



DRIPLINE



PNDU

Parenteral Nutrition Down Under

This is a jam-packed issue, filled with both upcoming events that PNDU members can be involved in, as well as reading about events already finished, including two stories featuring travel with two of our young HPN members. There is the opportunity for members to be involved in the AuSPEN Model of Care project, as well as attending the AuSPEN Brisbane consumer workshop and PNDU social gathering. There is still time to apply for the last 2 travel sponsorships! Plus, the winners of two of our sponsorships are announced. We can read about how HPN Awareness Week was celebrated by our members, hospital staffs and HPN pharmacy staff. Keep a copy of HPN Pump and Accessories Tips and Tricks information sheet, put together for us by Baxter, giving important information about our pumps.

I can't believe that the next issue is number 50! That I've been putting Dripline together for over 12 years! I'm not sure yet what's going to be in it, but I'll want some member input and/or stories, definitely.

Editor

Gillian

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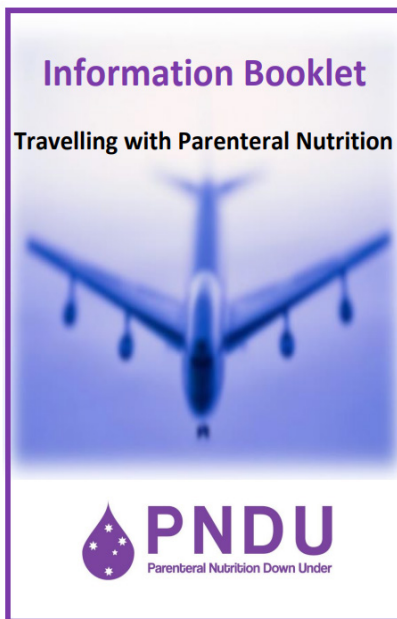


SNUG Respite Camp 15th – 18th November 2024

AuSPEN HPN Consumer Workshop Brisbane Saturday 16th November 2024

PNDU Annual Social Gathering Brisbane Sunday 17th November 2024

Winners of PNDU Travel Sponsorships to attend these two events in Brisbane



PNDU offered Four Travel Sponsorships, to the value of \$1000 each, to assist HPNers and Carers attend these events. Priority was 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 could still apply again.

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

PNDU Travel Sponsorship Winners 2024.

Bev C. New Zealand

Annie H. Adelaide South Australia

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

There are 2 travel sponsorships still available if you are able to join us.

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

AuSPEN Consumer Workshop Brisbane



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

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.

This workshop will be run in-person and will also be streamed online for those unable to attend.



AuSPEN HPN Consumer Workshop

10.00 AM - 12.30 PM, 16 NOVEMBER 2024
Brisbane Convention & Exhibition Centre, GREY ST,
SOUTH BANK, QLD 4101

Consumers and carers only.
Not for clinicians.

Register online with AuSPEN <https://cvent.me/13R7Zb>

Please note: this workshop is open to all adult HPNers, their carers and adult carers of children on HPN only, and is not open to clinicians.

Date: - 16th November 2024 10.00 AM – 12.30 PM

Brisbane Convention & Exhibition Centre, Grey St, South Bank QLD 4101

Further information or any questions, contact AuSPEN's secretariat directly at admin@auspen.org.au or PNDU at contactpndu@gmail.com



PNDU Annual Social Gathering Brisbane Sunday 17th November 2024



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 is a 'Free of Charge' event.

PNDU invites everyone living with Intestinal Failure requiring Home Parenteral Nutrition (HPN), Their family and carers, to join us in Brisbane QLD, for 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 the HPN community Down Under.

For more information and to register email contactpndu@gmail.com





AuSPEN is partnering with PNDU on two projects and would like your input as a person living with Intestinal Failure, or a carer of someone with Intestinal Failure.

Development of a National Model of Care for Intestinal Failure.

The AuSPEN Intestinal Failure model of care project is seeking HPNer and carer input into how you think intestinal failure care (including HPN) should be provided in Australia. This will involve a round of 3 surveys (approximately 1 per month) to gain agreement on what is important in Intestinal Failure care.

If you are living with or caring for someone with Intestinal Failure and live in Australia, we are asking for your input. Please click on the link or scan the QR code to get more information and participate.

<https://redcap.slhd.nsw.gov.au/surveys/?s=YXA39N88C8YKPFNE>



[What do you think should be included in Intestinal Failure Guidelines.](#)

The second project AuSPEN is seeking your input into what information you think needs to be included in Intestinal Failure guidelines for Australia and New Zealand.

This is also a round of 3 surveys to gain agreement on key topics to be included in Intestinal Failure Guidelines for Australia and New Zealand. If you are over 18 years of age, living with or caring for someone with Intestinal Failure and live in Australia or New Zealand, we are asking for your input for this project. Please click on the link or scan the QR code to get more information and participate.

<https://redcap.slhd.nsw.gov.au/surveys/?s=NTMAJ7JE3PWJMFWE>





By Claudia Borg, Clinical Nurse Consultant at The Children's Hospital at Westmead

Earlier this year I had the opportunity to present at the Baxter Healthcare Home Parenteral Nutrition Workshop. The workshop brings together health professionals including medical and surgical physicians, nurses, dietitians and pharmacists, both adult and paediatric based who care for patients on HPN.

With the spotlight back on travel, I presented an interesting case – a young child on PN 7 days per week travelling around Australia with their parents in a motor home for 8 months. There was a total of 34 alternate deliveries to be arranged across all states except for Northern Territory and Tasmania (see map). It took a huge effort from the family, the wonderful team at Baxter Healthcare and our medical team and to make this possible. I hope this story inspires you all to book that trip (with lots of notice and after speaking to your medical team first of course!).



It is important for you to discuss your travel plans with your medical team before making any bookings to discuss options and plan your trip to minimise disruptions to your treatment and keep you safe and well during your travels. Your medical team (aka unofficial travel agent) will be able to help you along the way so please discuss with them at least one month prior to domestic travel and six months for international travel. Based on my experience with domestic travel within Australia, here are a few important things to think about when planning your next holiday -

Deliveries:

In paediatrics, we use mostly custom bags that have a relatively short expiry which meant that my patient required weekly PN deliveries. As our patient was not going to have a fixed address during their travels, we decided the safest place for the PN

to be delivered was to a local hospital pharmacy. I contacted the pharmacies and they were happy to accept delivery and the patient was able to collect the bags from there. If you are staying in a hotel, please make sure reception staff know that you are expecting a medical delivery.

In the workshop, some adult clinicians identified that their patients have been able to receive long-life bags without vitamins which meant that travellers were able to take all their PN with them and did not need to worry about arranging alternative deliveries during their holidays. Some clinicians arranged for their patient to manually add their vitamins and trace elements into the bags before administration. Others were happy to not have vitamins and trace elements for short periods of time which meant that patients could travel with their bags for the duration of their holiday without requiring PN delivery.

You can also track the location of your PN bags using Baxter's live tracking tool. You can register for this service via this link: <https://www.baxterprofessional.com.au/nsw-registration-form-hpn-patients>

PN storage:

It is important to consider where you are going to store your PN solution and ancillaries. Bar fridges are not always reliable and can overheat if packed full of PN bags which can affect the stability of your solution. You will need to check with your accommodation provider if there is a fridge available in the room you will be staying in or if there is another fridge available where you can store your PN bags.



Ancillaries:

You will need to pack all the medical equipment needed for the duration of your trip. We encourage

our patients to take two infusion pumps with them in case of pump failure. A helpful tip from one our patients while travelling was to create packs for PN connection, disconnection and dressing changes. This made travelling with the supplies easier and took up less space. They also packed a box with spare supplies just in case!

Medical Emergencies:

It is important to have a Plan B in case of any unexpected emergencies. You will need to identify the nearest hospital and ensure you take with you some medical information to provide if needed. For our patients, we provide an acute management plan with contact information for our team. Some other documents to consider in your HPN passport include; medication list, previous clinic letter, current CVAD information, HPN prescription details.

Resources:

PNDU – Information Booklet: Travelling with Parenteral Nutrition

Baxter Healthcare – Parenteral Nutrition at Home: Patient Guide

HPN Pump and Accessory Tips and Tricks, by Baxter



HPN PUMP AND ACCESSORY TIPS AND TRICKS

Although infusion devices are an integral part of your care, and you are very adept at operating them we know that sometimes it's useful to be reminded of some of the basics!

Follow the tips below to ensure that the device (and its accessories) work well.



1 KEEP YOUR DEVICE CLEAN

Dust or fluid in the pumping chambers can cause blocked sensors or damage to the internal mechanisms. Do not submerge your pump in water, but keep it clean by using a damp clean, lint free cloth. Report any significant spills that may have affected your pump immediately to your provider.

If your pump is dropped by accident – report it to your provider immediately. Even if it seems to function normally and you can't see any external damage, there is a real risk that the internal mechanism is impacted and requires calibration.



2 HAVE YOUR DEVICE SERVICED ON TIME

Pumps used at home require regular servicing every 1-2 years depending on the model. Baxter offers two kinds of infusion pumps, each has a different service requirement. Bodyguard pumps are serviced annually, whereas Micrel pumps are serviced every 2 years or 400 infusions (whichever comes sooner). All HPN pumps should have a sticker on them stating a service/calibration date. Baxter will contact you when your next service is due. If you have not received maintenance notification from Baxter or if you are unsure of the service due date, contact us to book pump maintenance on **1800 229 837 (Australia)** or **0800 229 837 (New Zealand)** (choose Homecare option). Safety risks may arise if pumps are not serviced when due.

If there is a problem with your HPN pump, please report it to your hospital team or pump provider and organise to have it replaced. Most importantly, please don't hang on to your old pumps.



3 ONLY USE ACCESSORIES IF THEY ARE IN GOOD WORKING ORDER

You may have received some accessories from Baxter as part of your HPN service. These accessories are not manufactured by Baxter and should only be used for the duration of their expected lifetime and this is especially important for electronic items. For example, Bodyguard extended battery packs are past their expected lifetime and should not be used – continued use will give rise to severe safety risks, such as fire.

Baxter can answer questions regarding the age of your accessories and can also arrange collection of old or unwanted accessories that you may have.

Baxter may be able to arrange collection of old/unwanted electronic infusion device accessories should you have any in your possession. As a general rule, anything older than 2 years old should be disposed of.



4 BE FAMILIAR WITH BASIC TROUBLESHOOTING

Always go back to basics if you are having a problem.

Try turning the pump on and off, reset your giving set/tubing, check for any occlusions and make sure it is properly plugged into power. If the issue persists, call your provider and provide all the relevant details to report a product complaint.

Important details include: the device serial number, your regimen, when the issue occurs and how long you have experienced the issue.



5 KNOW WHAT TO DO IN CASE OF A PUMP FAILURE OR EMERGENCY

From time to time unforeseen events can happen: devices can malfunction, power outages can occur and PN bags can be damaged.

Discuss all the situations with your HPN Coordinator and have a plan in place so you can avoid panic and hopefully avoid presenting to hospital unnecessarily. Especially if things happen out of hours.

This may include checking what you should do if you cannot access PN, determining if you need spare products or devices on hand in case of emergency and knowing at what point you need to call for help.



6 REPORT ANY ISSUES AS SOON AS POSSIBLE

Being a HPNer, you are the expert in your own processes. If something isn't right or your device is not performing as it should, contact your provider as soon as possible to report it.

Again, be ready to report all the important details so that a product complaint can be raised and investigated with the manufacturer and you can access a replacement device to ensure you can continue infusion.

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Baxter



LIFE: - It's in the Bag

HPN Awareness Week started with the release of the PNDU Video, another wonderful production from Miranda and her team. The video is on the PNDU website pndu.org

Or click this link [HPN Awareness Week 2024](http://www.pndu.org)

This year we wanted to lift the covers and show everyone "what's in the Bag" HPN is life giving intravenous nutrition, which enables people with intestinal failure to live their life outside of the hospital. Parenteral Nutrition is a chance to feel the sunshine, a toe dip in the sea and a chance to spend time with your mates. HPN – LIFE: - It's in the Bag.

Encouraging everyone to wear their Awareness week stickers, share PNDU resources and start conversations about what life is really like living with a drip. It's always wonderful to see our members out and about enjoying life the best way they can.



The PNDU Closed Facebook Page is a great way for members to share their AW24 photos and Activities.

Our facebook administrator Renee, celebrated a wonderful milestone during HPN AW24.

Happy 70th Birthday Renee, proudly wearing AW24 stickers and honouring HPN Awareness Week with precious family and friends.



PNDU asked the question "What does HPN Awareness Week mean to you?"

Starship Hospital, Auckland NZ.

I am Jenifer, Nurse Educator of Medical Specialty Ward in Starship Hospital, Auckland NZ.

Below are some of the highlights during the HPN awareness week in Starship Hospital particularly from Medical Specialty Ward -26B.



1. We did a stop and watch station where people can watch the PNDU 1 minute video clip.
2. We decorated our bulletin Board with the activities you have posted to me.
3. One of our patients with intestinal failure actively participated by decorating her IVN pole and doing some of the activities like the puzzle and word hunt.
4. We have a day of short and sharp session, Kim Herbison our dietitian was our speaker discussing about the importance of IVN and what is HPN in the life of a child with intestinal failure and how it boosts their quality of life and support their growth.
5. We have the game to do the fastest who can finish the activities.
6. Play specialist got involved by giving away some of the activities to older children and parents in the ward.

Thanks, Jenifer

Alma, Medical Specialty ward. Starship Hospital, Auckland NZ.

Being a part of HPN AW24 has given me insight to what patients and their families truly feel when they are in the hospital— the things that worry them and the challenges they are going through. My involvement in HPN awareness week deepened my understanding, helping me become more sensitive to their needs and concerns.

Regards, Alma

Royal Brisbane Women’s Hospital (RBWH)– Specialist Nutrition support Team (SNST)

As always, we got great feedback on the resources PNDU provides and lots of feedback on learnings from staff in our dietetics, gastro and Pharmacy departments.

Thanks again for the support to share the awareness and lived experience of life on HPN.

Cheers

Emma and the RBWH SNST.

John Hunter Hospital - HPN team



Fiona Cobb (Dietitian), Peter Cocking NP wound, IV and enteral/parenteral), Lorrae Gilbert (Pharmacist)

Gold Coast University Hospital

GNAV-Parenteral Nutrition



It was a pleasure promoting our HPN families last week. Thank you so much for your support. We had 2 great sessions on our Gastro Wards increasing awareness and understanding. We shared stories and photos of some of our patients and all had shots of St Mark’s!! Thanks so much for the t-shirt and look forward to it again next year! Hope you get a giggle from our pic.

Kind Regards, Mel.

Children's Hospital Westmead

As always, a great week celebrating our HPN community.

Photo of the HPN awareness week display in Clancy Ward at CHW.

HPN awareness week is always a special week for me. It is a wonderful opportunity to celebrate the resilience of our HPNers and the dedication and commitment displayed by their caregivers, whilst raising awareness for our small but mighty community. The highlight for me is always the Baxter open day. Seeing the patients and families connect with each other and the team at Baxter is heartwarming. Thank you to PNDU for bringing our community together.

Kind regards, Claudia



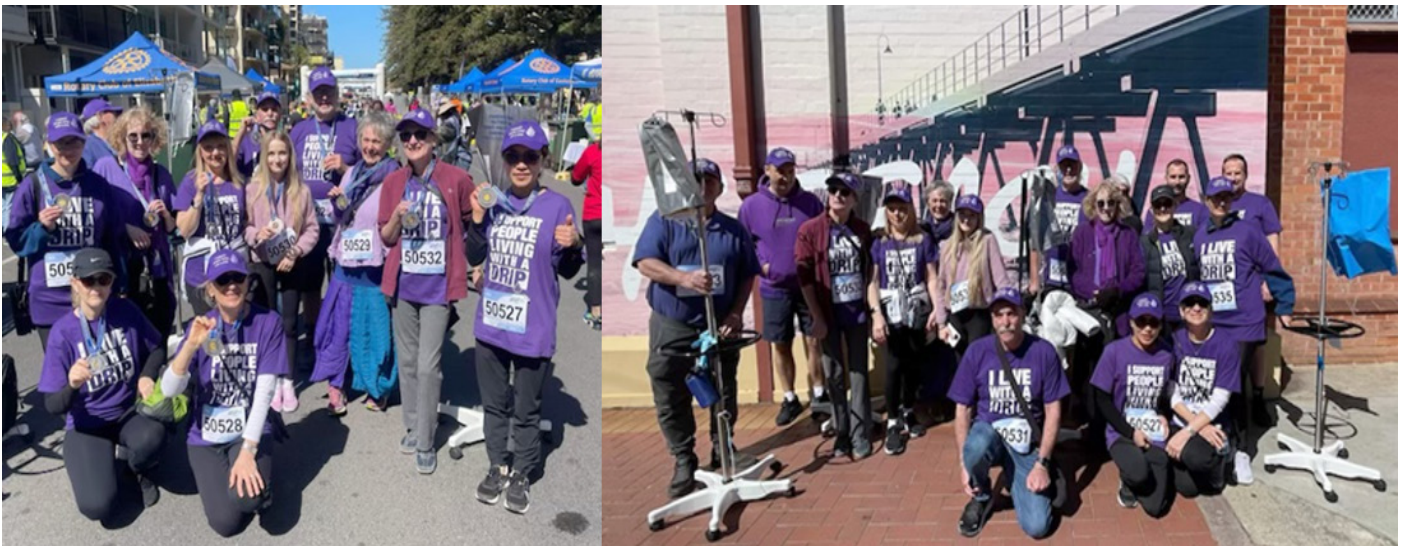
Flinders Medical Centre (FMC) South Australia

PNDU member Annaliese and FMC HPN Coordinator Mona contacted PNDU seeking some ideas to raise awareness for HPN in South Australia and provide an opportunity to say thank you to Dr. Holt from all their patients.

“Our famous HPN consultant Dr. Andrew Holt has recently retired. He has worked in HPN for more than 20 years. His dedication and contribution to all our HPNers and HPN field over the years have been invaluable.”

After several phone conversations with Annie & Mona, then an online team meeting with Mona, Dr. Holt and Dr. Sharifah, ideas and dates for 2 events were locked in.

SA Home Parenteral Nutrition unit, registered to join in one of Adelaide's iconic events, the “City 2 Bay Fun Run” on September 15, 2024. HPNers, family, caregivers along with HPN health professionals participated in the fun run to raise the awareness for SA HPN service, to connect HPNers together, and to gain the support from the wider community for the SA HPN service and their HPNers.

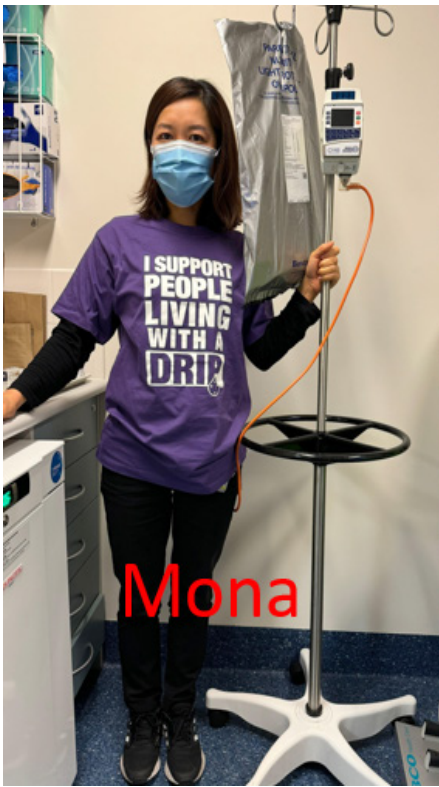


It was such a beautiful day! We had about 20 people who joined in the walk (a few patients, families, friends and HPN clinicians). We just simply enjoyed the walk, chatting and laughing.

The patients and families expressed their gratitude for this social event. They shared their stories and experiences and felt so connected with each other.

Thank you!

Mona



Mona



Annie & Dr Holt

PNDU donated several T-shirts and hats for the event and it was wonderful to see a sea of purple as Team Annie and Flinders Medical Centre competed in the Adelaide City 2 Bay Fun Run. Walking together pushing IV Poles, Pumps and HPN Bags, Raising Awareness for HPN and fundraising for the FMC SA HPN unit & PNDU.

Annie has set up a Go Fund Me Page <https://gofund.me/b71f36e4>



Annie's HPN Awareness Week Display at FMC

Adelaide Social Gathering

Wednesday 16th October 2024 was the chosen date for the Flinders Medical Centre event during HPN Awareness Week.

It truly was an amazing day at Flinders Medical Centre, Adelaide. FMC hosted their first HPN Awareness Week event. The day included a virtual tour of Baxter compounding facilities. Over 40 people attended, with an overwhelming outpouring of respect from the 13 of the 17 FMC HPNers who attended the event as they said farewell to Dr Holt, who has left an amazing legacy in the way he has managed the South Australian HPN community.



I wish everyone in South Australia all the very best for the future. I thank Mona, Dr Sharifah, Dr Holt and the FMC team for the invitation.

Chris, President PNDU

Laura Black

I can't say I love my PN - frequently I hate it, frequently I want to cry with frustration and throw the whole flipping lot out the window when I have alarm after alarm in the middle of the night - but I'd never have dreamed when I was so unwell a few years ago that I'd have managed this! Currently doing a wee road trip through NZ - caught up with the lovely Felicia Clark a few days ago and then headed south and west with my Mum and her friend - and today we took a chopper up to Franz Josef glacier. We debated using their ski-chair, as I'm not particularly steady on my feet and use a wheelchair over long distances even on solid ground - but decided that between the pilot, an extra support person and hiking poles, I'd manage without. Not hooked up, as I only run my PN at night - but at the same time, it's also not something I'd ever have been able to manage without the extra weight and strength the last few years on PN has given me. Trip hasn't been without a few hiccoughs, but it's proven to me that I *can* do it - and given me a lot more confidence about tackling Europe next year.



Thank You for your support during HPN Awareness Week 2024

To all of our members and friends, PNDU says a heartfelt thank you, your interactions during the week and on social media platforms were simply wonderful.

We thank our industry friends and hospitals who order resources and make HPN awareness week special for HPNers:

New Zealand National Intestinal Failure and Rehabilitation Service
Biomed NZ
Starship Hospital, Auckland NZ.
AuSPEN

Baxter Healthcare Australia & New Zealand
Fresenius Kabi
Takeda
Gold Coast University Hospital QLD- GNAV- Parenteral Nutrition
Royal Brisbane Women's Hospital (RBWH) QLD- Specialist Nutrition support Team (SNST)
Queensland Children's Hospital
Princess Alexandra Hospital QLD
John Hunter Hospital NSW - HPN team
John Hunter Children's Hospital NSW - HPN team
Children's Hospital Westmead NSW
Westmead Hospital NSW
Sydney Children's Hospital NSW
Flinders Medical Centre SA – Mona – Annie



HPN Awareness Week is always one of the most celebrated weeks at Baxter’s Australia and New Zealand offices and compounding centres.

Employees across all 6 compounding sites from Western Australia to Christchurch, New Zealand conducted tours and ran activities in conjunction with PNDU. Each year our teams look forward to opening the doors for HPN patients, their families, carers & health care professionals to see how their products are made. It is exciting to see several repeat visitors and our teams enjoy catching up on how much many of the younger members have grown and to hear all that has been achieved throughout the year.

HPN Awareness Week is a chance to raise awareness amongst the wider Baxter team and our customers, highlighting the benefits and challenges the patients face along with showcasing the environment in which their daily nutrition is manufactured.



One of the youngest visitors who stole the show in Brunswick, Victoria



Beautiful day to celebrate in Toongabbie, Sydney, along with some dress ups!



Wonderful to see both patients, families and HPN clinicians visiting sites in Christchurch & Auckland, New Zealand.

Along with the site tours, Baxter’s senior leadership team from around Australia & New Zealand experienced a small part of what it means to be a HPN patient. They spent three full days participating in a “day in a life challenge” by wearing a backpack filled with the parenteral nutrition solution & infusion pump like that of a patient. Simulation alarms and messages were used to remind them of the many tasks our patients attend to on a daily basis.

Claire Howse, NZ Country Manager - “It prompted a good discussion with my family & friends around our patients who experience this every day and how the wider Baxter team supports daily living, work and travel with Home PN.”

Michael Doyle, Communications Manager – “From pump alarms, constantly having to wash hands, being attached to the backpack containing the pump and fluids all day, and preparing the PN for the following day, it quickly became clear that our patients have a lot to contend with”

“My daughter also kept wanting to play with the tube which wouldn’t be ideal when you’ve got life sustaining nutrition flowing through it”

Linda Herd, Director of Strategy & Transformation – “Being attached to a bag housing your pump and nutrition +12 hours each day was eye opening, along with the typical alarms and complications that must be dealt with each day. I have lost count the number of times over the last 3 days I went to get up in a rush, to only be pulled back as I was attached to my bag that was sitting on the desk.”

Neha Sharma, Senior executive assistant – “A few days of wearing this backpack and the tube attached, made me realise that is a very small glimpse into the lives of HPN patients.”

Baxter Healthcare would like to thank all those who were able to attend a facility tour and especially those who were able to share their stories amongst the team. These are special connections that are held dear and help our team to strive each day in Baxter’s mission to save and sustain lives. We are already planning for HPN AW 2025 and cannot wait to see you there.



Awareness Week at Fresenius Kabi



At Fresenius Kabi, being “committed to life” is at the heart of everything we do. As a global leader in clinical nutrition and infusion therapies, we are committed to supporting patients, healthcare providers, and the broader medical community. One of the key areas where we actively contribute is through the sponsorship of HPN (Home Parenteral Nutrition) Awareness Week, an important initiative that resonates deeply with our core values.

HPN Awareness Week is dedicated to increasing the public’s knowledge about Home Parenteral Nutrition, a life-saving therapy for patients who cannot absorb sufficient nutrients through their gastrointestinal system. Despite its critical role in sustaining lives, public awareness of HPN and the challenges patients face is relatively low.

By sponsoring HPN Awareness Week, Fresenius Kabi helps shine a light on these challenges and opens a conversation about the complexities of living with HPN. This includes addressing topics such as the emotional and physical toll on patients and caregivers, the logistical hurdles of managing home infusion therapy, and the importance of safe, high-quality products in patient care.

For Fresenius Kabi, sponsoring HPN Awareness Week is not just a commitment to raising awareness—it’s a reflection of our dedication to patient care, innovation, and advocacy. We are proud to stand with PNDU, the hospitals and healthcare professionals supporting those whose lives depend on this vital therapy, and working to improve outcomes for all patients reliant on parenteral nutrition. Together, we can foster a deeper understanding of HPN, drive positive change in healthcare, and, most importantly, improve the lives of the patients we serve.



Serra Lems, Associate CNC Gastroenterology – Parenteral Nutrition Princess Alexandra Hospital Brisbane

Our Fabulous Family Holiday



By Julia

As Syena has grown up a little and her health has stabilised compared to when she was a sickly baby, we’ve slowly become more adventurous in our travelling adventures. At first, it was just quick car trips interstate, then flights to nearby cities, and then we were ready for flights across Australia and enjoyed a couple of trips to Perth.

Early this year, we started planning a big road trip from Canberra through NSW to Queensland. This was going to involve two families: ours (myself, Barry and 6yr old Syena) as well as our daughter’s family (Alix, her husband Trev and their kids, 10 yr old Shay and 9 yr old TJ).

Both of our families have children with complex needs who joined us through foster care. Syena has TPN-dependent Short Gut Syndrome after being born with Vanishing Gastroschisis, and Shay has disabilities including ASD3 and FASD, which resulted in a brain injury which leaves her with very

little capacity to manage frustration.

Our plan was to send Alix, Trev and TJ to Queensland a week ahead of us as they were in dire need of some respite. Shay stayed in our care for the final week of the school term and then the four of us set off in a huge 6-berth motorhome I’d booked early in the year through “Let’s Go” motorhomes.



I settled on the idea of hiring a large motorhome after considering a few options. We could drive our

own car and stay in hotels but nobody on HPN travels lightly. The idea of taking two children with complex needs on a long road trip and having to pack and unpack the car every night at a different hotel did not appeal at all. Also, Shay struggles with anything unfamiliar and unpredictable. She would not cope with staying in a different place every night – and if she didn't cope then the trip would have to be cancelled, as a previous holiday had been after only a couple of days.

Having a large, self-contained motorhome, however,



would mean we could pack everything in at home and then just head off. It would become familiar, safe and private. I wouldn't have to be concerned about finding somewhere clean to disconnect or connect Syena's HPN. We wouldn't have to search for an urgently-needed toilet while on the road. Everything we needed would be at hand, without having to look through luggage trying to find gloves, sanitiser or swabs. If we felt tired, we could just pull over in the next rest area, stretch out on the bed or make lunch wherever we liked.

It wasn't cheap to hire but neither is staying in hotels for 18 nights, and I figured this included our accommodation AND our transport. I checked that the motorhome would have everything we needed, particularly a 3-way fridge that would run on 240v power when we were in a caravan park, 12v battery that would charge while we were driving and LPG gas when we were parked without access to mains power. The fridge was more than big enough for a week's worth of TPN plus all our food. I kept a few freezer blocks in the separate freezer section in case we ran into problems (we didn't).

We had a double bed over the front cabin for (Barry



and Shay), and a queen bed (for Syena and me) in the midsection that expanded out when parked, giving extra room inside. At the rear, we had a bathroom with flushing toilet, sink and a hot shower.

The motorhome was a dream to drive, which came as both a relief and a surprise. I drove it nearly 3,000km. It was a big beast at 8 metres long and 3.5 metres high but we didn't run into any issues. It was an automatic with cruise control and comfortably kept up with traffic. I had felt particularly nervous about hitting Sydney's Northconnex tunnel at peak hour on a Friday evening only a couple of hours after leaving home but the tunnel proved to be incredibly spacious and absolutely nothing to worry about.

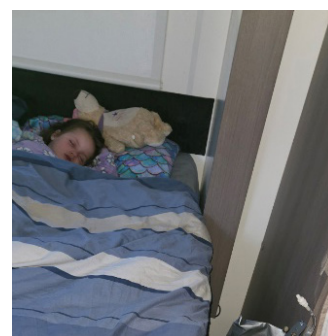
We had some fabulous times on our trip. I found a variety of places to stay, from a field on a farm to Treasure Island Caravan Park at the Gold Coast. We had a day at Movie World to celebrate Shay's



10th birthday and Alix and Trev's 10th wedding anniversary. Syena learned how to swing across the monkey bars in a playground. So many memories...

All in all, we found it a comfortable and very convenient way to travel and intend doing this again. I'm looking at hiring a motorhome for a trip around Tassie and possibly New Zealand.

Our next adventure, though, will be our 5-day Disney cruise from Sydney to Hobart return, coming up in January.





We recently were shocked to hear the sad news of the death of Fritz Schwenk, who was a great friend and supporter of PNDU as well as a past President of ASPEN.

Fritz was a great friend and mentor to many of us around the world and together with Dr Albert Baroccas was instrumental in helping us establish International Clinical Nutrition Section (ICNS.)



Dr Albert Baroccas, Gil Hardy, Fritz Schwenk (ASPEN 2015)

He was a much sought-after speaker at international conferences including our PNDU Australasian HPN patient's forum in New Zealand.



Fritz Schwenk, Patrick Ball, Chris Walker (PNDU NZ 2014)

He always put the patient at the centre of clinical nutrition practice. RIP Fritz. You'll be much missed.
Professor Gil Hardy PhD FRSC FASPEN

Thank You



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 \$10 370

Baxter healthcare	Kiera McGowan
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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](#).

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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.

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