


DRIPLINE PNDU

Parenteral Nutrition Down Under

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Welcome to the latest issue of Dripline. Firstly, I want to rectify an omission that I accidentally made in the last, special, 50th edition of PNDU's newsletter. I thanked some specific people for their help and support over the years, but neglected to thank one of the key people, who was there from conception, helped with editing early issues, as well as sourcing and writing some medical articles for me, and that is Emiritus Professor Gil Hardy. Gil is still very interested in PNDU and Dripline, and answered my request for an article on fish oil in intravenous lipids in our PN for this issue, so a big thank you, Gil, for both past and present (and hopefully future) help!!

In this issue there is information about upcoming events; how to vote in our PNDU Awards for 2025; save-the-date for our next annual social event and consumer workshop in Sydney in November; a write-up from AuSPEN about the outcomes of the first National Registry, for which PNDU provided consumer representation; read our members' thoughts on swimming and bathing while on HPN; learn how PNDU president, Chris, represented us at various conferences, advocating for HPNers and informing clinicians about PNDU as an appropriate support group for their HPNers; and read about a wonderful Disney cruise that one of our families enjoyed.

Gillian

Editor

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PNDU Upcoming Events and Representation 2025

- **Gastroenterological Nurses College of Australia (GENCA)**

National Conference Adelaide 16th – 18th May

The GENCA 2025 National Conference is proud to host a dedicated Not-for-Profit area within the conference exhibition space. This special section will feature a diverse range of not-for-profit and patient advocacy organisations, providing a platform to connect, collaborate, and share valuable resources with healthcare professionals.

Attendees will have the opportunity to engage with organisations that play a crucial role in supporting patients, driving awareness, and advocating for positive change in healthcare. Whether it's learning about new initiatives, accessing educational materials, or discovering ways to get involved, this space will highlight the vital contributions of the not-for-profit sector to gastroenterology nursing and patient care.

Join us in supporting these incredible organisations as we work together to enhance patient outcomes and strengthen our professional community.

- **Baxter Healthcare HPN Clinician Workshops 29th – 30th May Sydney**
- **The Australian Vascular Access Society (AVAS)**

2025 Scientific Meeting, taking place from Sunday, 20 to Tuesday 22 July 2025 Wollongong.

- **National Patient Organisation Network NPON**

24 July Brisbane.

PNDU Needs You!

PNDU need volunteers – YOU! - to help with planning events and staying engaged with our members.

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 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

Save The Dates

Save the Dates for the following free of charge events

PNDU Annual Social Gathering 9th November 2025

PNDU is organising our annual social gathering alongside the AuSPEN Scientific meeting & HPN Consumer workshop on 8th & 9th November 2025. 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.

HPN Consumer Workshop

PNDU is very grateful to be working with AuSPEN to deliver another HPN Consumer workshop alongside the AuSPEN Conference in Sydney 8th November 2025

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

Expression of Interest (EOI) to attend these events

PNDU Travel Sponsorship to attend these two events in Sydney

PNDU will offer two 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).

Please forward EOI to attend, so that numbers are roughly known. To apply for a PNDU Travel Sponsorship, please send an EOI to contactpndu@gmail.com

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

PNDU Awards 2025

As HPNers and carers, we know that it takes many hands to manage HPN care. Is there a professional or healthcare worker who does a marvellous job for you when it comes to HPN care? Here's your opportunity to give thanks and show you appreciate them!

This is PNDU's 9th year of bestowing awards on the dedicated people nominated by our members. PNDU Awards recognise the great work being done by our healthcare workers, or company employees who help with preparation and delivery of compounded PN and ancillary products for those of us living in Australia and New Zealand with HPN.

There are a few different categories and you can nominate as many people as you like. For the HPN Professional Awards categories, you can even nominate winners from previous years (see PNDU Annual Awards page on our website for a Roll of Honour listing all winners):

- **HPN Professional Awards** recognise positive efforts by health professionals and industry to provide high quality service to HPN consumers (nominate your favourite HPN clinician and/or a dedicated professional at your homecare company). There are 3 categories of HPN Professional Awards for which you can nominate:

- **Adult Parenteral Nutrition Professional of the Year**
- **Paediatric Parenteral Nutrition Professional of the Year**
- **Commitment to Patient Care - Company Employee of the Year**

- **Lifetime Membership Award** is a special award for any member who, as an HPN consumer, parent or carer, has given their time "over and above" for PNDU.

Nomination forms are available only online- look out for an email about the PNDU Awards in the coming weeks, or look up the PNDU Awards page on our website.

Simply **complete the online form(s) by Monday 1st September. All winners will be announced at PNDU's AGM.**

AuSPEN HPN Consumer Workshop 2024

AuSPEN and PNDU ran the Consumer workshop at the Brisbane Convention Centre last November, which was a huge success. We had 25 people attend the workshop, with 13 of those people attending in person, and 12 online. The program included an update on the AuSPEN HPN Registry and Intestinal Failure Model of Care development. We also had engaging presentations on central line infections and the economic burden for people living with HPN from a consumer perspective. Findings from a pilot NSW study were presented showing that adults living with HPN are living in financial crisis.

SAVE THE DATE - AuSPEN and PNDU are in the process of planning the 2025 AuSPEN HPN Consumer Workshop which will be on Saturday 8th November at the Hilton, George St, Sydney. We are currently seeking input on topics to include, so please email your PNDU contact with topics ideas (contactpndu@gmail.com). We look forward to seeing you, either in-person or online, in November '25.

HPN in Australia: What We've Learned from the First National Registry

By A/Prof Sharon Carey, Co-Chair of HPN Governance Committee.

Julia Fox, Co-Chair of HPN Governance Committee.

Lina Breik, HPN Registry Project Officer.

If you're living with home parenteral nutrition (HPN), you know how life-changing and complex it can be. Whether you're new to HPN or have been managing it for years, you're part of a growing community in Australia that relies on this life-saving treatment.Thanks to a new national registry run by the Australasian Society of Parenteral and Enteral Nutrition (AuSPEN), we now have the most accurate picture yet of how many people are on HPN, the challenges they face, and how care can be improved. Here's what we found out after surveying the 29 Australian healthcare organisations that provide HPN support!

Who's on HPN in Australia?

A total of 328 adults and children across Australia receive HPN, with the highest numbers in New South

Wales, Queensland, and Victoria. Some people also receive additional intravenous fluids (IVF) or medications like Revestive to help their intestines absorb more nutrients. Other characteristics of our Aussie HPN-ers include: average age is 42 with a range of 0-84 years, 82% are adults, 63% are female, average body mass index is 24.2kg/m2, and the average length of time on HPN is 1844 days with a range of 32-11,613 days.

Why Do People Need HPN?

The most common reason people need HPN is short bowel syndrome (SBS), where part of the intestine is missing or doesn't function properly. Other causes include intestinal motility disorders, Crohn's disease, surgical complications, and rare conditions like mitochondrial disease. No two people's journeys are exactly the same, but many share similar challenges in managing nutrition, hydration, and overall health.

What Are the Biggest Challenges?

One of the major concerns for HPN users is central line infections;16 people had infections last year, with an overall rate of 0.83 infections per 1,000 days on HPN. This shows that while infection prevention strategies are working for many, there's still room for improvement.

Another key issue is hospital readmissions. In the past year, more than one-third of people on HPN had to be admitted to the hospital at least once, with some needing multiple admissions. These hospital stays can be disruptive and stressful, highlighting the need for better home support to prevent complications.

How Much Clinician Support Do HPN Patients Get?

Managing HPN takes a team! On average, patients receive about 2 hours of dedicated clinical care per week, split between doctors, nurses, dietitians, and pharmacists. However, the amount of support varies between hospitals and states, and the registry aims to highlight gaps in care so that all HPN users receive the help they need.

What's Next?

This registry is a big step forward in making HPN care more consistent and evidence-based across Australia. The next phase will focus on collecting quality of life data, because HPN isn't just about nutrition, it's about how well people are living with it. The goal is to ensure that every person on HPN gets the best possible care, no matter where they live.

A Big Thank You!

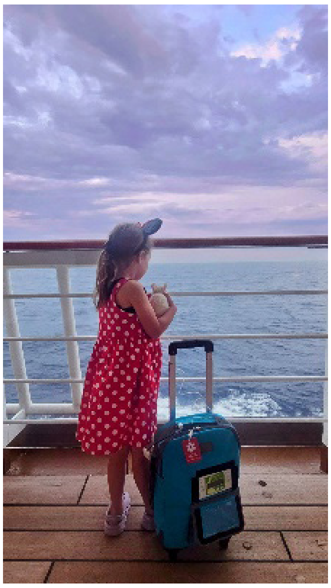
A huge shout-out to the 29 HPN services across Australia, the hardworking medical teams, and the patients who shared their experiences. Your input is shaping the future of HPN care in Australia!

Our Family's Disney Cruise

By Julia

In the 12 or so years before I'd heard of Home Parental Nutrition (HPN), our family became avid cruisers, heading overseas once, or sometimes twice, a year to such fascinating destinations as the Caribbean, the Baltic Sea and Türkiye. I had plans for many more trips, but those were cast aside, I assumed for good, when little Syena joined our family. She was such a sickly babe that I couldn't imagine having her more than a couple of hours from a hospital, and certainly not heading out to sea.

Now, it was 2025, and our constantly sick baby had become a robust little girl who hadn't had a line infection for over five years, so we were cautiously stepping back into cruising. One of my Facebook groups is 'Central Line Travelers' and families had praised Disney for their support of kids on HPN, both at Disney parks and on their ships, so I decided to book a five-day cruise from Sydney to Hobart return on the Disney Wonder. I figured we would be skirting the coastline of Australia, should Syena require evacuation, and we only had two separate sea-days where we would not be off the ship at any stage. There would



be a doctor and basic medical care on board, and I made sure we had top medical travel insurance that included evacuation from the ship. Although that was very expensive, it was also necessary.

I've travelled with six international cruise lines and found the care Disney gave us was excellent. We let them know about Syena's needs well ahead of time. She occasionally uses a wheelchair for fatigue, so we used that for boarding as I know the process of going through customs and check-in can be slow and Syena may not have anywhere to sit and rest. Disney staff (with giant Mickey Mouse gloves!) joyfully greeted us as we entered the Sydney terminal and escorted us through the waiting lines, fussing just the right amount to make Syena beam a continuous smile. We were helped with our extra medical luggage, and we were on board in no time at all. TPN bags were quickly and safely stored in the empty bar fridge in our balcony cabin, and we headed off for lunch in the restaurant while other passengers came aboard. ***

Pirate Night

I had picked up a few hints from the 'Central Line Travelers' group, and from the Sydney cruise valet car parking service who drove our car to the ship's entrance, so we didn't have to worry about parking our car for five days in the Sydney CBD and somehow transporting Syena and our many suitcases. Armed with their hints, we arrived early for the two stage shows, 'Frozen' and 'The Golden Mickeys', and sat at the front so Syena would experience snow falling from the theatre ceiling during 'Frozen'. As we had been told to let ushers know she had medical needs, they showed us through an alternate entrance which avoided the big waiting lines before the shows and ensured we were let in early to the reserved accessible seating. The cast also went out of their way to greet the children and adults in the rows towards the front, many of whom had disabilities. While waiting at the exit door after a show, I had a conversation with a young blind woman who was travelling on her own. She told me she was so impressed with Disney's staff and that it was such a different experience being in an environment where disability was normalised and assistance was offered in a helpful way.

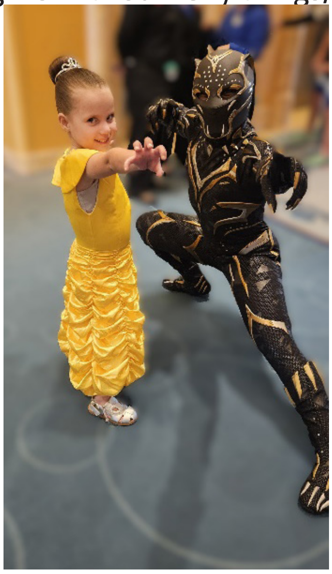
One of the best hints I'd read was to book immediately if I wanted my child to go to the 'Bibbidi Bobbidi Boutique' as bookings fill up very fast. This is 'a magical salon experience' at Disney parks and cruises which 'transforms children aged 3 to 12 into Disney princes and princesses'. Okay, this really isn't in line with my personal tendency towards more gender-neutral parenting and my utter lack of interest in make-up and fashion but what can I do … I have a little girl who despite all my efforts, loves pink and sparkles! So, I was ready on the right day and time and managed to nab one of only 3 remaining spots for Syena's makeover at the boutique. I did, however, feel satisfied to have bought her Princess Belle gown on Temu for $30 instead of buying one at the boutique for $155.

I took Syena to the boutique where she met her Fairy Godmother, who set about transforming her into a princess. It was a lovely process of fussing, magic, subtle

make-up, hair and magic wands, all while she was turned from the mirror so she couldn't see herself until completion. Syena beamed at herself in the mirror! I watched our little girl spend the rest of the day trying to catch reflections of herself in every shiny surface. Crew members bowed and said 'Hello Princess' or 'Welcome Princess' to her for the rest of the day. One perfect unscripted moment happened when we exited a lift and, by chance, walked right into a gathering of the Marvel Superheroes. Loki spotted Syena as she stepped out of the lift and bowed to her, reached out and took her hand, leading her from us to introduce her to Ant Man. Loki and Ant Man then introduced Syena to Shuri (Black Panther). This was all done with an air of formality, treating her as royalty. Shuri then took Syena aside and showed her how to make her hands into claws and how to do the Black Panther power moves. This whole special Syena day was magical from start to finish...

Syena is on a Short Gut Syndrome diet and a Low Oxalate diet. I was able to make selections from the various restaurant menus that were appealing to her and also suitable for her diet, with a few 'cheats' thrown in, because everyone cheats a bit on a cruise. For us, the food was great. I was worried there might be a bit too much focus on American fast food, but we ate in the main restaurants and couldn't fault the meals. Also, unlike all other cruise lines we've travelled on, Disney includes soft drink, coffee and juice without having to purchase a drinks package.

Our decision to take a cruise with Syena was a calculated risk. A few years ago, it is a risk I would not have considered taking. As with so many things, we have to weigh up the risks against the potential benefits, and I certainly had many moments leading up to the cruise where I stopped and re-evaluated whether it was sensible to go.



In the end, I fell back on advice given by another mum when I first brought Syena home from hospital: "Remember they are more than their diagnosis. Don't lose track of their childhood in the battle with the disease. There is no point in keeping them alive if you don't let them live."

So, we carried everything I thought we could possibly need for a medical issue at sea, short of evacuation. Our paediatric gastroenterologist had written an updated Emergency Plan for Syena and I carried extra antibiotics for her. Thankfully, she remained healthy and happy through the five days of our cruise and we all had a thoroughly wonderful time.

*** ***Editor's Note:*** I would just like to say that as an adult HPNer on 3L of PN per night, the fridge in my suite on my cruise wouldn't hold more than 1 bag at a time, as, apart from the size, the weight of the bags resting against the door pushed it open. Luckily, I had organised that the bulk of my PN would be stored in the hospital fridge, so I just had to collect a bag more often than I'd hoped. Obviously, Syena's bags were smaller, and for fewer days. Just ensure you outline your needs clearly when making your booking.

Fish Oil Containing Intravenous Lipids: a personal perspective

By Professor Gil Hardy. ASPEN 2025 Nutrition Champion

The role of intravenous lipid emulsions (ILE) containing omega-3 fatty acids for medical and surgical critical care patients was discussed in depth at the International lipids in PN Summit organized and funded by Fresenius Kabi in 2022.

Two dozen summit participants from 9 different countries (not including Australia or NZ) agreed that inclusion of fish oil (FO) in ILEs is associated with meaningful clinical benefits without harm.

The following 10 key points, assumed to be most relevant to PNDU, are summarized from a total of 39 consensus statements that were agreed and recently published as the collective opinion of the summit experts:

1. ILEs are an integral part of PN
2. The use of ILEs containing fish oil should be considered during the first week of ICU admission in adult patients requiring PN
3. Scientific evidence from systematic reviews and meta-analyses demonstrate that ILEs containing fish oil have clinically meaningful advantages over ILEs without fish oil when used in adult patients requiring PN.
4. The use of ILEs containing fish oil in PN is cost-effective
5. In adult medical and surgical ICU patients, the total lipid dose can be up to 1.5 g lipids/kg/day (including other lipid sources such as Propofol).
6. In patients dependent on HPN, a minimal supply of 1 g/kg/week of ILE should be given to prevent essential fatty acid deficiency (EFAD)
7. 0.1–0.2 g fish oil/kg/day, provided by ILE is recommended for PN
8. Serum triglycerides (TGs) should be assessed prior to the start of PN. Concentrations of TGs in adult PN patients should be within local guidelines, but if the level exceeds 4.5 mmol/L secondary causes should be investigated.
9. Supplemental PN is a combination of oral/enteral (EN) and PN. It may be considered as a strategy to maintain/improve the nutritional status of patients if oral or EN is insufficient. ILEs are an integral part of supplemental PN
10. Administration of supplemental PN through a peripheral line can be considered when central line access is unavailable or as a bridge until central line access is available or re-established. ILEs are an integral part of peripheral PN

Some of the data leading to these guidelines resulted from earlier studies of Prof Stanislaw Klek, now chairman of ESPEN, whose 2020 paper concluded that mixed ILEs containing FO are safe and effective for long-term HPN patients. A multicomponent ILE with FO can provide additional benefits in terms of liver function during long-term HPN.

This conclusion is based on the results of a clinical trial performed at the Intestinal Failure Center in Skawina, Poland, involving 67 HPN patients with stable chronic intestinal failure (CIF) resulting from Crohn's disease, vascular, surgical complications or radiation enteritis. Liver function was assessed clinically and by liver function tests (LFT) over 5 years, during which 3 groups received either PN with medium/long-chain triglycerides (MCT/LCT), some with olive oil/soybean oil (OO/SO) and others with a combination of SO/MCT/OO/FO (SMOFlipid).

Lipid HPN was effective in improving nutritional status and was associated with low rates of catheter infections and clinical complications in all patients with no significant differences in LFT for all up to 60 months. However, a significant reduction in bilirubin (BIL) concentration was observed in the SMOFlipid group.

Later, a multi-centre randomized study, including Kleks team, specifically evaluated the safety and tolerance of the SO/MCT/OO/FO (SMOFlipid) in 34 long-term PN patients compared to 39 patients who received the tried and tested soybean emulsion (Intralipid) over 4 weeks. Mean LFT levels, whilst remaining within the reference range, were significantly lower with SMOF compared to the Intralipid controls. The omega-3 fatty acids; eicosapentaenoic acid, docosahexaenoic acid and the n-3/n-6 fatty acid ratio increased in the SMOF group, while they remained unchanged in the controls. Serum a-tocopherol (vitamin E) concentrations significantly increased in the study group compared to controls. Serious adverse events occurred in only 2 SMOF patients compared to 8 in the control patients.

In pediatric patients with PN-associated cholestasis (PNAC), an interesting study of FO based ILE was published this year by an American group, including the ASPEN president-elect Kathleen M. Gura. This team conducted a cost-effectiveness analysis comparing a 100% fish oil lipid emulsion (FOLE) at a dose of 1.9g/kg compared to Intralipid, a 100% soybean oil lipid emulsion (SOLE) at 1g/kg in pediatric PN patients with PNAC over 6 years. They estimated healthcare costs, including the cost of PN, transplantation, and adverse events using a model simulating clinical outcomes from two US clinical trials.

The total cost with FOLE was US$69,847 vs US$141,605 for SOLE. The cost reduction of US$71,757 USD was attributable to the avoidance of liver transplantation (−15.7%) and reduction in adverse events (−4.8%). Life-years and the quality-adjusted life-years were increased with FOLE compared with SOLE.

These authors conclude that FOLE could increase the likelihood of PNAC resolution and reduce the likelihood of liver transplantation by providing time to transition to full enteral nutrition. FOLE use leads to cost-savings that support the use of FOLE in pediatric patients with PNAC.

Highlights from these recent publications are:

- Patients with chronic intestinal failure who require long-term PN are particularly prone to the development of intestinal failure–associated liver disease (IFALD) or PN-associated cholestasis (PNAC).
- The type of ILE plays an important role in decreasing or increasing the risk for IFALD.
- The use of soybean ILE at doses higher than 1 g/kg/d has been identified as a risk factor for IFALD.
- ILE with fish oil can provide additional benefits in terms of improved liver function in chronic intestinal failure patients during long-term HPN.
- In PN-dependent children with existing IFALD, cholestasis can be reversed by using fish oil containing ILE along with management of other risk factors, especially catheter-related infections and small-intestinal bacterial overgrowth.
- Pure fish oil ILE can be a valuable short-term rescue treatment in cholestatic pediatric PN patients but should not be used as the sole source of lipids over a long period.
- Fish oil containing ILE can reduce the need for liver transplant of paediatric patients with PNAC and facilitate transition to full enteral nutrition, leading to cost-savings.
- Mixed ILE containing fish oil are safe and effective for use in patients on long-term HPN

References:

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Key to Abbreviations: PN= Parenteral nutrition, HPN=Home parenteral nutrition, EN=Enteral nutrition, ILE =Intravenous lipid emulsion, FO= Fish oil, SO=soya oil, OO=Olive oil, MCT=Medium chain triglycerides, TG=Triglycerides, FOLE= Fish oil containing lipid emulsion, SOLE=Soya oil containing lipid emulsion, LFT=Liver function tests, EFAD=Essential fatty acid deficiency, IFALD= Intestinal failure associated liver disease, PNAC= Parenteral nutrition associated cholestasis, CIF= Chronic intestinal failure, ICU=Intensive care unit, ESPEN= European society for clinical nutrition and metabolism.

Swimming on HPN – Some Members' Thoughts

Editor's note: *One of life's little pleasures – swimming/bathing/splashing around in water – is something that most people take for granted, but for those on HPN (Home Parenteral Nutrition) it's something that is usually either not recommended, or forbidden, by our medical teams due to the perceived risk of life-threatening line infections. It was a topic that generated a great deal of discussion on our forum back in 2012/2013 and was written up in Issue #3 of Dripline, February 2013. It also led to a PNDU MC-led survey of members, found in the Resources section of PNDU's website, pndu.org, under 'Surveys and Studies'.*

I decided to see if there have been any changes in hospital team attitudes and HPNer and carer feelings. ***This article is not meant to encourage our HPNers to go against their hospital team's advice.*** *Our teams know our medical history and unique problems, and what might be an acceptable risk for someone might be extremely dangerous for another. It is simply meant to see what our members are thinking and doing, and to get members thinking about whether or not it is an issue they wish to raise with their teams during their next visit.*

Justine
I go in salt water with a pool noodle at chest height, so nothing above the noodle gets submerged. I was an absolute water-baby before getting a line, and although like Annie I've never had a site or external line infection, I've had enough near-fatal sepsis to fear the risk. Studies/data out of Europe is very encouraging for well-healed established lines in controlled settings ie not public spas etc.

It's a personal decision each person/family needs to make according to their wants, desires and needs, but 'clean' water on a completely healed line (especially if its cuffed) is comparable to pierced earrings after 6 weeks, according to what I've read.

Anna
Nope. I'm so over infections I won't risk it. Haven't swam in 5+ years.

Jessica
My baby has a bath once a week. [My hospital] told me that once the dressing is wet it needs to be changed, so we do his dressing change after his bath.

I'm hoping he will get his line out within a year and then we can go swimming. I think if he still has the line around age 4-5 I'd probably insist on him going swimming so he learns how to swim.

Lea
Our son, nearly 15, has been in our pool and Singapore /Darwin wave pools. To us it's simple Quality of Life and we change dressings immediately after and have had not one line infection in 12 years (touch wood). Life to him is being part of the family - next week we head off to Alice Springs with PN.

Hannah
I used to wear no dressing and used to shower, bath, swim etc no issues. Same when I wore dressings, I would shower or bath without changing the dressing as long as no water got under the dressing. As for swimming, I only went to a public pool once - the rest of the times were at the lake and I would sometimes change my dressing straight after, sometimes not. I never got any infection as a result of this. I was never told by my team to not shower or to shower normally, same with swimming. I was never told anything about swimming or not swimming. (I don't have a line now as I'm on hospice care)

Rob
I understand it is risky, but as a beach-lover I can't resist going for swims. The way I protect my insertion site is by applying extra tegaderm so the water cannot enter underneath (and then I change my dressing back to normal when I get home). Now and then the water can breach underneath the tegaderm, but has never caused any infections for me (touch wood).

Julia
I was told to give a proper bath (splashing, wash hair, etc) once a week and change Syena's dressing immediately afterwards. Six years later, we still do this and she hasn't had any problems. The only time I am cautious is following surgery for a new line, until the site is fully healed.

I wasn't given any direction or advice about swimming from our hospital. However, I assumed the same advice around bath/shower time would apply and I didn't want to do a dressing change at a pool or a beach. Syena is highly allergic to nearly all dressings, so I couldn't simply cover her existing dressing with a large tegaderm or similar.

We didn't take her swimming until I discovered Hammond drysuit when she was two years old. Since then, she swims whenever she likes and enjoys jumping in our backyard heated spa. Her torso is kept completely dry.

This (see pictures below) was the moment that I became determined to work out a way for our little girl to join us in the water. I saw this little face looking out the lounge room window, watching our grandkids in our backyard spa.

Several months later, her first time joining us in the water.

Sheila
My teen daughter has been given permission by her team doctor to swim in our apartment pool, but not public pools. However, she refuses as doesn't want line infections. Also, she doesn't like the Hammond suits and would rather not swim than wear it due to the look of it attracting more attention than the line showing. If she decided to swim I was told to cover the line with larger tegaderm and then immediately change smart sites and dressing afterwards. We also use a biopatch around the exit site and it's a sponge, so worry that water will get in and put her at risk.

When she was 3, she had a Hickman line for cancer treatment. We bathed her daily in a baby bath sitting up with the shower head to rinse carefully and not get the dressing wet. Part of good hygiene and not risk her life with infections. Swimming was also banned then as she would have been high risk for infections due to the line, but also due to low immunity. Now as teen she's very careful regarding water getting into dressing.

Annie
I wasn't allowed to get my line wet at all when I was at the children's hospital - they really hammer it into you.

Once I moved to the adults' hospital, my consultant said if it was him he would still swim because it means so much to him that it's worth the risk. Enjoyment in life is more important. Quality over quantity. I've been swimming more than ever and I have had the least amount of infections. I obviously don't swim in lakes, rivers or public pools, especially a pool that has kids in it. Or hot tubs / hot water where bacteria can spread and live in the water.

As long as you change the dressing afterwards and look after your line it's no different.

If it's your own pool (not sure about beach as I haven't swum there) it's kind of no different than getting wet in the shower.

Swimming has been life saving for pain. It allows my joints to be light and free. Relieving pain.

But always go by what YOUR consultant says because you may have other issues that make it unsafe or at higher risk.

I'm immunosuppressed and still in 10 years never had an exit site infection or skin infection.

I've had bloodstream sepsis but not caused by the exit site .

Teresa
We were told a bath once a week and dressing change immediately after. Like Julia, we discovered Hammond Drysuits, but we're still frowned upon by our team (didn't want to know) I even took her suit in for them to look at but they said seems good but not approved here in Australia. Karma has been swimming since she was 5yrs and now at 11 has now had her line removed and a port in place. Her team is excited to hear about all the activities she can do that she "wasn't supposed to do"...swimming, soccer, climbing trees etc we just haven't told them about any of those

Sarah (Sal)
I was told no to swimming but if I had to, it was in salt water.

So when I go to a pool, or river, I go in up to just below my line s o it's not submerged at all.

So at least I can cool down. So for my big top end trip, that's what I will do there.

Jacqueline
The department that I work in has a considerable amount of patients with central lines. We're very strict

PNDU at New Zealand National Intestinal Failure & Rehabilitation Service (NZ NIFRS) 6th Education and Network Event Auckland

28th March 2025

By Chris, PNDU president

It is always wonderful to have the opportunity to represent and promote PNDU by engaging with HPN Clinicians in New Zealand, continuing PNDU's mission to support, research and inform consumers, carers and providers of Parenteral Nutrition for Intestinal Failure across Australia & New Zealand.

Extending special thanks to Cate Fraser – Irwin and Candice Gemmell. I accepted the invitations from the NZ NIFRS Team and travelled to Auckland for the 6th NIFRS Education and Network Event.

A warm welcome was extended to attendees by the NZ NIFRS Team.

"We're excited to be here with you today to share our experiences, research, and insights into the care of patients with intestinal failure. Our team is passionate about advancing care and improving outcomes, and we look forward to connecting with you all during this education day".

Meet the team (left to right) Cate Fraser - Clinical Nurse Specialist – Paediatric, Kim Herbison - Advanced Clinician - Paediatric/Adult Dietitian, Andrew Xia - Advanced Clinician - Paediatric/Adult Dietitian, Candice Gemmell - Clinical Nurse Specialist – Adult, Rajani Mutyala - Service Administrator, Mr Ian Bissett - Clinical Director - Adult Colorectal/General Surgeon, Dr Amin Roberts - Clinical Director - Paediatric Gastroenterologist, Amy Andrews - Advanced Clinician - Paediatric/Adult Dietitian, Dr Tim King - Adult Gastroenterologist, Kristin Wilson - Business Manager (not pictured), Dawson Ward - Equity lead Surgical Services Te Toka Tumai (not pictured)

The program for the NZ NIFRS Education Day was packed with informative and interactive presentations from leaders in Intestinal Failure rehabilitation.

The NZ NIFRS Education & Network Event also provides the opportunity to expand the reach of PNDU and provide printed informative resources as I engaged with HPN Clinicians during the day. It was also a great opportunity to catch up with Industry friends and PNDU founder/life member Gil Hardy.

The program:

NIFRS Update 2023-25 - Ian Bissett & Amin Roberts (NIFRS Clinical Directors)

An Update on Intestinal Failure Associated Liver Disease (IFALD) - Jonathan Hind

Clinical Management of ARFID/DGBI: An MDT approach - Lee Martin

Contemporary Indications & Outcomes of Intestinal Transplantation – Jonathan Hind

The post-transplant period: Surveillance for Short and Longterm complications - Yaron Avitzur

The path to intestinal transplantation in Aotearoa NZ - Helen Evans

Setup and Evolution of an MDT Rehab Service for patients with ARFID/DGBI - Lee Martin

Living with Home IVN/PN:

Adult patient perspective - Jude Simpson (We first met PNDU member Jude at the Auckland gathering in 2023)

Paediatric patient perspective Eva Mitchel (A very brave young HPN warrior – I extended an invitation for Eva's family/carers to join PNDU)

A couple of truly inspirational presentations from HPNers that highlighted what life is really like living with a drip.

Managing high output stomas - Adult NIFRS Team

Managing central line complications Cate Fraser

Chris Walker PNDU President

Chris Walker PNDU President – Emeritus Professor Gil Hardy PhD FRSC FASPEN PNDU Life Member & Co-Founder

Hanna McLaren – Baxter Healthcare

Rare Voices Australia Parliamentary event – Rare Disease Day 2025

By Chris

On behalf of PNDU, I attended the Rare Voices Australia (RVA) Parliamentary event to mark Rare Disease Day at Parliament House in Canberra. Rare Disease Day is a global event observed each year on the last day of February. This year, given the upcoming 2025 Federal Election being a busy time in Canberra, the event was held slightly earlier on 11 February 2025.

The event was hosted by the Parliamentary Friends of Australians Living with Rare Diseases and attended by over 100 guests, including people living with a rare disease; RVA partner organisations; politicians; clinicians; researchers and industry members.

RVA extended their thanks to the following parliamentarians who spoke at the event:

- Hon Mark Butler MP, Minister for Health and Aged Care
- Senator the Hon Anne Ruston, Shadow Minister for Health and Aged Care
- Dr Mike Freelander MP, Co-Chair of the Parliamentary Friends of Australians Living with Rare Diseases and Member for Macarthur
- Dr Monique Ryan, Co-Chair of the Parliamentary Friends of Australians Living with Rare Diseases and Member for Kooyong
- Senator Wendy Askew, Co-Chair of the Parliamentary Friends of Australians Living with Rare Diseases and Senator for Tasmania

Fiona Lawton, RVA's Disability Advocacy Manager, shared her family's story and her experience with rare disease disability advocacy.

"The Politicians repeatedly affirmed their unwavering support for the rare disease community, irrespective of the Federal Election outcome. This multipartisan backing is vital for advocating the best outcomes for the approximately two million Australians affected by rare diseases, nearly all of whom face daily long-term impacts defined as a disability by the Australian Government. These disability impacts often go unrecognized by policymakers. (RVA 2025)"

Attending the RVA Parliamentary Event provides a unique opportunity to engage with politicians and policy makers and share our lived experiences. PNDU members share similar experiences to Fiona Lawton, of living with a rare disease and advocating for access to disability supports.

I personally thank RVA for the invitation to attend this event.

Chris Walker PNDU President

Nicole Millis RVA CEO

PNDU Represented at APAA, Parliament House, Canberra

by Chris

It was a busy week in Canberra as I represented PNDU at the APAA Summit, held at Parliament House the day after the RVA Parliamentary Event. Attending back-to-back events strengthens PNDU's presence in Canberra and provides another opportunity to engage with policy makers.

Australian Patient Advocacy Alliance (APAA)

The Australian Patient Advocacy Alliance (APAA) comprises leading health advocacy organisations representing over 13 million individuals living with chronic and complex health conditions. We offer a coordinated and unified approach to government on behalf of our members, ensuring efficiency for both parties. Guided by the principle of 'working above the disease', our objective is to guarantee meaningful and informed contributions from a diverse patient voice in health strategy and decision-making.

APAA Summit Parliament House Canberra 12th February 2025

Living with, or caring for, someone with a chronic condition can significantly impact social and economic circumstances, creating additional obstacles to earning an income, participating in education, and engaging socially within communities.

Presentation from Jon Kite Assistant Director, Chronic Conditions Strategic Policy

Refresh of the National Strategic Framework for Chronic Conditions (including the National Strategic Action Plan for Rare Diseases)

The National Strategic Framework for Chronic Conditions 2017-2025 provides overarching policy guidance for the prevention and management of chronic conditions in Australia. This framework allows all levels of government and health professionals to deliver an effective and coordinated national response to chronic conditions. The framework is currently undergoing a refresh to ensure alignment with primary health care reforms and other relevant domestic and international policies. It aims to guide sustainable, evidence-based support for chronic conditions in the future.

Government Response to APAA Roadmap - Minister Mark Butler

Opposition Response to APAA Roadmap - Senator Anne Ruston

Roadmap One

Our 2034 vision is for Australia to have an efficient and seamless healthcare system across primary and tertiary care, aligned with broader societal needs and facilitated by equitable, value-based funding to achieve optimal outcomes in chronic disease management, with a focus on prevention, ultimately leading to a healthy Australia.

Objectives of Roadmap One

As we implement Roadmap One, aligned with the 48th Federal Parliament (2025-2027), we see alignment of timing with the culmination of several key activities. Specifically, the National Strategic Framework for Chronic Conditions (2017-2025), the Health Technology Assessment (HTA) review, and the initiatives around Strengthening Medicare, among others, create opportunities that must be coordinated and cohesive to avoid confusion and duplication of effort. Importantly, these efforts must address the needs of patients.

APAA aims to progress towards our 10-year vision through the implementation of three 3-year high-level advocacy roadmaps, each corresponding to a federal government's term of office. Annual advocacy plans outlining specific actions and embracing collaborative approaches will be developed to support our work for each of the three years covered by each roadmap. Each roadmap will seek to work alongside existing strategies, frameworks, and plans from both the Department of Health and other health-oriented organisations. As advocates and effective conduits to patients, we can assist in shaping and implementing these plans, enabling the government to achieve its vision for health consistent with the needs of Australians living with chronic and complex diseases. The advocacy priorities within each roadmap are determined by the status of the healthcare system and input from APAA Members, considering the needs of the patient communities they represent.

Workshop: APAA Advocacy Priorities 2025 (APAA Members) - Peta Lange led the workshop; Deidre Mackechnie provided the wrap-up and next steps; Closing Remarks - Leanne Raven, APAA Chair

Post Summit Outcomes

The APAA Advocacy Working Group and the Board have met to review the outcomes of our annual summit and endorse the work plan for the coming year. Two key focus areas, consistent with our roadmap, are the Chronic Disease Framework and Digital Health. We will continue to advance our responsive advocacy on current issues such as the HTA review.

I extend my personal thanks to APAA for inviting me to represent PNDU & attend this event.

Deidre Mackechnie (APAA)
Chris Walker (PNDU)

Hon Mark Butler MP, Minister for Health Aged Care

Senator the Hon Anne Ruston, Shadow Minister for Health and Aged Care

Recycling Our Blister Packs

By Gillian

Most of us take medication for various reasons, in addition to our PN. As well as masses of waste materials associated with our PN regime, HPNers probably have lots of blister packs from tablets and capsules, which aren't suitable for kerbside recycling due to their make-up. I was surprised and very happy to read that there is a 'Pharmacycle' recycling program, that allows you to recycle these waste packs through participating chemists. Chemist Warehouse and Blooms

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 $5,000.

Takeda

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.)

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

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