups and Downs of Living on Nutrition Support. Trinity, a 2024 Paris Paralympian, is the first Olympic or Paralympic athlete to live on parenteral nutrition, and she shared her inspiring journey of perseverance and triumph. As a Paralympian and Oley member with an Honours Bachelor of Food and Nutrition Sciences from the University of Ottawa, Trinity offered a unique perspective on navigating the good and bad moments of life with HPN.

By overcoming obstacles to achieve remarkable feats, including competing on the world stage as a Paralympian, setting realistic, yet ambitious goals and creating a pathway to achieve them—whether in sports, academics, or personal growth, Trinity's story was a testament to resilience and determination, offering inspiration and practical insights for anyone facing life's challenges with nutrition support.

That afternoon saw excellent presentations from Oley medical director Dr Dan Mercer and other Oley health professionals who addressed 'Real World Evidence: bridging the gap between clinical trials and Everyday practice for SBF/IF'. Other topics were Quality of Life on Nutrition Support , Empowering Patients and Enteral Devices, followed by the very popular "Wear your pump" fashion show that was designed to encourage HEN and HPN patients to show off how they wear their pump, take it wherever they go, and live their best life. Many delegates, young and old, participated to show how they have adapted their clothing and nutrition delivery systems to their personal lifestyle.

The first five concurrent Breakout sessions on day 3 addressed Perspectives of Caregivers of Children with IF; Home to Hospital transition; Chyme Reinfusion Therapy as a third way for nutritional management of IF; Enteral medication administration; and a Patient centred journey through PN. Later sessions addressed the Psychosocial needs of adolescents, Tube feeding intolerance, Personalised PN and Dietary approaches to managing complication in SBS.

OLEY ANNUAL CONFERENCE:
PRIMED & READY TO GROW
JUNE 17-20, 2025
CHARLESTON, SC

PARENTERAL SESSIONS

CRAFTING A PERSONALIZED INFUSION HPEN SCHEDULE: IS THERE A "RIGHT TIME"? - CE AVAILABLE
HASSAN S DASHTI, PH.D., R.D.
MICHELLE BARFORD, RN
CAROL IRETON-JONES, PHD, RDN, LD, CNSC, FASPEN, FAND9423650702
SWAPNA KAKANI, MPH
MARK DELEGGE, MD

CHYME REINFUSION THERAPY: THE THIRD WAY FOR NUTRITIONAL MANAGEMENT OF INTESTINAL FAILURE
PROFESSOR GIL HARDY, PHD, FRSC, FASPEN, ASPEN 2025 NUTRITION CHAMPION,

REAL WORLD EVIDENCE: BRIDGING THE GAP BETWEEN CLINICAL TRIALS & EVERYDAY PRACTICE FOR SBS-IF
DEJAN MICIC, MD

The Oley Awards and Partner recognition ceremony was followed by a lively debate on Advocacy, Communication and Care transitions. Later on, during the third evening, everyone was invited to a chaperoned PJ party and karaoke for kids of all ages. Many grabbed their pillows and blankets for "Jammin Jammies" to sing their hearts out assisted by a professional DJ.

Friday breakout sessions covered choline deficiency, central line complications, treatment of IFALD, tube feeding intolerance, HPEN sustainability. And wrap up on the final day's lunch included the ever-popular charity auction in which our donated Pendoo attracted by far the most interest.

It was a privilege to be an invited speaker at this most successful Oley conference ever. It was motivational to experience at firsthand how our 'PN Cousins' are facing the current challenges of living with HPN/HEN. Beth Gore and her new Oley team of volunteers are well placed to build on the tremendous legacy of recently retired and long-time friend of PNDU, Joan Bishop. I foresee a very bright future for patients/consumers under the new direction and advocacy of Beth (a mother and carer of HPNer Manny and his 5 siblings).

Thank You

PNDU is very grateful for the support given by the donor listed below. We wish to thank them for their generous gift. Total donations $160.

G. Marshall **E. Little** **M.Toomey**

Membership for Aussie and Kiwi HPNers and carers:

We welcome all Aussie and Kiwi HPNers (ie those living at home on Home Parenteral Nutrition) and carers to become PNDU members. To become a member, we invite you to go to our website Membership page.

Benefits:

- Access to all areas of our website, including Members Only pages (Travel, Kiddies Korner, Pharmacy Scripts, Hints & Tips, Clinical Info and more ...).
- Access to one or both of our private on-line groups (email and Facebook), connecting you with a wonderful network of support from other HPNers and carers.
- Receive news/information on HPN-related issues.
- Opportunity to contribute to PNDU Inc.'s work in raising awareness of HPN and supporting HPN research.

For HPN clinicians, industry employees, overseas HPNers, carers and those just interested:

We also welcome others to join PNDU as members, giving you access to all pages of our website, receipt of our newsletter Dripline and other HPN-related news, as well as opportunity to contribute to PNDU Inc.'s work in raising awareness of HPN and supporting HPN research. To join, please go to our website Membership page.

Donations

If you would like to support the work of PNDU, we would welcome your donation, no matter how big or small. Please go to the Donate page on our website for PayPal and Direct Deposit details.

All donations over $2 made to PNDU in Australia are tax deductible!

For our New Zealand supporters, PNDU has partnered with IPANEMA, to make supporting PNDU from NZ easy! Tax deductible donations to PNDU can be made by NZ based companies to IPANEMA, while individuals in NZ making a donation to PNDU through IPANEMA may claim a tax credit for their donations*. IPANEMA will pass on to PNDU 100% of such funds. (*This is general information only, please see your accountant for specific advice about your financial rights and obligations.)

Donating via direct deposit
Please provide your name as a reference. If you require an acknowledgement/receipt of your donation, please email us at contactpndu@gmail.com.

Australia ($AUD)	**NEW ZEALAND: ($NZD):**
Bank: Westpac Account Name: **PNDU Inc.** BSB: 032 056 A/C No.: 482 738	Bank: ANZ Account name: IPANEMA A/c No: 06 0273 0308799 00 Please include reference “PNDU” IPANEMA (Charities Commission Registration CC21178) is a NZ charity

Management Committee Members

President - Chris
Vice-President - Gillian
Secretary/Public Officer - Miranda
Treasurer - Chris
Dripline Editor - Gillian
Committee Members - Julia

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