DRIPLINE

PNDU

Parenteral Nutrition Down Under

ISSUE 56
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2026

Welcome to the July issue of Dripline. Read the three articles written by our members: one about their liver/small intestine transplant; one about their achievements and ambitions in running; and one about a SNUG camp that three of our HPNer children attended. AuSPEN has sent the latest national report on the Home Parenteral Nutrition registry, the first of its kind in Australia. PNDU President, Chris, reports on two conferences that he has attended, representing PNDU – GENCA in Melbourne and OLEY in Wisconsin, USA. Also write the dates for HPN Awareness Week, and associated Pharmacy tours in your diary. And add a very important date to your diary – PNDU's upcoming AGM. Consider if you can help with our need for volunteers for a treasurer and social media and community builder, or just join the meeting to listen to what PNDU has been doing during the past year.

Gillian Anderson

Dripline Editor

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Upcoming Events

- PNDU's AGM, Tuesday 18th August, 10:00am AEST; New Zealand 12:00pm.
- HPN Awareness Week 2026, Sunday 27th September - Saturday 3rd October.
- Tasmania – social gathering, Launceston, Sunday 8th November – venue and time to be decided.

Help Keep Our PNDU Community Thriving

PNDU is built by people who care about our community—and we'd love a little more help.

We're looking for volunteers for two small but important roles:

- **Treasurer**
- **Social Media & Community Builder**

These are flexible volunteer roles, and we're happy to work around your health, family and other commitments. Every little bit of help makes a real difference in supporting people living with HPN and their families.

If you've ever thought, "I'd love to help, but I don't have a lot of time," we'd still love to hear from you. Please get in touch at **contact@pndu.org** for a friendly, no-obligation chat.

You're Invited to the PNDU AGM!

Our **2026 Annual General Meeting** will be held **online via Microsoft Teams** on **Tuesday 18 August 2026** at AEST: **10:00 am** New Zealand: **12:00 pm**

Everyone is welcome to attend!

We'll also be electing our Management Committee for the coming year, and nominations are open for all committee roles. If you're interested in joining the committee or would like information about nominations, voting or proxy votes, we'd love to hear from you.

Please RSVP by 10 August 2026 to **contactpndu@gmail.com**, including the email address you'd like to join the meeting from. Committee nominations also close **5:00 pm, 10 August 2026**.

Thank you for being part of the PNDU community—we hope you can join us!

By Rachelle

A few months ago, I received a phone call that I had been anticipating for seven months. I was told that a donor had become available for liver and intestinal transplant. So began my newest major health chapter and chance at a better life.

But first – how did I get here? My transplant story really begins in 1983 when I was nine years old and had emergency surgery for small bowel malrotation involving a lot of necrotic bowel. I spent 6 months in Melbourne's Royal Children's Hospital having multiple resections of small bowel, until I was left with about thirty centimetres of duodenum and a new diagnosis of Short Bowel Syndrome. During that time, I contracted Hepatitis B through blood infusion but was so sick that it went undiagnosed until decades later when antibodies were detected in my blood. I was discharged on then standard soy-based HPN, one of the first in Australia. When I was twelve, my gall bladder was removed as it was chock-full of gallstones due to the PN formulation. At age thirteen I had a blood clot related to the PN and moved from a central vein catheter to overnight naso-gastric feeding. At age eighteen the naso-gastric feeding stopped as I was able to sustain my nutrition orally, but was diagnosed with chronic oxalate kidney stones due to imbalance in calcium absorption from the missing bowel sections.

Despite my health status, I went on to have a good quality of life in my twenties and thirties. I worked full-time, got married and had two children, and even lived overseas for a few years. Until my late forties, my main concern was kidney stones. Many stents, lithotripsy procedures and kidney infections left my kidneys worse for wear. It was at this time that over a period of about twelve months, I lost a lot of weight and began to battle uncontrollable diarrhoea and progressive collapse, such that I experienced multiple falls, vomiting and eventually, confusion. I was rushed to hospital. I was discharged after 11 weeks with a Hickman catheter and back on PN. However, I was also diagnosed with Intestinal Failure of my large bowel and IF-related liver disease. Decades of hardship to my liver via hepatitis, toxic PN and the burden of supporting Short Bowel Syndrome had taken its toll. Eventually the conversation turned into a multi-visceral transplant of the intestine and liver as the only remaining option, as the long-term prognosis of my liver was not a happy one.

Last March, I had a week of transplant assessment and was waitlisted for transplant in July. There was no guidance on how long I would be waiting for a donor match. I worked with my employer on how we would manage the time when I would receive the call and need sudden long-term medical leave. I informed only a small group of friends and family as discussing transplant was stressful. I made sure to regularly see a psychologist to manage my mental health. I also made sure to begin community physio pre-habilitation, as it was very important that when the time came for surgery that I was as healthy as possible to improve my recovery and decrease the chances of complication. Unlike liver transplant alone, where patients can become very ill with liver failure and still have a positive outcome, transplant for intestine requires patients to be relatively well. I received as many vaccinations as possible during my wait time and made sure I was up to date with all my cancer checks.

I was shopping for a birthday present for a friend on Saturday the 28th of February this year when I received the phone call from the Austin hospital Liver Transplant Unit to tell me that a donor had become available. Final tissue matching was still being completed, however I needed to be at the hospital by 5pm. The timing was not good – my son is completing Year 12 and my parents, who are our usual carers for our children, were not available. With a final family selfie and a promise from our neighbours to look in on our children until my parents could arrive the next day, my husband and I set off on the three-and-a-half-hour drive to hospital. I was admitted and at 10am the next morning it was confirmed that the donor was a good match. I was in theatre within 30 minutes and soon my husband received the message: "knife to skin". I am patient number 19 to have received this type of transplant in Australia and New Zealand since they began about 15 years ago.

My surgery was almost exactly 12 hours long. I spent 6 days in ICU. I don't recall Day One. On Day Two they had me very shakily standing up and taking a slow walk around the nurses' station with two heavily laden IV poles trailing behind me. I was so thankful to have taken the time to keep myself strong! I was moved to the ward and so began the slew of immunosuppressants and antibiotics. I remained on PN for about 6 weeks. I was discharged at 7 weeks with an ileostomy, a PICC and a drain. The PICC and drain were removed two weeks later and I was able to then return home.

It's now two and a half months since my transplant and my recovery has been very slow. One week after arriving home I contracted a blood infection due to extremely low white blood cell count and returned to Austin hospital for a week of antibiotics and blood infusions. This set me back physically and mentally. I'm back home now, still with my Hickman, but also the ileostomy. I have a heavy regime of medication which is strictly time-managed. I use my Hickman for bloods and by exception, IV fluids to support my kidneys which are impacted by the drugs. I am managing post-surgical pain and some brain fog from the medication. I am very immunosuppressed and need to make sure I use precautions to prevent further infection. Return to work is still some weeks away. I have fortnightly ileoscopies via the stoma to check for any organ rejection and twice weekly liver clinic appointments either in person or telehealth.

Today I'm feeling very positive and grateful for my transplant. In fact, I have gained three organs: a liver replacement, a new-to-me intestine and a bonus pancreas (fairly standard with intestinal transplant). In time my Hickman is planned to be removed, which is a very strange thought! It is also planned for stoma reversal once the chance of rejection has lessened. I will be on anti-rejection medication for the rest of my life, although the dosage will be reduced over time. I have side effects from the medication, such as tremors, brain fog and mild headaches. I need to be vigilant about skin cancer for the rest of my life as immunosuppression increases the likelihood. I plan to return to physio rehab very soon once my pain is under control a little more. I'm even looking forward to putting on some weight due to having a fully-functioning intestine – something I've always struggled to do!

Several more people have had intestinal/liver transplant since my surgery. It's certainly a drastic type of surgery to undergo and there is a lot more to my story if anyone is interested. Outcomes for this type of surgery are positive and the team at the Austin hospital have been exceptional. My family and I feel extremely well-supported. I still have a long journey ahead, but I know that my quality of life will improve immensely. I look forward to a life with a lot less pain, without medical devices, more energy and a chance at a longer life than I was previously expected to have.

In 1983, when I was having most of my small bowel removed, my surgeon told my mother that one day medical science would figure out how to do intestinal transplants for patients like me. How lucky are we, decades later, that we now have the technology to do that?

Editor's note: If anyone has questions for Rachelle, you can send an email to contactpndu@gmail.com and they will be forwarded to her.

To the Finish Line, with a Line

By Freya

Growing up as a TPN-dependent child, sport and physical activity never came naturally to me, nor did I particularly enjoy it. However, being a product of my environment, with very physically fit family members and sporty friends, I eventually found running in my late teens. Like so many other runners, once I found it, I never looked back. These days I run multiple times a week and am currently training for my third half marathon!

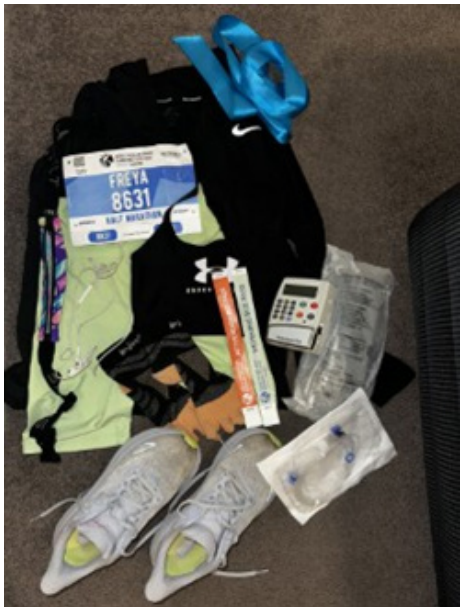
While I'm still on TPN seven nights a week, my physical activity often brings up a lot of questions. How do I do it? Well, to be honest, it's been quite the journey—and one that I'm still navigating! Fortunately, my health has been generally very well managed for a long time, which has allowed me to explore and discover the things I love. However, when you can't eat or drink like I can't, meeting your nutritional requirements isn't as simple as carb loading with pasta the night before, or drinking three litres of water a day. Instead, I've worked very closely with my dietitian, reporting my training and physical activity so we can adjust my TPN formulation to provide the nutrients I need.

Throughout my years of training, there have been times where I've naively increased my mileage without considering my nutritional requirements, which led to unintentional weight loss and fatigue. Experiencing those lows taught me the importance of consistency over intensity, and that's the approach I take today. Growing up with a chronic illness meant I learnt to understand my body from a young age, and I have really leant into what I call "intuitive running". It can be as simple as running longer when I feel good and taking it easy when I don't. Listening to my body isn't a sign of weakness—it's what allows me to keep showing up week after week. They say running is 90% mental and I think there's a lot of truth in that. The long runs, training blocks and crossing the finish line have taught me just how powerful my mind can be. That's something I carry with me in my work, my relationships and the way I manage my health.

So far, I've only gone as far as the half marathon distance, and I've managed to complete each one without any nutrition or hydration during the race itself. Instead, I compensate with extra IV fluids before and after the event—quite literally connecting my line while sitting on the curb at the finish line of the Great Ocean Road Running Festival!

Looking to the future, one of my biggest goals is to run the New York City Marathon in 2028. I turn 26 that year, and the marathon is 26.2 miles, so it just feels like it was meant to be! Of course, a marathon is a very different challenge. Running that distance without nutrition or hydration simply won't be possible, so one of the biggest hurdles I'll need to overcome is working out how to safely receive both while I'm running. Before then, I'll be trialling a pressurised infusion pump with glucose fluids—a solution that's still very much being workshopped. I'm excited to see where it takes me!

For me, running is more than just exercise - it's my sport, my hobby, a way to connect with others and a big part of my identity. As someone living with a chronic illness, it is a constant reminder of what my body is capable of despite its challenges. It might take a bit more planning than it does for most runners, but if there's one thing TPN has taught me, it's that there is almost always a way—you just have to be willing to find it.



"Save the Dates" HPN Awareness Week 2026

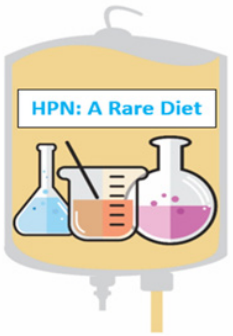
Sunday 27th September – Saturday 3rd October 2026

HPN AW26 Baxter Pharmacy Tours

Monday 28th September - Toongabbie, SYDNEY Coorparoo, Brisbane

Wednesday 30th September - Melbourne - Brunswick

Friday 3rd October: - Perth – WA, Christchurch & Auckland (NZ)



SNUG (Special Needs Unlimited Group) Camp, Lake Macquarie

By Mariann

What happens when 2 mums, 3 active boys and Aunty Katie stay in cabins at Lake Macquarie?

Hours were filled with basketball, running between cabins, painting rocks, organised activities and the kind of silliness only boys do.

In April we were fortunate to attend a relaxing and fun weekend on Lake Macquarie at the NSW Sport and Recreation centre at the invitation of SNUG Retreats, supported and organised by the University of Newcastle Family Action Centre and for 17 years sponsored by the Steve Waugh Foundation.

Many of the original families who attended many times over the years with little ones returned with teenagers and younger siblings who thanks to SNUG camp have become lifelong friends and shared their lives, birthdays, admissions and grief.

There were new families who blended in at their own pace, alongside our PNDU boys who'd been before and were happy to show off their archery and damper making skills. For the first time, with as many risk mitigations in place as possible, the boys went paddling on the lake with the biggest smiles while nervous mums and Aunty Katie watched on and with both hope, happiness and fear.

Connection for children with complex conditions and families who have experienced the rollercoaster of rare diseases is sometimes vital to know you are not alone or as my 8 year old says 'the boys are just like me'.

Just like most days out in the world, no one can tell what goes on under our boys clothes — the attachments, buttons, lines, dressings and scars, the really hard nighttime routines, the chronic and acute pain and life threatening risks. And the frustration of moving around like young boys do but with pumps and backpacks and lines that get in the way.

Being with families at SNUG and other catch ups with PNDU families is one of the few times you don't have to continually explain and justify why they do what they do. It's understood, supportive and even helpful.

There have been previous weekends with just PNDU families, and we sincerely hope The Family Action Centre can source funding to continue the weekends now that the Steve Waugh Foundation sponsorship has ended.

Because it matters that someone else cooks the meals; that boys sitting at the table but not eating is just normal. That playing basketball with pumps and lines in backpacks is safe.

It matters that parents and carers can share the achievements and the hard times with families who actually get it and walk away feeling a little less alone.

Sincerest thanks to Liz, her team at SNUG, the volunteers, Hayden at Sport and Rec and the beautiful families.

2 mums, 3 boys and Aunty Katie drove a long way home in opposite directions from camp, tired, but filled with memories and happiness that our boys know each other.

Samuela

Samuela, Logan, Jordan

Ready to infuse

Samuela, Logan, Jordan

Fun afloat

By Chris Walker, PNDU President

Over the years, I have been warmly invited several times to attend the Oley Foundation's annual conference in the United States. While I have always appreciated these invitations, the cost of international travel and PNDU's limited funding options have meant that, until now, I have had to respectfully decline.

That possibility resurfaced at Australian Gastro Week 2025, held as part of the World Congress of Gastroenterologists, when I was encouraged to submit an abstract for a guest speaker presentation at Oley's 2026 Infusing Hope Educational Session. With the generous support and encouragement of Professors Gil Hardy, Alan Buchman and Sharon Carey, and valuable assistance in preparing the submission, I put forward an abstract titled "Living with a Drip Down Under: A Carer's 25-Year Lived HPN Experience." Although Oley was unable to include my presentation in the final program, the opportunity did not end there.

Oley responded with a kind invitation to attend the conference and contribute to another session.

In their response, Oley acknowledged the time, care and expertise behind the submission. They explained that the conference had received many strong and innovative proposals, all of which were carefully peer reviewed, and that the decision reflected the highly competitive process and limited space in the program. Importantly, they also made clear that the outcome did not diminish the value of the work or its contribution to the community. Instead, they invited me to bring my experience to the conference by partnering with another speaker or session.

After discussing the opportunity with the PNDU management committee, we agreed that attending the Oley Conference could offer meaningful benefits for the PNDU community and help strengthen the connection between PNDU and Oley. I was pleased to accept the invitation and began making plans to travel to Wisconsin.

Madison, Wisconsin Capital Building.
The exterior stone is Bethel white granite from Vermont, making the exterior dome the largest granite dome in the world.

Oley and PNDU Connect at the Oley Annual Conference

Words by **Vincent**

Community Engagement Coordinator

The Oley Foundation, Inc

This year at the Oley Annual Conference in Madison, Wisconsin, I had the pleasure of connecting with Chris from PNDU in Australia. Chris reached out to The Oley Foundation with interest in attending the conference, learning more about our community, and finding ways to connect with people who understand life on nutrition support.

As Oley's Community Engagement Coordinator, it was a pleasure to welcome Chris and work with him on a roundtable session focused on creating a personal health "elevator speech." In the months leading up to conference, Chris and I connected regularly and worked together on a shared document to organize our ideas, talking points, and key messages.

Our goal was to help attendees feel more confident sharing their health story in different settings. Whether speaking with another patient, a caregiver, a clinician, or someone who may not know much about nutrition support, we wanted people to have a clear and meaningful way to explain their experience.

Together, we created a take-home toolkit for people who visited the roundtable. The toolkit included simple steps to help attendees build a short health pitch that was personal, organized, and easy to adjust depending on who they were speaking with.

The roundtable was a great experience. Each group brought thoughtful questions, shared pieces of their own stories, and practiced building their health pitch. Many attendees left the table with their own starting point and a resource they could continue using after conference.

Outside of the roundtable, I was also able to spend time with Chris throughout the conference and introduce him to members of the Oley community. It was exciting to share that he was visiting from Australia and representing PNDU, an organization with a mission similar to Oley's.

Connecting with Chris was a reminder that even though Oley and PNDU serve communities in different parts of the world, many of the needs are the same. Patients and caregivers want connection, understanding, education, and support from people who truly understand their journey.

I am grateful for the opportunity to partner with Chris and learn more about PNDU. I look forward to seeing how Oley and PNDU may continue to connect and support the nutrition support community moving forward.

Vincent Rosche

Community Engagement Coordinator

Under the Big Top: PNDU at Oley 2026 Part 2

After a long journey from Newcastle to Madison, Wisconsin, it was wonderful to arrive at the Oley 2026 Conference and be welcomed so warmly by Oley CEO Beth and Community Engagement Coordinator Vincent, who immediately made me feel part of the extended Oley family.

With this year's lively "**CIRCUS OLEY**" theme bringing colour, energy and fun to the event, the conference was a valuable opportunity to connect with HPNers, carers, families, clinicians and industry partners while representing PNDU on an international stage. More than just a conference, Oley 2026 was a celebration of community, advocacy, lived experience and the powerful connections that bring the HPN community together.

Photo caption: Vincent, Chris and Beth at Oley 2026.

A warm welcome under the big top

The opening event, **Welcome to Oley 2026: Under the Big Top Circus Spectacular,** set the tone beautifully. From the beginning, it was clear that Oley is about far more than a conference program — it is about bringing people together.

Across the event, HPNers, carers, family members, clinicians and industry representatives had the opportunity to network, share experiences and build meaningful connections in a warm and welcoming environment. While each day included informative educational presentations, the evening events provided a much-needed chance to relax, celebrate and enjoy the community spirit.

Highlights included an inspiring fashion parade, where nutrition support patients proudly showed how they live life confidently while wearing and carrying their pumps. The final evening brought plenty of fun with karaoke and entertainment, while younger attendees enjoyed a chaperoned pyjama party and movie night. These social moments added joy, energy and a lasting sense of connection to the conference.

Community, service and connection

Each day of the conference offered valuable breakout sessions and networking opportunities. One special highlight was **Knots and Notes**, a community service activity supporting the local Ronald McDonald House.

Volunteers came together in a relaxed and friendly setting to tie blankets and write notes of encouragement for children receiving care. Oley staff then presented the completed blankets and messages to Ronald McDonald House, creating a meaningful moment of generosity and connection with the wider Madison community.

Knots and Notes: - A volunteer community service supporting the local Ronald McDonald House

Photo caption: PNDU President Chris lending a hand during Knots and Notes.

Sharing the PNDU message

One of the most valuable sessions focused on the importance of raising awareness and becoming an everyday advocate for your support group. Although the session was Oley focused, it was a practical and inspiring opportunity to think about how we can share the message of **Parenteral Nutrition Down Under (PNDU)** in a clear, confident and meaningful way.

The session encouraged us to develop a short, memorable pitch for people who may not yet know about PNDU. A simple message might be: "Have you heard of PNDU? It is an incredible not-for-profit patient support group for people who rely on intravenous parenteral nutrition. When you or a family member first starts home parenteral nutrition, it can feel overwhelming, isolating and lonely. PNDU provides a lifeline by connecting people with others who understand a similar journey, offering free educational resources and sharing hope so no one feels alone. Support makes a difference. To learn more, visit www.pndu.org."

Voices of hope

Keynote speaker and Australian advocate Melanie Dimmitt, from **The Blend**, delivered an inspiring presentation titled **"Voices of Hope: Rewriting What's Possible."**

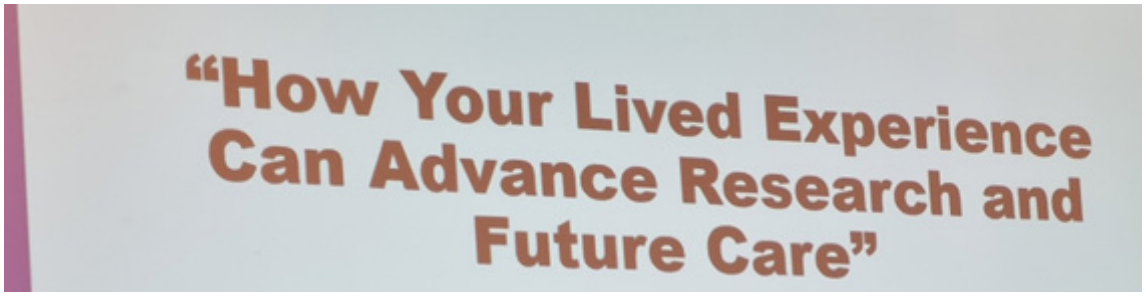
The Blend is the world's only lifestyle magazine for the enteral and parenteral nutrition communities. If you are interested in obtaining copies of The Blend magazine, please contact PNDU at contactpndu@gmail.com.

It was also wonderful to see PNDU members featured in presentations at the Oley conference. Many of our members continue to inspire others by sharing their experiences through social media and other community channels.

You can also catch up with PNDU's own Steph Kelly on **Tubie Talks: Hooked Up with Steph Kelly**, a Heart Out Media podcast available through The Blend website.

Photo caption: Keynote speaker Australia's own Melanie Dimmitt

Photo caption: Catch up with our own Steph Kelly Tubie Talks Podcast — The Blend. https://www.theblendmag.com/tubie-talks-podcast



Research, lived experience and future care

With so many informative breakout sessions available, it was difficult to choose which one to attend next. I focused on several research-based sessions that explored how lived experience can help advance research and improve future care.

Supporting research is about inspiring hope and bringing families, consumers and clinicians together to improve quality of life for all HPNers.

Keep an eye on PNDU's social media channels for updates on current research projects and opportunities to contribute.

Research and consumer involvement opportunities available to PNDU members:

James Lind Alliance: Hospital-associated infections

This project aims to identify consumer priorities for healthcare-associated infection prevention through a priority-setting partnership involving patients, carers and clinicians.

James Lind Alliance: Nutrition for critically ill adults

This initiative aims to identify research priorities that could improve nutrition care and outcomes for critically ill adults, including input from carers with lived experience following ICU discharge.

RESPOND-BSI

RESPOND-BSI is a statewide partnership focused on implementing and evaluating a multidisciplinary rapid response model of care for bloodstream infections across Queensland hospitals.

Blended tube feeding consumer input

The AuSPEN blended tube feeding committee is seeking consumer perspectives for a 2026 conference session and is asking: **What do you wish your clinician understood about blended tube feeding?**

Scan the QR code or contactpndu@gmail.com

Complications and home parenteral nutrition registry study

This study will use 2023–2025 HPN registry data to better understand factors contributing to HPN-related complications and support targeted strategies to reduce complication rates.

Financial distress in people living with intestinal failure

This national survey aims to expand existing research using a co-design framework and better understand out-of-pocket expenses and loss of income for people living with intestinal failure on HPN.

Learning from leaders and reconnecting with colleagues

Over many years representing PNDU, I have had the pleasure of meeting many inspirational people working in chronic intestinal failure and home parenteral nutrition. Oley 2026 was a wonderful opportunity to reconnect with old friends, colleagues and associates.

It was especially valuable to hear from leaders including Dr Paul Wischmeyer, whose message to "**just do it**" and live life to the fullest left a lasting impression; Dr Marion F. Winkler, who spoke about how lived experience can advance research and future care; and Dr Alan Buchman, who presented on the current status of intestinal transplant.

Closing Reflections

Oley 2026 was a powerful reminder that community, connection and shared experience are at the heart of support and advocacy. From educational sessions and research discussions to social events and personal conversations, the conference offered many opportunities to learn, reflect and strengthen relationships across the international HPN community.

I am grateful for the opportunity to represent PNDU, share our story and bring back new ideas, inspiration and hope for our members. On behalf of PNDU, I would like to thank Oley for the opportunity to attend the 2026 conference, and I look forward to continuing to build connections and work together in the future.

Thank you,

Chris Walker

President, PNDU

AuSPEN HPN Registry Update

Australia's Home Parenteral Nutrition Registry: What the Latest Results Mean for You

The Australasian Society of Parenteral and Enteral Nutrition (AuSPEN) has released its second national report on home parenteral nutrition (HPN), which reports data related to the year of 2024.

This registry is the first of its kind in Australia, designed to track how HPN services are delivered, what outcomes people experience, and where improvements can be made. For consumers, it offers a rare window into the bigger picture of care across the country.

Why the Registry Matters

HPN is life-sustaining for people living with intestinal failure. Until now, there hasn't been a national way to measure how services are performing or how patients are faring. The registry:

- Collects information from hospitals and clinics that manage HPN at home.
- Tracks both clinical outcomes (like infections and hospital readmissions) and patient-reported outcomes (like quality of life).
- Helps identify gaps and variations in care so services can improve.

Who's Receiving HPN in Australia

- Twenty-nine health services across Australia provide HPN, with 20 adult services and 9 paediatric services.
- The average age of people requiring parenteral support is 45 years, ranging from infants to 85 years old.
- Most are women (62% female vs 35% male).
- The most common reasons for people being on HPN were motility disorders (27%) and short bowel syndrome with ileostomy (20%).

What the Numbers Show

- **Therapies:** Out of 366 people requiring parenteral support nationally, **304 (75%)** are on HPN, **41 (10%)** on intravenous fluids alone, and **21 (5%)** on Revestive™ alone. Of the 304 people on HPN, 39 of these people are on Revestive™ medications.
- **Line infections:** The overall infection rate was **0.91 per 1000 days**. The majority of people had one line infection in 2024.
- **Hospital readmissions:** For the 178 people that had data entered, there were **440 hospital admissions** in 2024. While **42% had no admissions**, others had multiple, with **19 people admitted more than four times**.
- **Quality of life:** Fifty-two people receiving or looking after people receiving parenteral support completed questionnaires. On the HPN patient-reported questionnaire and the quality-of-life questionnaire, average scores were 70 out of 100, where 0 = lowest possible health and 100 = best possible health. The most common issues reported were **pain/discomfort** which was reported in 86% of people, followed by **limitations in usual activities** reported by 71% of people.

What This Means for Consumers

The registry confirms what many families already know: HPN care is complex, but with the right support, people can live at home and maintain a good quality of life. It also shows:

- Our line infection rates are slightly higher than other equivalent countries
- Pain and discomfort are the biggest barriers to wellbeing.
- Revestive™ is having positive outcomes for people who are eligible. If you are not sure whether you are eligible for Revestive™ talk with your HPN team.

Looking Ahead

This registry is still young, but it's already proving its worth. By capturing both clinical and lived experience data, it strengthens the case for better funding, staffing, and support. For people living with home parenteral support, it means your voice, through patient-reported outcomes, is shaping the future of HPN care in Australia.

If you have any questions about this registry, please do not hesitate to contact Professor Sharon Carey (Principal Investigator and Co-Chair of the AuSPEN HPN Governance Steering Committee) or Julia Fox (President of AuSPEN, Intestinal Failure Dietitian, and Co-Chair of the AuSPEN HPN Governance Steering Committee).

PNDU Connects with Gastroenterology Nurses at GENCA 2026

Melbourne | 15–17 May 2026

Words by Chris.

PNDU was pleased to be represented at the Gastroenterological Nurses College of Australia (GENCA) National Conference, held in Melbourne from 15–17 May 2026. The conference brought together gastroenterology nurses, clinicians, and industry representatives from across Australia to exchange knowledge, strengthen professional connections, and explore ways to improve patient care.

Sharing resources and building connections

A key focus of PNDU's presence was sharing practical, accessible information for patients receiving home parenteral nutrition, as well as their families and carers. PNDU's printed resources were showcased throughout the event, helping healthcare professionals learn how they can introduce patients to the support, information, and community available through PNDU.

The conference provided a valuable opportunity to raise awareness of PNDU's work and build relationships within the gastroenterology nursing community. These conversations reinforced the importance of shared learning, collaboration, and clear patient information in supporting better outcomes for people who rely on home parenteral nutrition.

Thank you to GENCA

PNDU thanks the Gastroenterological Nurses College of Australia for the opportunity to connect with colleagues, share free patient resources, and contribute to conversations that support informed, compassionate care. To learn more about PNDU and access resources, visit www.pndu.org.

Thank You

PNDU is very grateful for the support given by the donor listed below. We wish to thank the following for their generous gift.

S Thong

Membership for Aussie and Kiwi HPNers and carers:

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

Benefits:

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

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

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

Donations

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

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

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

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

Australia ($AUD) Bank: Westpac Account Name: **PNDU Inc.** BSB: 032 056 A/C No.: 482 738	**NEW ZEALAND: ($NZD):** 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

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Vice-President - Gillian
Secretary/Public Officer - Miranda
Treasurer - Sal
Dripline Editor - Gillian
Committee Members - Julia and Mariann
Volunteer - Rachelle

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