

It's amazing to think that we've made it to the 50th issue, eleven and a half years after the first issue, and 16 years after PNDU began! It's thanks to you, PNDU's members, that we've been able to achieve this, because without your stories, Dripline would be much poorer and less interesting to read...so keep them coming! I'd like to particularly thank these people for their assistance over the years in producing Dripline: our inaugural president, Karen, who for the first few years provided invaluable support and feedback as well as spoon-feeding me through the use of Mailchimp, our mailing company; our current president, Chris, who provides many of the PNDU involvement articles as well as checking the final document before I send it to the designer; Renee, who ensures that my requests get put onto Facebook and provides endless encouraging words; the original designer, Carla and her successor, Sally (my daughter), who designed the layout and did the work voluntarily for many years; and lastly Ryan (and now Sally) for putting the final product on our website. I'm not expecting to be the editor for the 100th issue, so start thinking about whether it might be you! Gillian



CONTENTS

Editor

- Upcoming Events
- What Dripline has Meant to Me
- Happy 50th Birthday Wishes from AuSPEN
- PNDU's SNUG Camp 2024
- PNDU at AuSPEN's Scientific Conference, November, 2024
- <u>AuSPEN's Consumer Workshop, Brisbane, November, 2024</u>
- PNDU's Annual Social Gathering in Brisbane, November, 2024
- Love thy Neighbour a member story
- <u>Chris' HPN Family Holiday Road Trip</u>
- Dr Gil Hardy to Receive ASPEN Champion Award
- PINNT's Carolyn Wheatley Receives an MBE Award
- Thank You
- PNDU information: Membership, donations and contact information





Rare Disease Day parliamentary events:

- 1. RVA 11th February, 2025
- 2. APAA 11-12th February, 2025

What Dripline has Meant to Me

<u>Karen</u>

I've so enjoyed and appreciated the wide variety of articles in Dripline over so many years - from HPNer holidays; to funny experiences; to wonderful milestones; ideas and tips; clinical articles; PNDU news and achievements; and far more besides. Dripline has also always been specifically HPN and 'down under' focused. Well done Gillian and congratulations on such an amazing milestone of Dripline's 50th issue. Thank you!

<u>Sal</u>

Dripline, for me, has been a great way to encourage others and to be encouraged. By sharing my own adventures around Australia, hopefully I inspire others to do the same, and in return I also love to read about what others are able to do and conquer whilst living on HPN. I am continually in awe of my fellow HPNers. I also enjoy learning more about HPN and the tireless work of our amazing president and committee and all the advocacy and work with AuSPEN and the like to better our access to and healthcare experiences and quality of life.

<u>Mariann</u>

Dripline has been such an incredible resource for me, especially before my boy came home from the hospital for the first time. Learning from others' experiences and tips, particularly about setting up at home and getting out into the world, made such a difference. It gave me hope and inspiration about what's possible for our kids. I'm so grateful to all the PNDU members who share their stories and to Gillian, whose dedication make Dripline what it is today. It's a truly invaluable resource of knowledge, support, and community.

<u>Rachel</u>

I have learnt so much reading stories in Dripline. From travelling with PN, to dealing with storage of supplies. It is great for my daughter to see others who are on home on HPN.

Thanks for your hard work.

Denise

My hubby is a very new PNDU member, having started PN at home approx. 7 weeks ago. We found it reassuring that there is a community out there and I know it made me feel less isolated, and that 'we're not the only folks going through this'. I found Dripline, with the stories of folks travelling around Australia, really inspiring. The website was so beneficial as well, especially when I went to the Resources Tab and found out about the electricity rebate, which we applied for and now have on our account.

Jacqueline VW

I love reading Dripline. You always learn something new, or you find out that you're doing everything right and it makes you feel at ease. I also like the members stories. Like holidays or a day in their life's. Hobbies etc. Very much appreciated.

<u>Renee</u>

I deeply value each edition of Dripline. It helps me feel connected to the PNDU community – I am inspired by the personal stories which speak of enormous challenges overcome, great adventures, imaginative solutions to problems we face and profound connection with the range of emotions we share. I also learn a great deal from the professional input on relevant topics, the reports on conferences and relevant research undertaken and wisdom shared. Congratulations on achieving 50 editions of Dripline – keep them coming. Thank you, Gillian and all who have helped you.

<u>Julia</u>

When I first became the mum of a little one on HPN, I felt alone in our journey. Dripline connected me with my community then, as it still does today. I can't wait to read every new issue.

<u>Gillian</u>

In 2016 I developed PNALD (Parenteral Nutrition Associated Liver Disease) and my gastro was thinking I might eventually need a transplant, much to my shock. My hospital team tried a couple of things, but it was remembering an article on PNALD given to me as editor of Dripline and published not that long prior to this (issue 11 and also another article in issue 15), that made me remember the benefits of SMOF lipids in this situation. I gave my team the article to read, they trialled me on SMOF, and in a few months, my liver had repaired itself! A great outcome!

Wishing Dripline a Happy 50th Edition from AuSPEN

Editor's Note: PNDU is grateful for the close relationship that has developed over recent years with AuSPEN, Australasia's professional society for clinical nutrition.

AuSPEN would like to congratulate PNDU on 50 editions of Dripline. Over the past years AuSPEN has loved contributing to the Dripline newsletter and we strongly value our relationship with PNDU.

The Dripline newsletter is such an important link for people living with Home Parenteral Nutrition, and their carers. But Dripline is also highly valued by clinicians working in the area of home parenteral nutrition to stay informed and learn from people with lived experience.

AuSPEN is excited to continue to work with PNDU and strengthen our partnership, including continued contributions to Dripline for many years to come. Happy 50th Edition from all the team at AuSPEN.

PNDU SNUG Camp 2024

Editor's note: PNDU is grateful to the Steve Waugh Foundation for providing the recent SNUG (Special Needs Unlimited Group) camp for our HPN families to enjoy.

By Julia

One of the downsides of living with a rare disease can be social and emotional isolation, both for the person living with the condition and their loved ones. For children growing up with Intestinal Failure and relying on HPN, it is also a life that includes social and dietary restrictions, hospitalisation, feeling different to their friends and schoolmates, pain and discomfort, sometimes being very unwell, and always having some uncertainty about their future. As parents and carers, we do what we can to be a buffer for our kids, but their reality is also our reality.

So, when I heard about SNUG Retreats Program, run out of the University of Newcastle with the incredible support of the Steve Waugh Foundation,





I was very excited. Since 2009, these camps have provided a unique break for families of children living with rare conditions. There is nothing else like this in Australia! I'd heard that PNDU had been involved with SNUG and had a camp in 2017, so with Covid restrictions eased, I contacted the lovely Liz at



SNUG and we booked another camp for PNDU.

On November 15, 2024, six PNDU families with seven fabulous HPN warriors, varying from toddler through to mid-teen, along with their siblings, gathered together at a beautiful bush setting on the banks of Lake Macquarie, NSW. A seventh family, unfortunately, had to pull out at the last minute due to illness. Families travelled from Queensland, Victoria, NSW and the ACT but distance was soon



forgotten as kids quickly made new friends and parents unpacked sooo much medical luggage. Volunteer helpers, led by Liz, were there to greet us and show us to our rooms. Each family had their own room with an ensuite in one of two dormitories, with a large, shared space in each to socialise and a kitchen for snacks, beverages, and fridges to store TPN and meds.

A short walk away was a huge hall where three meals a day were provided by the facility's kitchen staff. Meals were lovely and even better when we didn't need to purchase, prepare or clean up afterwards. We were all very well fed over the four days of the SNUG Retreat. Kids quickly decided on seating arrangements, with adults down one end of the long



tables and children claiming their own space.

Our camp days were full of fun and exciting activities, including ice-breaker craft, making name badges, archery, fishing from a pier, colouring and games, Christmas wreath-making, slime craziness, music therapy, movie night, learning how to make a camp fire, and some of the bigger lads went mountain bike-riding while the younger kids hit the swimming pool.

For us grown-ups, it was lovely being able to sit back

and chat with people who just get it! We shared tips and tricks. We also shared heartwarming moments such as watching the special power of peer support as our children did things they'd previously refused - but were willing to try because they were with a group of kids just like them.

I am hugely grateful to SNUG and the Steve Waugh Foundation for making this wonderful opportunity possible for our children and their families.

A quote on SNUG's Instagram spoke well for all of us. "I never dreamt it would be possible to meet as many families going through a similar journey as my own. I have never met as many brave people in my life. To see so many wonderful children like my own so happy and content around each other was just incredible."

















The AusPEN Conference 2024

Once again, PNDU had the privilege of being represented at the recent AusPEN Conference "The Many Faces of Clinical Nutrition". This annual event, which brings together leading experts and healthcare professionals focused on clinical nutrition, was held on 14th - 16th November 2024 at the Brisbane Convention & Exhibition Centre, Queensland.

The AusPEN Conference began with an engaging pre-conference program that set the tone for the main event. Designed to provide specialized insights, the pre-conference sessions included the HPN Symposium, which focused on practical and clinical advancements in Home Parenteral Nutrition (HPN). This symposium addressed key challenges, such as central line infections and transitioning from paediatric to adult care. For the main conference event, this year's special guest speaker was Dr. Carla Prado, Director of the Human Nutrition Research Unit at the University of Alberta, Canada, who along with other amazing speakers shared expertise on sarcopenia, body composition, and clinical nutrition- topics of importance and impact for the HPN community.

The AuSPEN Conference continues to be a vital platform for education, advocacy, and connection between PNDU, PN clinicians and industry. PNDU's inclusion helps raise awareness of our community and ensures that our community is represented through personal engagement. Through these personal interactions, we are able to more effectively connect with industry and clinicians and share updates on PNDU's activities and the many resources available to the community. PNDU was provided with an exhibition stand by AusPEN at the conference, which offered a fantastic opportunity to connect with clinicians and corporate representatives. Having been granted a well-positioned stand at the entrance in the exhibition hall, we were lucky to have had wonderful access to greet and speak with delegates. Throughout the 2-day conference, PNDU President, Chris, and Miranda (Secretary), were able to engage and connect with PNDU supporters and industry friends.

We would like to extend a special thanks to our friends Baxter Healthcare, Fresenius Kabi, and Takeda, as well as the numerous HPN clinicians who attended the AuSPEN conference who took the time to visit the PNDU display and chat to us! A heartfelt thank you also to Dr. Sharon Carey, president of AuSPEN, and AusPEN for inviting PNDU to participate and for their continued generous support of our community.



and Miranda with our friends at Takeda

PNDL

JVING WITH A DRIF

Consumer Workshop for PNDU Members



Another key highlight for our community is the dedicated Consumer Workshop organized specifically for HPN consumers and carers, which runs alongside the AusPEN conference every year. Held on November 16, 2024, at the Brisbane Convention & Exhibition Centre, this year's workshop provided a unique opportunity for consumers and carers to gain insights into Home Parenteral Nutrition (HPN) from expert clinicians. Organized with the assistance of Dr Sharon Carey, the workshop featured a range of informative sessions. Highlights included:

- An update on the HPN Registry by Dr. Sharon Carey
- An update on PNU activities and achievements by President Chris Walker
- A presentation "What is the Cost to Patients?" by Maddison Breen, Dietitian
- Update on the HPN Model of Care by Emma Osland, Dietitian
- Line Infections clinical update The Royal Brisbane & Women's Hospital Experience by Dr. Niwansa Adris and Dr. Paris Hoey; and
- Panel Discussion on Travelling with HPN featuring Freya Steindl (HPN Consumer), Emma Osland (Dietitian) and representatives from Baxter and Fresenius Kabi

This workshop was open exclusively to consumers and carers, both in-person and via online streaming, ensuring accessibility for members unable to travel to Brisbane. Feedback from participants highlighted the value of the expert-led sessions and the supportive environment provided. It was a very interactive session (!) with wonderful insights. Thank you to all the presenters for sharing their insights and to attendees for their questions; it was a fantastic morning of learning for our community.

Social Gathering in Brisbane

by Miranda

Following the conference, PNDU members had the chance to connect on a more personal level at a social gathering held at the West End Croquet Club in Brisbane. The event was hosted by Chris and myself, who welcomed 10 of our members. The weather was spectacular, providing the perfect backdrop for a lively afternoon of croquet games and conversations. Attendees included members from Queensland, New South Wales, Victoria, South Australia, and even New Zealand, making it a truly diverse and memorable gathering. These informal moments of connection allow members to share personal stories, HPN-life tips, offer support, and enjoy each other's company in a truly relaxed and welcoming setting.

Personally, I am so grateful and want to thank you to everyone who attended; it was such a great privilege to have a chance to connect with all of you! It really makes a huge difference to my family, particularly on this occasion for Ariel, to be able to talk to and meet young adult members. These in-person social events are such a wonderful opportunity to share.





By Denise

We receive PN supplies weekly and medical supplies monthly, but unfortunately the medical supplies this month were delivered to the wrong address: it was the correct street but the wrong number. I had a phone call from the daughter of the gentlemen who lives at the top of the street who it was accidentally delivered to, and although he is not PN (he does dialysis) he receives medical supplies from the same company. After talking with his daughter, I found out she really had no-one to contact if she needed someone close by to do a quick check on her Dad if she felt that something was wrong, so I offered to do that if ever she was concerned. She was so grateful, she had tears in her eyes and threw her arms around me. Now that my hubby is having PN at home, it's made me so aware that with the busy lives we lead, that we just don't know what's going on in our own backyard (or street). I'm also forever grateful for the wonderful support we receive from the specialist nurse and our family.

HPN Family Holiday Road Trip



Words by Chris

Jordan, 15, and Logan, 12, had previously visited Seaworld and Movie World, but they were too small to ride the rollercoasters and larger rides. Back then, they spent their time watching shows and parades, with a few rides in the kiddie's corner. Their older brother Dylan enjoyed the larger rides, while Jordan and Logan eagerly measured their height, only to find they were too short. We promised to return when they were tall enough.

The next few years were tough for our family due to the pandemic and the loss of loved ones. We needed a break, and what better way than a family holiday to QLD, visiting relatives and theme parks? After discussing with Jordan and Logan's hospital team, we got a cautious OK to proceed, provided the boys met certain height, weight, and medical goals. Logan was thrilled and eagerly awaited his height checks. After more than four years, Logan finally reached 140 cm, and we began planning our holiday.

Planning a two-week holiday 1,000 km away for two HPNers was a massive task. We coordinated HPN schedules, contacted hospital teams, and developed emergency plans. Our previous holiday during the bushfires taught us the importance of planning. We worked closely with our hospital team and Baxter's homecare team to organize everything.

Finding accommodation for four adults and three children within our budget was crucial. We chose a holiday house at Sylvan Beach on Bribie Island, central to theme parks, Australia Zoo, and our relatives. Baxter confirmed they could deliver to Bribie Island, and our planning began.

With accommodation confirmed, we planned our road trip from Newcastle to Bribie Island. We meticulously packed HPN supplies and consumables into plastic tubs for easy transport.





We prepared individual HPN take down and dressing packs for each boy. We packed our vehicles carefully to conduct HPN take downs and dressing changes safely.

Our journey began at 4 am on a Monday. Baxter confirmed HPN delivery dates, so we only had to transport two bags of HPN for each boy. With four adults, three children, and a ton of supplies packed into three vehicles, we hit the highway. The boys were excited and knew the name of every ride at Seaworld and Movie World. After a few hours, we arrived at our first stop, Nambucca Heads service centre, for a break and to disconnect the boys' HPN. We continued our journey with stops at Ballina and Sleepy Hollow rest area before reaching Bribie Island.



Day 3: A rest day and the first HPN delivery day. We explored the area, walked on the beach, and relaxed before meeting relatives for dinner.

Day 4: Movie World. We arrived early to beat the traffic and enjoyed rides, shows, and the grand parade. The excitement never diminished for Jordan and Logan.



Day 5: Another rest day and the second HPN delivery. We relaxed, enjoyed cold beverages, fresh prawns, and a BBQ.

Day 6: A picnic day for Brooke's 40th birthday. Our QLD family joined us for a wonderful day in the park at Sylvan Beach.



Day 7: A family day at Seaworld with our QLD relatives. We arrived early and were surprised by the small crowd. The boys enjoyed the rides and shows with their cousins. Logan rode the vortex ride 10 times. We had an amazing day and headed back to Bribie Island.



Day 8: Australia Zoo. We arrived early and were surprised by the lack of crowds. Logan assigned himself as our guide for the day. We enjoyed the animal encounters and shows. The heat and humidity were intense, so we took frequent breaks. A thunderstorm hit before closing time, and we sought shelter in the gift shop before touring the zoo hospital.



Day 9: A return trip to Movie World. Despite the weather, the boys were excited. We split into groups and enjoyed the rides and shows. An afternoon thunderstorm closed some rides, but we ended the day with a friendly competition on the Justice League 3D ride.

Day 10: Another rest day and the final HPN delivery. Logan's HPN was lost in transit, so we contacted our hospital team and prepared to take Logan to the hospital if needed. Thankfully, Logan was allowed a night off HPN, and he enjoyed his newfound freedom.

Day 11: We rescheduled our plans to receive Logan's HPN delivery. With the weather turning bad, we stayed indoors for board games and movies. My van's gearbox failed, so we devised a new plan and transported non-essential items to relatives in Caboolture.

Day 12: The road trip home. We packed essential equipment into two small vehicles and left at 7 am. We made several stops along the way and arrived home at 9 pm, realizing our holiday was over but grateful for the memories we made.



Our family were refreshed and grateful that we took the time to touch the sun.

Dr Gil Hardy to Receive ASPEN Champion Award



Editor's note: Dr Hardy is a retired emeritus Professor of Clinical Nutrition, who helped found PNDU, served on the Management Committee for many years and is a Life Member of PNDU. He has published over 250 papers on Parenteral Nutrition and has written several articles, and adapted others, for Dripline. He is always willing to assist PNDU in any way he can. A well-deserved accolade.

The ASPEN Board of Directors is pleased to announce that Gil Hardy, PhD, FRSC, FASPEN, has been selected to receive the 2025 ASPEN Champion Award for his significant and sustained contributions to the association.

Dr Hardy is an emeritus professor of clinical nutrition at Massey University, Auckland, New Zealand. He will receive the Champion Award at the ASPEN 2025 Nutrition Science & Practice Conference in Columbus, Ohio.

Worldwide Influencer

"Throughout his long and illustrious career, Dr Hardy has been one of the most influential leaders in clinical nutrition and its very strong advocate on a global level," said ASPEN President Dr Ajay Jain, MD, DNB, MHA. "He has inspired and mentored researchers and clinicians on five continents, developed guidelines and advisory reports for professional societies and regulatory agencies around the world, and conducted research that has improved patient care everywhere."

Decades of Service

Dr Hardy has been associated with ASPEN since he crossed the Atlantic in 1977 to attend the first ASPEN congress. Since then, he has served on the Research, Membership, Awards, Publication Review, and FASPEN Awards committees. Dr Hardy founded and was the first chairman of ASPEN's International Clinical Nutrition Section, served on the Board of Directors, and represented ASPEN on the International Human Rights for Clinical Nutrition working group. He has provided leadership as vice



president of AuSPEN and a board member of the West African Society of Parenteral and Enteral Nutrition (WASPEN). He is also a founder and life member of the British Pharmaceutical Nutrition Group and has been an active member of the European Society of Clinical Nutrition and Metabolism (ESPEN) since

its inception. Dr Hardy has earned acclaim and recognition worldwide. In 2014, he was presented with ASPEN's Distinguished International Nutrition Support Specialist Award for his international presence, commitment to multidisciplinary clinical collaboration, and many contributions to advancing clinical nutrition. The following year, he was named an ASPEN Fellow.

Steeped in Experience

Born in the UK, Dr Hardy received his BSc in chemistry from the Bristol College of Science and Technology and his PhD in biochemistry from the University of Bath. He conducted research in the Metabolic Research Laboratory of Nobel Prize Winner Professor Sir Hans Krebs at the University of Oxford. Working with colleagues at Baxter Labs and St. Marks Hospital, London, Dr Hardy developed the first disposable 3-liter parenteral nutrition bag for patients with intestinal failure. Dr Hardy's extensive research on lipids, glutamine, micronutrients, and, most recently, chyme reinfusion therapy has resulted in more than 250 publications. He is a sought-after guest lecturer, and his international reputation in pharmaceutical and clinical nutrition has earned him awards and honorary fellowships from Asia, Australasia, Europe, Latin America, and the USA.

Educator and Mentor

Dr Hardy was a professor of pharmaceutical nutrition at Oxford Brookes University in the UK for 5 years and later at the University of Auckland in New Zealand. He was also a professor of clinical nutrition at Massey University, where he helped establish a new research-focused master's degree in nutrition and dietetics.

"Dr Hardy's track record in basic and clinical research is impressive, but his exceptional commitment to education truly sets him apart. His research excellence and highly rated performance in teaching and academic service make him a true champion," said William Manzanares, MD, PhD, professor of critical care medicine at the Universidad de la República (UdelaR) Montevideo, Uruguay.

"Professor Hardy's influence extends far beyond the research lab. He encourages clinicians like myself to become future leaders in complex clinical nutrition. He not only offers technical expertise and in-depth knowledge but also shows a genuine commitment to the personal and professional growth of his mentees. I know that many others who have worked with him feel similarly," said Advanced Clinical Dietitian Yizhou Andrew Xia, MSc, NZRD, Advanced Clinical Dietitian, Health New Zealand.

Shake His Hand

Dr Hardy is admired worldwide for his enthusiasm, knowledge, and expertise in clinical nutrition, particularly in parenteral nutrition and micronutrients. Please take the opportunity to congratulate and thank him for his service to ASPEN and the many ways he helped advance clinical nutrition. In New Zealand, the Maori would say, "ngā mihi."

PINNT



PINNT is incredibly proud to celebrate our Chair, Carolyn Wheatley, on being awarded an MBE as part of the King's New Years Honours List for 2025. This prestigious recognition highlights Carolyn's unwavering dedication to supporting individuals living with intestinal failure and her tireless efforts to enhance the quality of life for people relying on artificial nutrition. Carolyn Wheatley, Chair PINNT, awarded an MBE in the King's New Years Honours List 2025.



Carolyn's journey, rooted in her personal experience, has been a beacon of hope and inspiration for many. Her leadership in PINNT has fostered a community where patients feel empowered and supported, and PINNT has a voice in many healthcare and service provider settings.

We are thrilled to see her commitment and hard work honoured in such a meaningful way. Congratulations, Carolyn, on this well-deserved accolade!

Mr Richard Shawyer-Clarke, Trustee

Read more via https://bit.ly/40gmlcw



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 \$1,040.

J. Lee and G. Banner

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 USTERED for specific advice about your financial rights and obligations.)

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