



# DRIPLINE



# PNDU

Parenteral Nutrition Down Under

This issue advises of several opportunities for members to be involved in PNDU activities: PNDU's AGM; AuSPEN's HPN consumer workshop and PNDU's annual social gathering, both in Brisbane (and the opportunity to apply for a travel sponsorship to assist with costs of attending); the Adelaide social gathering; and volunteering to assist PNDU's MC! We also share 15 year-old Emily's joy at being able to have a family touring holiday – I'm sure it will inspire other families to give travel a go. There is also an update of the Model of Care project, following on from the updates in issue 46. Sadly, we also farewell another member, James Barry, remembered in In Memoriam.

Editor

Gillian

## CONTENTS

- [PNDU We Need you](#)
- [Upcoming Events](#)
- [PNDU AGM 2024](#)
- [Living the Good Life – Emily's Family Holiday](#)
- [HPN Consumer Workshop 2024, Brisbane](#)
- [PNDU Annual Social Gathering 2014, Brisbane](#)
- [PNDU Travel Sponsorships](#)
- [Adelaide Social Gathering](#)
- [Model of Care \(MOC\) Project Phase 2, July 2024](#)
- [In Memoriam](#)
- [Thank You](#)
- [PNDU information: Membership, donations and contact information](#)





## Would you like to be part of a team and help out at PNDU?

*PNDU need volunteers to help with planning events and staying engaged with our members*

*Do you have skills in Event Planning*

*Communication & Social Media,*

*Book-keeping or Treasurer?*

*PNDU has a mission to support, research and inform consumers, carers and providers of parenteral nutrition for Intestinal Failure across Australia and New Zealand.*

*We do this with the help of a small group of dedicated volunteers, the PNDU Management Committee (MC), who meet online every 6 – 8 weeks and stay in regular contact via email.*

*PNDU membership has grown significantly over the past 15 years and now it's time for the PNDU MC to reach out and grow with the help of our wonderful members.*

*If you would like to help out, please [contactpndu@gmail.com](mailto:contactpndu@gmail.com) for more information.*



## About PNDU



Parenteral Nutrition Down Under Inc. (PNDU) is a self-funded, non-profit support group for consumers and carers in Australia and New Zealand on Home Parenteral Nutrition (HPN). PNDU is a registered charity.

## Follow us on Instagram





- **PNDU AGM Thursday 12th September, 2024 at 12pm AEST**
- **HPN Awareness Week 13th – 19th October 2024**
- **Adelaide Social Gathering Flinders medical centre Wednesday 16th October 2024**
- **SNUG Respite Camp 15th – 18th November 2024**
- **AuSPEN HPN Consumer Workshop Brisbane Saturday 16th November 2024**
- **PNDU Annual Social Gathering Brisbane Sunday 17th November 2024**

## PNDU AGM 2024



### **Please save the date – Thursday 12th September 2024, 12pm (AEST) - online**

All members are warmly invited to attend PNDU's Annual General Meeting. If you would like to hear a snapshot of what activities PNDU has been involved in throughout the year, meet the Management Committee, or would like to have a sneak peek at what we have in store for the following year, we highly encourage you to (virtually) come along!

The agenda for the AGM and details of how to join us will follow, so please look out for a further notice in your inboxes.

## Living the Good Life – Emily's Family Holiday



### **By Emily, 15 year-old HPNer**

During the Christmas holidays my TPN and I went on a phenomenal adventure. I went with my family as well.

My Mum, Dad, Phoebe and I went down to Adelaide via Victoria and The Great Ocean Road.

We first went to Melbourne. In Melbourne we visited the library, old gaol, Phillip Island, watched the penguins, were able to go to ArtVo (this is a place where it has artworks that look 3D and you can be a part of the artwork, such as being trapped in a bubble), visited a friend, Sovereign Hill and visited the hospital. We visited the hospital in 2017, because at that point I was quite ill and had to go down and meet the transplant team and have a plan if I was going to have the multi-organ transplant. In the 4 weeks I was

down there, the wonderful medical team was able to get me off daily IV fluids and only onto a daily 14 hours of TPN. Not having to live with a backpack was amazing. When I was younger it gave me the freedom to not need my mum to come to school and disconnect me, I was able to use a slide and do more things without assistance. Now as a 15 year-old, it has given me a more normal life as a teenage girl. By this I mean I am able to go to school without a TA (someone to help me and others with different needs) and am able to fit in more with the school kids and my friends.





We decided to show Phoebe the hospital because both my parents and I know that one day I will have to have a transplant, but not right now because I am too well and possibly living my best life.

At that point in time, I was still having pain in my

sacroiliac joints, meaning that they were inflamed, causing me to walk only short distances, so I was using a wheelchair around the city.

On the Thursday that we were meant to get my weekly delivery, a little incident occurred. The lady at the front desk sent away the TPN, saying that there was no one under the name Emily Collett or Malcolm Collett. So, my amazing parents had to contact Baxter and try to track down the driver. It turned out that the driver had kept it in his van overnight. The lady at the desk said that we could still use it, but no, we had to order a new batch. The best part was that it was flown down specifically for me in a private plane. I know I am special, but I did not know that I was that special!

After spending 4 days in Melbourne, we were on our way to Adelaide. On the way down we decided to take the longer way, along the Great Ocean Road.

We were able to stop off at the most well-known sights, such as the 12 Apostles, the 'London Bridge', Warrnambool and Port Fairy.

On New Year's Eve we stayed in Warrnambool. We stayed up late and watched the fireworks, which meant having a late connection. In the morning, we put my TPN in my rolly bag and set off. We disconnected at Port Fairy. Before disconnection I was lucky enough to experience going on an amazing beach with old lava rocks. Yes, I brought my rolly bag on the beach with me; it was ok to roll on sand, but I just picked it up and carried it over my shoulder when the sand was not suitable and when I was climbing on the rocks.

We found a table away from the wind and disconnected it. Multiple times we disconnected along the way in the car.

Despite the infection risk this allowed my family and I to get more places and do more sight-seeing.

In Adelaide we stayed with my older brother in his house. Surprisingly, his house was perfect for someone connected to TPN.

Probably the only down-side was when we had to wait for the final holiday TPN delivery. So, we stayed and played board games (such as Catan) while we waited.

Even though I am not connected for much during the day, I was not able to do things like the giant jumping castle slides, but I was able to play a mean game of mini golf.

At Ryan's house, with someone's help, I was able to go outside and both just hang out, but also learn and play pool.

So yes, holidays may look different for my family and I, but it is just so amazing to know that even though the way we do things it not exactly 'normal', I am living my life to the fullest with God and my friends and family beside me.

This was such an amazing opportunity for me. As someone whose health is never promising, it was so amazing to see some of these well-known places.

Never let your disability stop you from doing anything, because it's not, it is just helping you to always make the best of every situation.





## HPN Consumer Workshop Key Topics Include: -

- Management of Line Infections
- What is the cost of HPN to Patients
- Update on the AuSPEN HPN Model of Care and HPN Registry
- Travelling with HPN

PNDU is very grateful to be working with AuSPEN to deliver another HPN Consumer workshop alongside the AuSPEN Conference in Brisbane

**Save the Date: - 16th November 2024**

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.

Further information will be available soon on the AuSPEN website. [auspen.org.au](http://auspen.org.au)

For any questions, contact AuSPEN's secretariat directly at [admin@auspen.org.au](mailto:admin@auspen.org.au) or PNDU at [contactpndu@gmail.com](mailto:contactpndu@gmail.com)

[auspen.org.au](http://auspen.org.au)

**SAVE THE DATE - 16/11**

**HPN Consumer Workshop**

**Brisbane Convention & Exhibition Centre  
Brisbane, QLD, Australia**

**PNDU**  
Parenteral Nutrition Down Under

**AuSPEN**



PNDU will be hosting our annual social gathering at the South Brisbane Croquet Club Hall, 91 Cordelia St, South Brisbane, 11.00 am – 3.00 pm. We hope to welcome as many HPNers and their Carers as possible in Brisbane on Sunday 17th November, 2024, to this 'Free of Charge' event.

PNDU invites all our HPN members, family and carers who are able to join us in Brisbane, QLD, to come along to a social gathering, meet with other HPNers and carers in a relaxed friendly atmosphere, exchange stories of life on HPN with other HPNers who really understand your journey. Learn more about PNDU and what we do for you.



For more information and to register email [contactpndu@gmail.com](mailto:contactpndu@gmail.com)

## PNDU Travel Sponsorship



### PNDU Travel Sponsorship to attend these two events in Brisbane

PNDU will offer four travel sponsorships, 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](mailto:contactpndu@gmail.com)

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

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



PNDU invites our members to attend a social gathering in Adelaide during HPN Awareness Week. The social event will be held at Flinders Medical Centre on Wednesday 16th October 2024, to celebrate the invaluable contribution to the HPN Community by Dr Andrew Holt. His dedication and contribution to the HPN field over more than 20 years, has been invaluable to HPNers in South Australia.

Long time PNDU member Annie Holland and family will help coordinate a fundraiser to support this event. Proceeds will support the Flinders MC and PNDU.

If you would like to attend this event, please RSVP by email to [contactpndu@gmail.com](mailto:contactpndu@gmail.com)



## AuSPEN Model of Care Update – Publication of Australian Funding and Resourcing in HPN Study Results



As you may be aware, AuSPEN has been working towards developing a strong foundation from which to progress a national model of care for HPN service provision in Australia for a number of years.

Phase 2 of the Model of Care work involved surveying the hospitals in Australia that provide a HPN service to obtain a snapshot of the current resources being committed to HPN. After much hard work on the part of Dr Darren Wong, who led this project, we are delighted to report that the results were published in the Journal of Enteral and Parenteral Nutrition in June this year.

In short, the survey results have confirmed what many of us have felt to be the case in the services we work in and receive care from -- HPN in Australia is woefully under-resourced and underfunded.

- The majority of hospitals providing HPN in Australia took part in the survey (24 out of 27);
- The flip side of this statistic is that there are A LOT hospitals providing HPN, and ~1/3 of these are looking after a small number of patients.
- Most HPN services are providing care to HPN patients without having funded positions to do so;
- If care provided was limited to what is funded, this would only allow for 7mins per adult patient and 14mins per child on HPN every week!!
- Nurses are most likely to have at least part of their role funded;
- 86% of paediatric hospitals and 65% of adult hospitals have funded nursing positions
- Because of the limited resources and these are being focused on clinical care, many services are unable to fit in the important work of auditing and quality improvement activities around the HPN service.

**For the full details, you can access the article on line (for free!) here:**

<https://pubmed.ncbi.nlm.nih.gov/38850512/>

Moving forward, the AuSPEN HPN Registry has built in data points to continue to monitor resourcing of the participating sites to follow changes in these findings over time.

The Model of Care Project is continuing to the next phase of the project, where we are undertaking a codesign process of collating consumer and clinician input to help outline what the model of care should look like in practice. You will have the opportunity to participate in this in the coming months through email surveys that will be sent out by PNDU so stay tuned!



## PNDU remembers past HPNers

Over the years, PNDU has been reminded of the fragility of life, especially for those with Intestinal Failure. Sadly, PNDU has shared with family and friends in saying good-bye to these precious loved ones who have passed away, but who have also left wonderful memories of love, strength and courage.

### PNDU Remembers Past HPNers

**James Barry** – 21st March, 2024, aged 17 years

**Frances (Frankie) Shaw** – 28th January, 2024 aged 69 years

**Rosie Crosland** - 30th August 2023, aged 70 years

**Fay Boyd** - 23rd August 2023, aged 76 years

**Lily** - 21 June 2023, aged 23 years

**Lynden** – 14 July 2022, aged 68 years

**Tracie** - 5 February 2022, aged 47 years

**Aidan** – 21 May 2020, aged 14 1/2 years

**Lara** – 24 April 2020, aged 37 years

**James** – 9 November 2019, aged 28 years

**Elise** – 19 August 2019, aged 43 years

**Ross** – 23 January 2019, aged 67 years

**Celena** – 27 November 2017, aged 43 years

**Emma** – 9 April 2017, aged 35 years

**Lara** – 16 February 2017, aged 7 years

**Teresa** – 15 February 2017 aged 58 years

**Natalie** – 18 September 2016, aged 27 years

**Sam** – 13 September 2016, aged 14 years

**Carol** – 2 September 2016, aged 67 years

**Jessica** – 24 January 2014, aged 20 years

**Tynesha Rose** – 29 October 2012, aged 5 years

**Aria** – 20 June 2011, aged 5 years

**Pauline** – 29 April 2011, aged 38 years

**Hebe** – 3 January 2008, aged 2½ years



May the cherished memories of these dear ones  
never fade





PNDU is very grateful for the support given by the donors listed below. We wish to thank the following for their generous gift. Total donations, \$3,350.

**Sarah Smith**  
**Sarah Joyce**  
**Fresenius Kabi**

## 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](#).



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](mailto:contactpndu@gmail.com).



<p><b>Australia (\$AUD)</b> Bank: Westpac Account Name: <b>PNDU Inc.</b> BSB: 032 056 A/C No.: 482 738</p>	<p><b>NEW ZEALAND: (\$NZD):</b> 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</p>
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## Management Committee Members

**President** - Chris  
**Vice-President** - Gillian  
**Secretary/Public Officer** - Miranda  
**Treasurer** - Naomi  
**Dripline Editor** - Gillian  
**Committee Members** - Ryan

## Contact Us

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