



DRIPLINE



PNDU
Parenteral Nutrition Down Under

Read about PNDU MC members, Chris (president) and Gillians (vice president and Dripline editor's) time in Auckland at the AuSPEN Annual Scientific Conference, as well as the Auckland social gathering. Read PNDU adult professional award winner, Emma Osland's, response and thank you, as well as an update on a project that is very important for all HPNers – the HPN Model of Care project. Discover a possible alternate type of PN used by a member for travel when a fridge isn't available; and we reprint Julia's article about toys and resources that she has discovered to help her little HPNer adjust to life on HPN. Karen remembers, Rosie, a past PNDU member as well as updating us on the World's first IV Passport Award; and most importantly: save the dates for upcoming events, especially February 3rd, for the Sydney social gathering and a second PNDU SNUG camp later this year. I hope you find some useful and/or informative articles in this issue.

Gillian



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

"Alone we can do so little; together we can do so much" – Helen Keller

Would you like to learn new skills? Or do you have skills you would like to improve?

- Leadership & Teamwork, Mentoring & Training
- Organisation, planning, time management & problem solving.
- Book keeping Treasurer.
- Communication & social media.

Volunteers enjoy better physical and mental health, make new friendships and enjoy new social experiences.

"As you grow older, you will discover that you have two hands – one for helping yourself, the other for helping others" – Audrey Hepburn

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 meets online via skype every 6 – 8 weeks and stays in regular contact via email.

As a result of the great work done by the Management Committee - planning PNDU events and social gatherings; organising HPN Workshops; Awareness Week activities; attending conferences and advocating for all HPNers down under; administrating the PNDU Forum, Facebook Page, Instagram and Website - 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.

"Unless someone like you cares a whole awful lot, nothing is going to get better. It's not" – Dr. Seuss

Upcoming Events



Save the Dates for the following free of charge events

PNDU Social Gatherings 2024

2024 is shaping up to be another busy year for PNDU and it would be wonderful if our members are able to come together and be part of something special. PNDU has organised several social gatherings for 2024 with dates already set for Sydney and Brisbane, keep an eye out for other gatherings and events throughout the year.

PNDU Gatherings are great opportunities to meet other HPNers, carers and their families and get to know each other during a relaxed afternoon.

Sydney Social Gathering

It's hard to believe it's been nearly a year since our last Sydney PNDU get together!

PNDU HPNers, carers and their families are all invited to our next Sydney Social Gathering.

Saturday 3rd February 2024

Where: Sal's Home Doonside (thanks Sal and family for offering to host this event.)

Time: - 12:30 – 4:30

For more information and to RSVP please email contactpndu@gmail.com

Brisbane Social Gathering

Open to all PNDU HPNers (adults and children), carers and their families.

Saturday 16th March

11am – 3pm

Roma Street Parkland, 1 Parkland Blvd, Brisbane City

For more information and to RSVP please email contactpndu@gmail.com

PNDU Annual Social Gathering

Sunday 17th November Brisbane

Venue (TBC)

HPN Consumer Workshop

PNDU is very grateful to be working with AuSPEN to deliver another HPN Consumer workshop alongside the AuSPEN Conference in Brisbane 14th – 18th November 2024

The AuSPEN HPN Consumer Workshop is a unique opportunity to learn more about your HPN from expert clinicians working in the field. This event is open to all adult HPNers, their carers and adult carers of children on HPN only.

More information will be provided in Dripline and on the PNDU forums during 2024

Expression of Interest (EOI) to attend these events

PNDU Travel Sponsorship to attend these two events in Brisbane

PNDU will offer Two Travel Sponsorships, to the value of \$600 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).

More information and details on how to apply will be provided in the April edition of Dripline

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

Please forward EOI to attend and EOI for travel sponsorship to contactpndu@gmail.com

Upcoming Events for PNDU advocacy in 2024

- a) Patient Voice Initiative (PVI) & CaPPre Patient Based Evidence Research Workshop 26th February Canberra
- b) Australian Patient Advocacy Alliance (APAA) Summit 27th – 28th Feb Canberra
- c) Rare Voices Australia (RVA) rare disease day Parliamentary event Canberra 29th Feb

PNDU Respite Retreat for HPN children under 18 years and their families. 15th – 18th November 2024

PNDU is excited to announce that we are organising our second Respite Retreat for families - SNUG Camp 15th – 18th November 2024 – A wonderful respite retreat for eligible HPN Children 18 years and under.

For more information on the first PNDU SNUG Family Retreat please see the 21st Edition of Dripline Newsletter www.pndu.org https://drive.google.com/file/d/16KtJORSednfhUHxCJUR8p6LML2nf_HSE/view

The SNUG (Special Needs Unlimited Group) program provides retreats for families caring for a child with a rare health condition. Coordinated by PNDU through the Family Action Centre at the University of Newcastle and funded by the Steve Waugh Foundation, SNUG combines a family holiday with coordinated medical support, aiming to help families by providing better access to medical care and creating support networks. The retreats are held at the Point Wolstoncroft Sport and Recreation Centre on the shores of Lake Macquarie, a short drive south of Newcastle, NSW and about 2 hour's drive north of Sydney.

The SNUG program provides organised fun activities for special needs children and their siblings, access to recreational facilities for the whole family, activities for families to get to know each other so enduring support networks can be formed between families who have children with similar disabilities, and a team of trained volunteers to assist families during their stay.

The PNDU SNUG Family Respite Retreat is open to all Australian PNDU HPN Children (Under 18 Years) and their families. (PNDU apologises to our members in New Zealand – we are unable to extend an invite to you at this time)

The respite retreat, including all food and activities, are fully funded

Please note: - Travel to and from the respite retreat is not funded and will be the responsibility of the attending family.

PNDU will offer 2 travel sponsorships of \$600 each for families who live outside of NSW to offset travel costs for families who haven't yet attended this camp before.

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

For further information and to obtain an application form please contact PNDU by email contactpndu@gmail.com





By Gillian

Exhibiting at the Annual AuSPEN (Australasian Society for Parenteral and Enteral Nutrition) Conference is PNDU's main way of introducing our support group to hospital clinicians – dietitians, nurses and doctors – so that when they have patients on HPN, they are able to refer them to us for support when they are home. For this reason, PNDU pays to send two MC members, usually the president and one other, to man the exhibit and to talk to conference attendees over the course of two days.

Highlights

- The day before the conference opened, Chris met with AuSPEN president Dr Sharon Carey for a two-hour discussion of common HPN interests.
- In Dr Carey's opening speech at the conference, as well as thanking the Gold sponsors, she specifically thanked PNDU for our presence.
- In Professor Simon Lal's (Gastroenterologist and Clinical Lead, Salford Royal Intestinal Failure Unit) keynote talk, he specifically spoke of the importance of support for patients going home on PN, for them as well as their family members.
- Professor Lal also spoke of the impact of HPN on the various members of the family and the importance of having a psychologist as part of the hospital team.
- We were approached by many clinicians, mainly from parts of New Zealand, who didn't know of PNDU and were pleased to be able to have a support group to which they could refer their patients.
- We were welcome to attend any of the talks that interested us.
- We were able to chat in a relaxed situation with staff from industry companies which give their support to PNDU – Baxter Pharmaceutical, Fresenius Kabi, and Takeda. As well as familiar faces, we met several new (to us) staff members.
- We were able to present the PNDU Award for Adult Parenteral Nutrition Professional of the Year to dietician, Emma Osland, who said, very sincerely, that winning this award from patients means much more to her than recognition from peers. Wonderful feedback!
- We gave out many PNDU handouts, including business cards, toilet cards, restaurant cards, a find-the-word with many HPN related words, Dripline issues, travel booklets and more.

All in all, a very busy and worthwhile few days of spreading the PNDU word, followed by the PNDU HPNer social gathering.



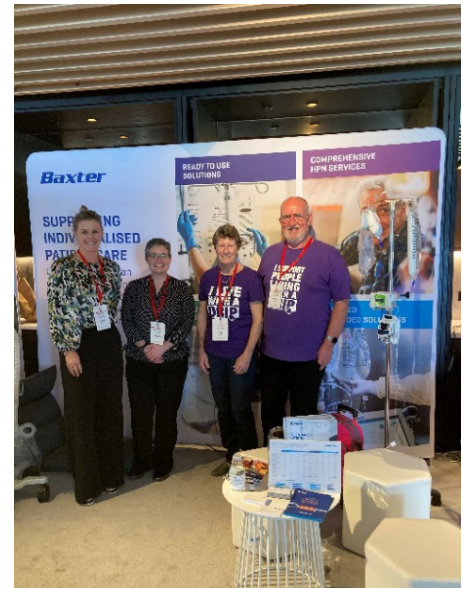
Gillian and Chris at our stand.



Chris speaking to some of the clinicians



Gillian and Chris with interested clinicians



Baxter staff Hanna and Claudine (Nicola absent) with Gillian and Chris



Fresenius Kabi staff Michele Pink, Fiona Bainbridge, and Donal McGoldrick, with Chris and Gillian



Takeda staff Sue Rudolph and Chris Wiggins, with Gillian and Chris



Chris and Gillian with AuSPEN president Dr Sharon Carey



Chris presenting Emma Osland with her PNDU Adult Professional of the Year Award.



Sunday 12th October was the day of the annual PNDU Social Gathering, occurring in conjunction with AuSPEN's annual conference. Chris had booked a venue through Auckland Council, a small hall with kitchen facilities, situated on a park with play equipment. Chris and I went shopping for basics – tea, coffee, milk, cake – then caught a taxi to the venue. After a bit of confusion, we found Outhwaite Hall – car park and entrance around the corner from its street address. Opening the hall went smoothly – Chris had to ring a number of a council worker who was rostered on to remotely unlock the door. Upon entering, we discovered that the full kitchen meant a fridge, stove, kettle and sink (no plug), but no cups/mugs for a hot drink, nor plates nor cutlery to cut up and serve cake – how embarrassing! However, PNDU get togethers aren't about food, for obvious reasons, so we were confident that the members who were able to come wouldn't complain.

Seven PNDU members, plus Chris and myself, were able to attend. It was lovely to see Bev and her adult daughter, Judy; Jude and her husband, David; Lisa and her mum, Anne; and Thiloma and her baby, Lilith.

Bev and Jude were both from the Hamilton area, and had travelled 1 ½ -2 hours to attend. Both were relatively new to HPN – less than a year – and it was

interesting to share experiences with them, as well as learn from them. For example, I'd forgotten that PN makes a good plant fertiliser, diluted 10x, so Jude uses the leftover bits for her vegetable garden.

Unfortunately, Lisa and Anne could only stay a short while and had gone by the time Thiloma arrived with her gorgeous baby.

One family of 6, with a child on HPN, couldn't make it due to illness, and another couple didn't make it, reason unknown. However, life on HPN can be very unpredictable, so we were grateful for those who did come and made it a worthwhile event.

PNDU's next annual social gathering will be in Sydney, February, 2024.



A beautiful venue, Outhwaite Park, Grafton



Anne, Lisa and Chris



Judy, Bev (HPNer), Jude (HPNer) and David



Our HPNers (Lisa had left)
Thiloma (ex-HPNer), Bev, Gillian, Jud



Judy, Bev (HPNer), Jude (HPNer) and David

PNDU Lifetime Award



By Gillian

Last year, it was announced that the PNDU Lifetime Award – our highest accolade for a member who has given active and on-going support to PNDU – was awarded to Renee (see issue 45 for details). This award is a perpetual trophy, kept by the recipient until it is awarded to the next person. Usually it is presented by the president, but as Chris lives near Newcastle, and Renee lives down the south Coast, this made it tricky. Chris was happy to visit Renee, but finding a mutually suitable time proved a challenge. Finally, a date was made in mid-January...but on the way, Chris' car's engine caught fire, understandably shocking him. Luckily, he escaped safely...with the award! Well done, Chris!

Since Chris is currently without a car, it was decided to express post the trophy to Renee instead. Luckily, it was delivered safely, and her husband took the photo to prove it. Congratulations, Renee, and thanks for your help, especially with Facebook.



Renee with her PNDU Lifetime Award



PNDU is grateful for the invitation and opportunity provided by AuSPEN to have Consumer representation within the AuSPEN working groups and be able to provide input into the development of a HPN Registry and a National HPN Model of Care.

The objective of the working groups is to develop guidance documents to support practice around the delivery of HPN services that is of high quality within the Australasian setting and to lead the development, implementation and monitoring of the AuSPEN HPN Registry.

What is a registry and why are they important

Rare diseases are recognised as a public health priority and a global health issue because of their impact on the individual and the health system. Rare disease registries are fundamental to supporting collaborative research that will improve outcomes for people with rare conditions by increasing knowledge and supporting health.

Rare disease registries are important for several reasons, they help collect and organize data on rare diseases, which can be used to improve patient care, develop new treatments, and advance research. Registries can also help identify patients who may be eligible for clinical trials, which can lead to the development of new treatments. Additionally, registries can help researchers better understand the natural history of rare diseases, which can help them identify new targets for treatment. Finally, registries can help rare disease patients connect with others who have similar conditions, which can provide emotional support and help them feel less isolated.

A HPN Registry will provide the basis of information required to develop the HPN MOC and be a useful tool for advocacy to government for change to current HPN funding and management in Australia.

Below is an update from AuSPEN on the HPN Registry and HPN Model of Care. PNDU would like to take this opportunity to thank AuSPEN and everyone involved in progressing these projects.

PNDU President – Chris

AuSPEN HPN Registry Update

The launch of the AuSPEN Australian HPN Registry is planned for March this year. All adult and paediatric HPN sites across Australia have been invited to participate. There are a number of levels of data collection, including service level information (staffing levels and total number of people being care for on HPN), clinical information such as line infection rates and readmission rates, and consumer-level information (quality of life and patient-outcomes). Where consumer level data is not collected routinely, our HPN consumers will be invited to participate and consent for this information to be gathered. The registry has ethics approval through the Sydney Local Health District under a National Mutual Agreement.

AuSPEN would like to thank PNDU for their ongoing input and support in the development of the registry. Regular updates will be provided to all sites and PNDU as we progress this project.

Sharon Carey

President, AuSPEN



Since 2018 the AuSPEN Model of Care (MOC) working group have been developing the resources and data required to form a strong foundation for advocacy and positive change to how HPN is provided in Australia.

| AuSPEN Model of Care Work – Summary to Date | | | |
|---|---------|---|---|
| 2018-2019 | Phase 1 | Development of Framework for Quality HPN Care https://pubmed.ncbi.nlm.nih.gov/31441085/ | Framework provides an evidence-based structure for HPN care to underpin MOC |
| 2020-2022 | Phase 2 | National survey of Centre's providing HPN to determine current clinical resourcing of HPN services in Australia Home Parenteral Model of Care Phase 1 Report | Results provided baseline data on key structural and process indicators outlined in the Framework. This will underpin further advocacy work and tie in with the HPN registry for ongoing monitoring of these. |
| 2023 | Phase 3 | Planning for co-design process by which to describe what the MOC should be | Basis for advocacy to government for change to current HPN management in Australia |

2023 has been a year of regrouping and planning for the MOC working group. With the changes to the internal structure of HPN projects within AuSPEN, our working group reformed in 2022. We said goodbye to some of our original team (Dr Julie Bines, Dr Peter de Cruz, Dr Callum Pearce, Dr Helen Evans, Suzie Daniells, Kath Angstmann, Catilin Watson, Varsha Asrani, Kirsty McDowell, Helen Shalley, Margie O'Callahan (retired), Azmat Ali (retired), Lynn Jones (retired), Jane Gillard (sadly passed away, I understand)) and welcomed some new members (Dr Darren Wong, Emma Bidgood, Claudia Borg, Clara Newsome), while a few of us have continued on (Emma Osland, Dr Kathleen McGrath).

After finalizing the national survey results, we have moved our sights onto the third phase of this project – working out what a national model of care should look like, according to what HPNers, their families and carers, clinicians and HPN services think it should look like.

Because this phase of the MOC project requires a different set of skills to the previous ones – ones that as clinicians we don't have! - we have been consulting with some experts in the field of consumer engagement and co-design to guide us through the process we will need to undertake (many thanks to Drs Lucy Holland and Adrienne Young, and Health Consumers Queensland). There has been A LOT of discussion around how this would best be navigated from everything to whether this meets the definition of research and whether ethical approval will be required (so far, advice has been it doesn't), to how do we practically manage the scope required - which will need to cover adults and paediatrics, metro and non-metropolitan areas, all states and territories.

But in short – we have a roadmap that we will start to bring together in 2024. We are looking forward to working more closely with PNDU throughout this process as it moves forward.

Expressions of Interest (EOI)

The AuSPEN HPN Model of Care working group will soon be seeking expressions of interest from HPNers interested in becoming a member of the working group as we work towards finalizing the process by which we arrive at what a HPN model of care should look like in Australia. A formal Expression of Interest process

will be undertaken once we have sorted out some further logistics.

Who will we be looking for?

One or two people receiving HPN and/or supporting someone receiving HPN who would be keen to take an active role in the planning and implementation of the process the obtain the thoughts, experiences and opinions of other HPNers and their carers/families that will help shape the model of care developed through a co-design process.

Those who have had several years on HPN would be ideal, and availability during office hours would also be desirable.

Why are we looking for a consumer member of the working group?

Though the specifics of the project are still being determined, we are working towards undertaking a codesign process to determine what a model of care for HPN should look like in Australia. Codesign in an approach to health service planning that brings patients and carers alongside clinicians and administrators to combine their knowledge and lived experiences to improve health care services. For this reason, consumer representatives are invited to join the working group to help influence the direction of the whole project and be involved in how it is run and how the data is interpreted, not just provide input into the results and outcomes.

Further information should be available soon and will be communicated through PNDU.

Home Parenteral Model of Care Phase 1 Report



AuSPEN MOC Working Group

2023-10-24

Final Summary Report

Please accept our sincere thanks for your ongoing support of this phase of the model of care project. You have enabled AuSPEN to gain valuable insight into the state of funding for the provision of care across Australia. Below you will find summary tables and graphs from this study.

Caseload

Centres were asked to quantify the number of patients they cared for classified according to treatment. These numbers do not reflect overall caseload, as patients who are seen by the service but do not have type III intestinal failure are not reported.

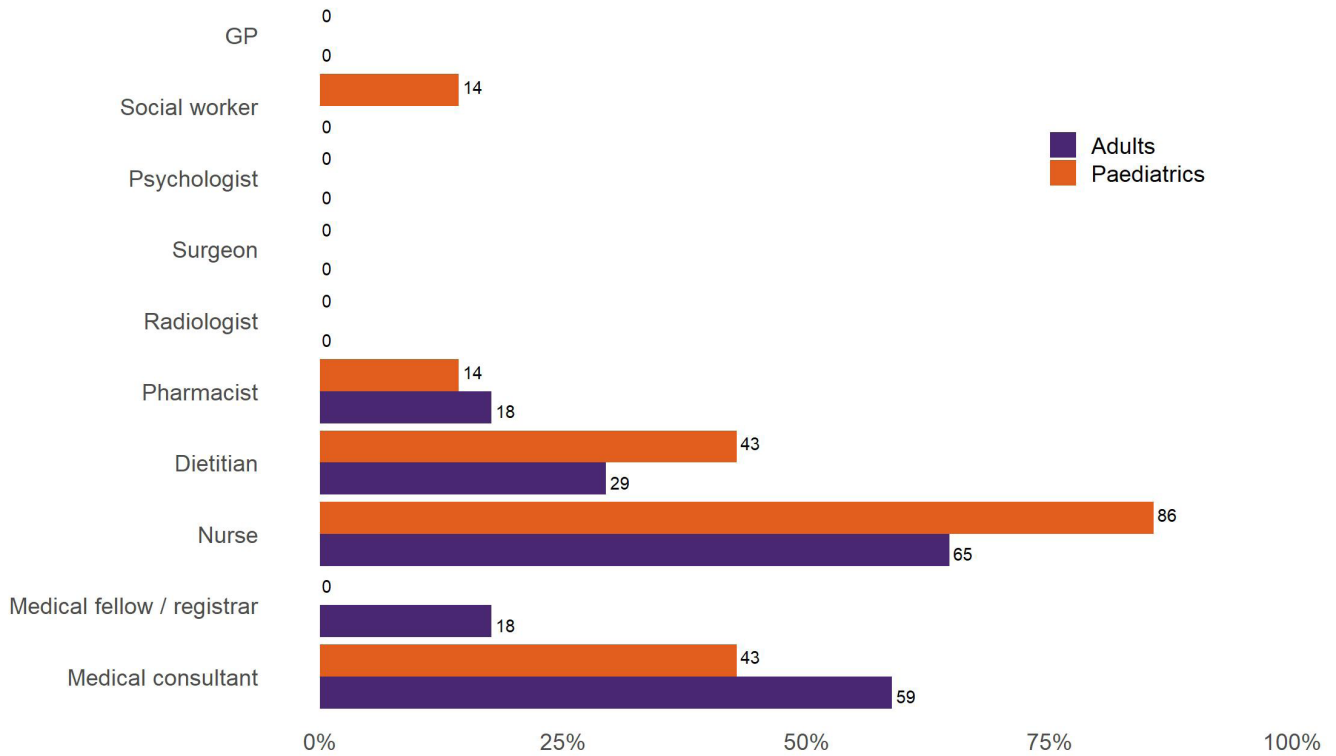
| Patient classification | | |
|------------------------|-----------------------------|---------------------------------|
| Patient Therapy | Adults, N = 17 ¹ | Paediatrics, N = 7 ¹ |
| PN only | 9 (1 - 30) | 9 (6 - 14) |
| IVT only | 1 (0 - 8) | 0 (0 - 8) |
| Teduglutide only | 0 (0 - 5) | 0 (0 - 4) |
| Teduglutide and PS | 1 (0 - 5) | 1 (0 - 3) |
| Median (0% - 100%) | | |

HPN Team Members

These data aimed to fulfill the primary goal of phase I of the model of care project, namely to identify heterogeneity in funding / staffing between centres providing care for patients with type III intestinal failure. Graphs and statistics summarise data from all participating centres.

Team composition

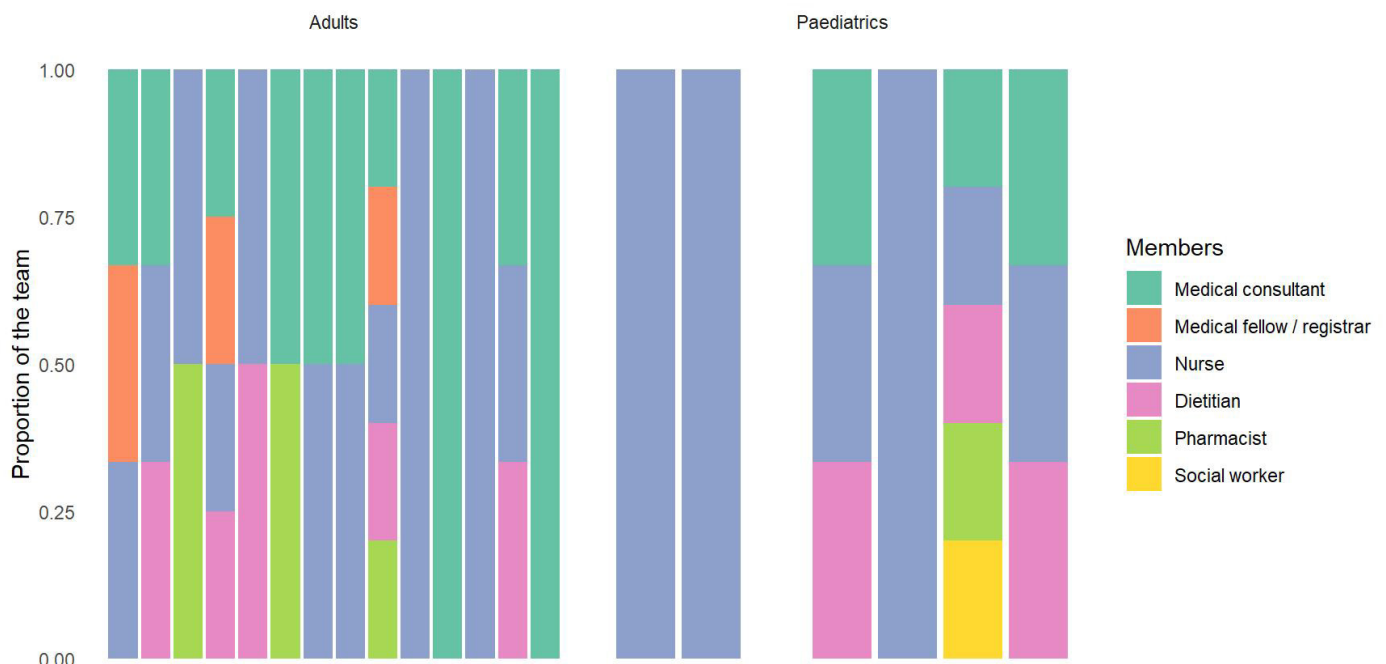
Staff funded for provision of HPN services



This graph shows the percentage of centres with funding for a given staff member specifically for the purpose of providing care to HPN patients.

The graph below provides a more granular look at the breakdown of funded staff members across centres.

Staff funded at each HPN centre



Funded time per patient

Staffing levels were captured using a standardised Full Time Equivalent (FTE) measure. This assumes that 0.1 FTE equates to 3.5 hours of paid time. The table below shows the median weekly total FTE funded for staff providing HPN care. This was divided by the total number of patients to calculate the average time available to care for each patient.

Funded time per week

| Measure | Adults, N = 17 ¹ | Paediatrics, N = 7 ¹ |
|------------------------------|-----------------------------|---------------------------------|
| Weekly Total FTE | 0.6 (0.0 - 3.8) | 1.0 (0.0 - 3.3) |
| Minutes per patient per week | 7.0 (0.0 - 31.9) | 13.6 (0.0 - 34.7) |
| Median (0% - 100%) | | |

Audit and data capture

The following graph summarise the proportion of centres who have the capacity to routinely capture and audit data for key performance metrics in the management of patients requiring HPN.



Challenges in running an HPN service

The word cloud below aims to summarise the free text responses to an open ended question requesting respondents to describe the current challenges they face in running an HPN service. The centrality of the words and size of the font is proportional to the frequency that a given word occurs.



Finding representation in books and toys for young HPN kids



By Julia

As we were raising our family, which includes seven children we adopted who had been born in Korea, Taiwan, India and Papua New Guinea, I knew it was important that children see themselves represented in the books, toys and entertainment around them. It wasn't easy, but over the years I found many great resources for our kids.

Our older nine kids had grown up by the time our youngest, Syena, joined our family nearly three and a half years ago. She was born with Vanishing Gastroschisis and lost most of her small intestine and her ascending colon, resulting in Ultra Short Gut Syndrome. Now that she is a busy and social four-year-old, we are preparing for preschool next year.

Since Syena was a baby, I've looked for toys and books to show she is not alone in her life with HPN. Despite the internet bringing the world within reach, this has been much more challenging than the job I had gathering suitable toys and books for our older kids. There simply aren't as many toys and books available that normalise life for kids who use HPN.

When we joined PNDU, we were delighted to receive a little doll that was customised to reflect Syena's medical devices at that time ... a central line and a Mic-Key gastric button.

There are also people online who customise dolls at various sites including Etsy. I also found a wonderful organisation in the US called "Tubie Friends", whose volunteer surgeons "operate" on a soft toy the child's can pick from several options, to mirror the child's own medical equipment. Our beloved puppy was provided to Syena free of charge, with us just



paying for his shipping.

Through chats on various Facebook groups, as well as many searches of online bookstores, I found some fabulous children's books. Ours are aimed at children from maybe 3 years old through to around 10 or so. I love that all of them could be shared with a child's preschool or school class to better their understanding of the various ways you can eat.

My favourite simple book for little ones is "My

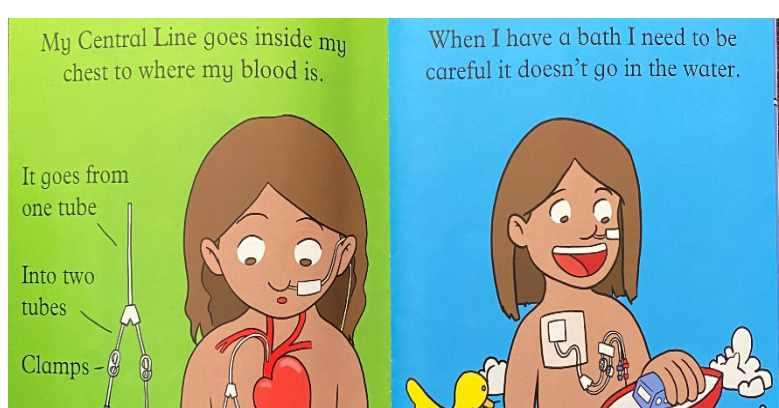
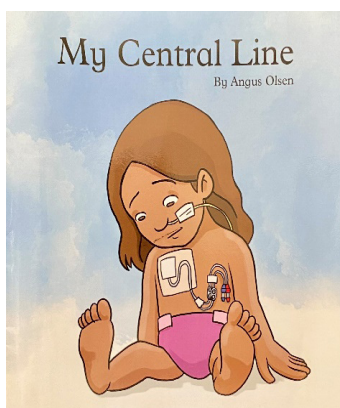
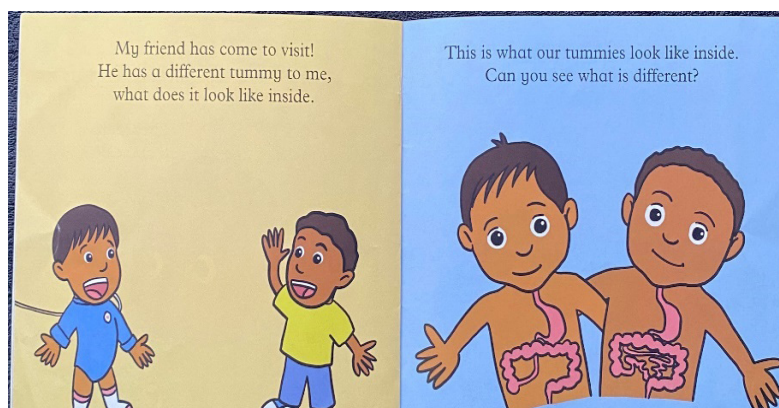
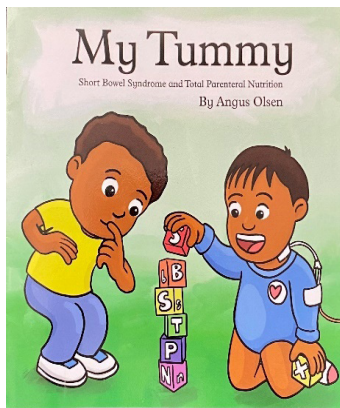


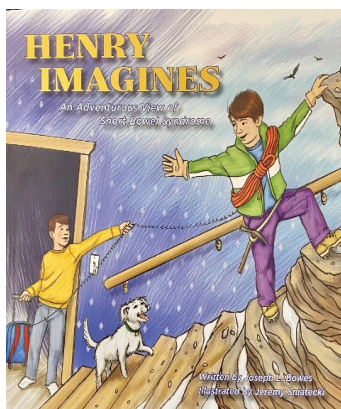
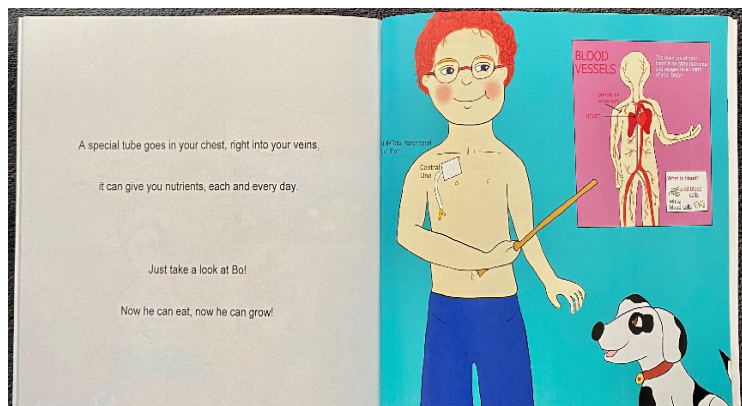
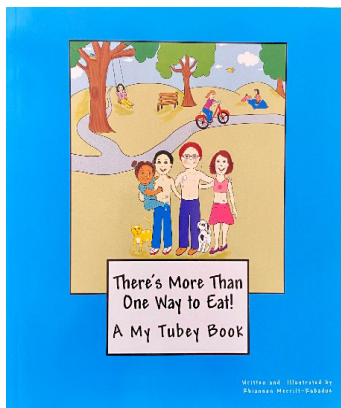
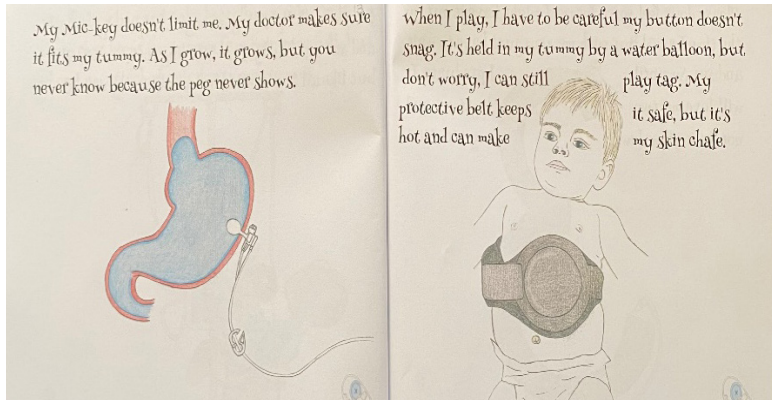
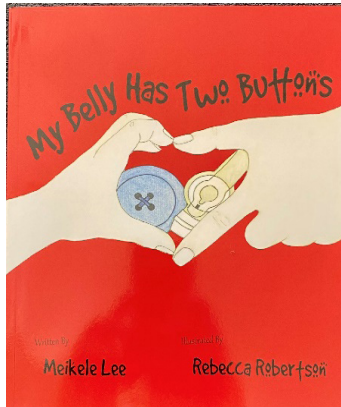
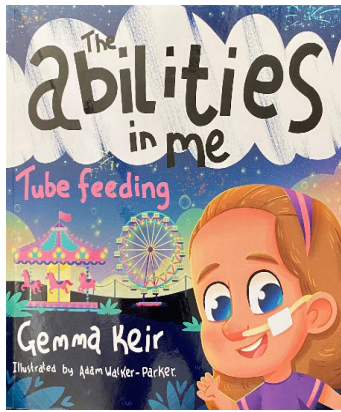
"Tummy" by Angus Olsen. Angus is an Aussie who was an illustrator for Disney when his small daughter was diagnosed with cancer. Through this harrowing personal experience, he found that hospital kids lacked books that talked of their reality. He has written many fabulous little books for children that relate to their medical lives and the illustrations are both simple and delightful. Angus has a Facebook group and a website, both called "I draw childhood cancer", where you can find all his books, many of which can be downloaded as pdfs free of charge.

Through chats on various Facebook groups, as well as many searches of online bookstores, I found some fabulous children's books. Ours are aimed at children from maybe 3 years old through to around 10 or so. I love that all of them could be shared with a child's preschool or school class to better their understanding of the various ways you can eat.

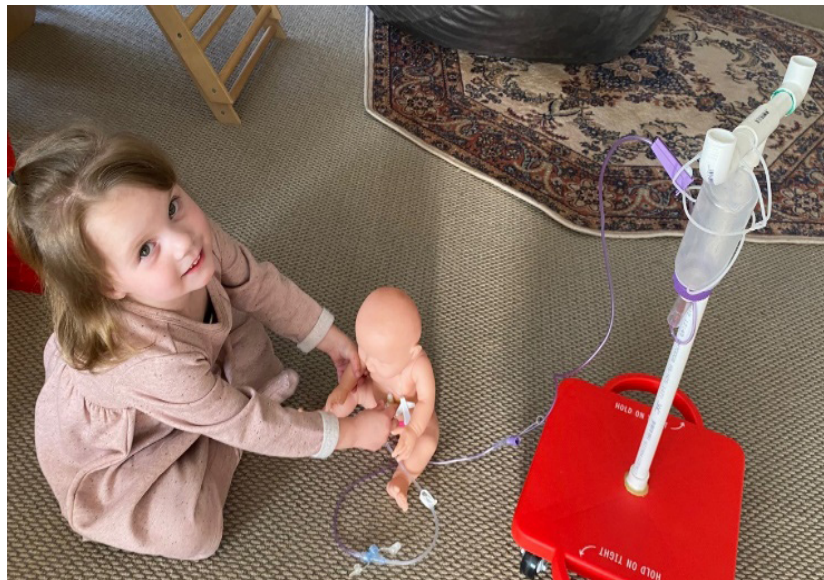
My favourite simple book for little ones is "My Tummy" by Angus Olsen. Angus is an Aussie who was an illustrator for Disney when his small daughter was diagnosed with cancer. Through this harrowing personal experience, he found that hospital kids lacked books that talked of their reality. He has written many fabulous little books for children that

relate to their medical lives and the illustrations are both simple and delightful. Angus has a Facebook group and a website, both called "I draw childhood cancer", where you can find all his books, many of which can be downloaded as pdfs free of charge.





We have had toy doctor sets but I wanted Syena's play to be able to also include lines and stands, so I made her a simple toy IV pole and attached a hanging bottle and gastric feed line. She hooks up her doll and puppy's gastric buttons to her play IV pole.



When her 4th birthday was nearing, I was happy to hear that a toy company called Our Generation were bringing out a hospital room, complete with accessories including an IV bag and line, light-up x-ray display and an oxygen mask. Although they aren't cheap, she has delighted in playing with this pretty much every day since she's received it. Pretty quickly, the doctor doll was relegated to the role of the second patient and Syena took over as the doctor.



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As none of these resources could be found in our local toy shops or bookstores, I thought other parents may be interested in looking at some of the things we've gathered. I would love to hear about any books or toys you've found for your own little warriors.

How to Make Syena's Dripstand

Medical play is a big part of play time in our home, for our little girl as well as any visiting children. If anyone is interested in making a toy IV pole for a child in their life, here's how I made ours.

The red wheelie base was bought for \$12 from Kmart in the toy section, near children's bikes and skateboards. An alternative would be a wheeled base for large pot plants but the Kmart toy had the advantage of already having a hole in the centre. I then bought a length of PVC pipe from Bunnings plumbing section, along with a T-joint to fix the crossbars to the upright bars, and two corner joints to go on the end of the crossbars to stop her "feeds" from sliding off. PVC pipe is easily cut to size and it slides into the joints - and a dab of glue will hold it secure. You can make the IV pole as tall as you like, but shorter is more stable for play.

We then hung inverted baby bottles for her pretend enteral feeds and expired IV fluid bags for play HPN, with a cut down silver cover bag to make it look the part. Pumps were fun to make out of suitably sized small boxes covered with paper and then decorated to suit.

PNDU Professional Award 2023 Recipient, Emma Osland, Thanks Us



PNDU Professional Awards 2023 , Update

The winners of these awards were announced in the November issue of Dripline, along with the reasons for their nomination. Two of the awards were presented last year, but we were only able to get together with the Adult Parenteral Nutrition Professional of the Year, Emma Osland from Brisbane, at the AuSPEN conference. Emma has written a wonderful thank you response, included below.

Words by Emma Osland

I would like to thank PNDU for the great honour of being voted your Australian Adult HPN Clinician of the Year for 2023. Without a doubt, this is the most meaningful award I have ever received: to be acknowledged by one's peers for professional service or achievements is one thing, but to be recognized by the people my work is seeking to serve is quite another.



I was lucky enough early in my career to get to work in parenteral nutrition, and shortly after that, HPN. In the last 20+ years I've seen the world of PN and HPN transition and evolve considerably!! We've moved away from the old "Christmas tree" system of individual nutritional components being hung in glass bottles and run by three separate pumps, to dual and triple chamber bags which are easier to administer and safer to use. We're no longer limited to the 100% soy oils which were the only option back in the early 2000s, as we can now have access to more diverse lipid (fat) sources for PN solutions that better protect the liver in long term use. We now have portable infusion pumps (not the brick-like hospital versions!) that make getting out and about to allow participation in school, work, socialization and other activities that allow life to be lived more fully. There are exciting new treatment developments which have the potential to provide new therapeutic avenues for many people living with intestinal failure. I have been witness to the expansion of HPN services. What started out as a few isolated hospitals caring for a handful of people with HPN requirements has over the years evolved into more formal HPN services that are increasingly communicating with each other and developing unofficial networks to help improve HPN care. While we are a long way from where we need to be in this regard as the recent results of the of the recent '[Home Parenteral Nutrition Model of Care Phase 1 Report](#)' showed, it is encouraging to see the national interest in HPN service development that is working towards the establishment of a national model of care for HPN

gaining momentum. And this is one area that I'm particularly passionate about, working with AuSPEN and my own HPN networks to see come to fruition. [AuSPEN's HPN Model of Care Update](#)

I also don't think I can accept this award without acknowledging some key influencers of my professional journey to this point. The wonderful dietitian Azmat Ali, who some of you will know from her work at the Princess Alexandra Hospital in Brisbane and AuSPEN prior to her retirement a few years back, has been a great mentor to me. She generously shared her extensive clinical knowledge with me and anyone who approached her for clinical guidance, and consistently demonstrated genuine care and compassion for her patients and their families (and colleagues, for that matter) in all aspects of her life and work. Azmat's encouragement has given me the confidence to undertake ambitious projects in the HPN space and beyond. And most importantly, I think I've probably learned as much from my patients and their families as I have from any formal means of study over the years. The resilience and courage I've seen them deal with the setbacks as well as the daily grind of treatment burden of HPN and underlying symptoms, humour despite significant challenges experienced, ingenuity in the life hacks for making HPN work for them never cease to inspire and humble me. I know I am extremely fortunate to be in the role I am in and look forward to seeing how the world of HPN continues to progress over the next 20-something years. :)

Emma.

Two Trips, Two Types of PN



By Gillian

Recently I made two trips; the first, a two-week holiday in Victoria, the second, a six-day conference in Auckland.

Until five years ago, all trips were planned around delivery and being able to keep 6 bags of PN refrigerated upon delivery (plus one bag out for that night). And this is how I planned my Victorian trip. But five years ago, I accepted my elderly father's invitation to accompany him on a week's bus trip, flying to Uluru, then travelling to Alice Springs before flying home again. I wanted to go and have this time with him, but it was too hard to ensure that the PN would be refrigerated properly, because on arrival at the airport, the bus immediately set off on tour for the remainder of the day, with no time for me to unpack my boxes of PN and find a good-sized refrigerator.

I mentioned the problem to my team, and they suggested I use non-refrigerated PN, something I didn't realise existed. My team decided that it would be alright for me to use for a short time.

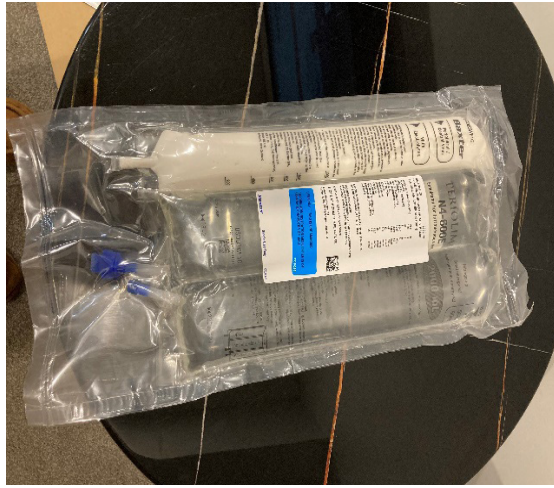
It made such a difference, being able to still get my nutrition without worrying about the fridge aspect. Last November, I represented PNDU at the AuSPEN Conference in Auckland, and again asked permission to use these bags, because I was staying at a city hotel, which have tiny fridges. Baxter had it delivered before my arrival to the hotel reception, and I was able to leave bags in the delivery boxes until I set up each night.

The bags are 3 vertical chambers, with a seal in between. The seals have to be broken to allow the 3 PN sections to mix. It does take a bit of force to roll and push the bags to get the seals to break and open out, so some wrist strength is required. But it certainly made the trip much easier to manage.

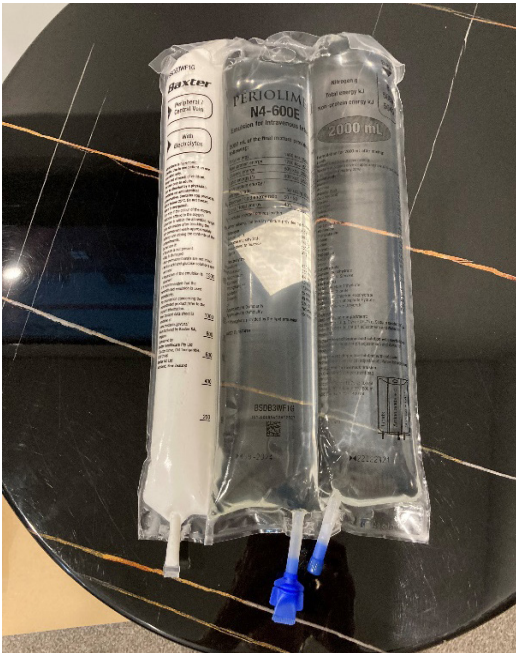
If you think this type of PN, for a short time, might make a trip possible that otherwise might not be able to be contemplated, then you should discuss with your team if they think you would be able to use it without compromising your health.



The same light-proof overbag as my usual PN.



The PN is inside a very tough vacuumed sealed bag, so have scissors ready to cut open. Remember not to travel with scissors in hand luggage on a plane.



Rolling and pushing the top of the bag breaks the 2 middle seals and mixes the contents

World's First IV Passport Earns Prestigious Award



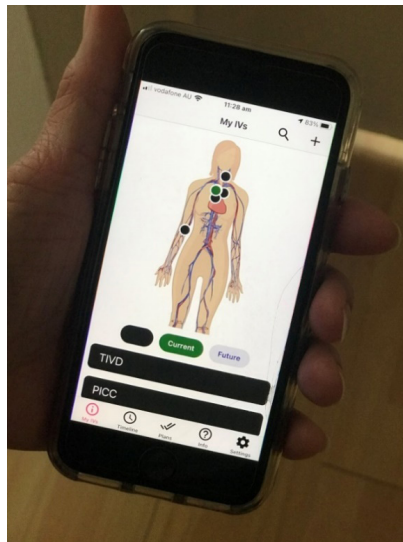
Words by Karen

We're a bit late sharing this news, but it's still exciting and well worth sharing!

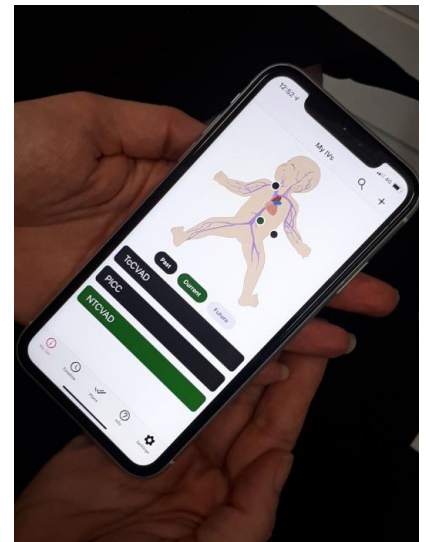
Many will already have heard of PNDU's involvement from the outset in the development of the exciting app – IV Passport. As HPNers and carers of HPNers, we all know how precious our vascular access is, and the need for good management. Our central lines are literally our life-lines! IV Passport was designed "to reduce the need to carry around your medical history and replace this with a simple-to-use app on both Android and iOS" - a one-stop depository of our personal IV details - past, current and planned future IV access, as well as resources. All data is secure and consumer/carer-owned and managed, with the option to share with chosen clinicians. And it travels with us, should we end up in a different hospital.



In July 2023, IV Passport won the **Most Outstanding Patients Innovation** award at the Australian Patient's Association annual awards ceremony. Project lead Amanda Ullman attended the ceremony to accept the award and here is Griffith University's media release of the award: <https://news.griffith.edu.au/2023/07/24/world-first-iv-passport-earns-prestigious-award/>. A great recognition of the IV Passport's value (and for us, PNDU's involvement in its creation too).



Adult display of the app



Child display

This free app has now been downloaded in 20 countries. If you haven't already made use of it, do it today!

(The app continues to be updated. Any difficulties, contact the developers.)

Android: <https://play.google.com/store/apps/details?id=au.edu.griffith.passport>

Apple: <https://apps.apple.com/au/app/passport/id1555412253>

Remembering Rosie



By Karen (past PNDU president)

Rosie was an amazing woman who had been totally dependent on HPN for 31 years (sometimes up to 24hrs/day) as a result of surgery for cancer, in which she lost all of her small intestine. At the time she was a busy mum to three growing children, and continued to live life as normally as possible in her rural community. She experienced some major medical hiccups along the way (including liver damage, losing almost all central vein access and ending up on the transplant list some years ago), but tried to never let these get her down, even continuing to do part-time volunteer work up until recent years. Rosie turned 70 in April last year.

Thanks to the dynamics of rural communities as well as the PNDU chat forums, it can be quite easy for HPNers in a country town to get to know each other (as well as their delivery drivers). Rosie lived in my hometown, so I got to know her personally, and over the years we would catch up when I was there. I enjoyed our talk fests about life in general as well as everything HPN - the highs and lows.



Rosie (left) and Karen

Sadly, my hometown has lost a number of dear HPNers over recent years, and the impact of this was brought home to me by the local delivery driver last time I was there. Teary-eyed, Michael talked of how heart-breaking it is for them too on the death an HPNer they've delivered to for years and got to know well. He said the hardest part is collecting her equipment afterwards. It was a beautiful reminder to me of the lives we touch - not just family and friends, but even our caring HPN delivery drivers.

Rosie's is another dear life to honour and celebrate, and I will miss our chats. My heart and prayers go out to all who have been touched by her life. As one who was dependent on HPN for decades, I believe we owe a lot to Rosie, as well as Fay and others for helping pave the way for us to follow.



Michael, Rosies PN delivery driver

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, \$3,350.

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Planning Overseas Travel



As a founding member of [PACIFHAN](#) (International Alliance of Patient Organisations for Chronic Intestinal Failure & Home Artificial Nutrition), PNDU can put you in contact with sister organisations in various countries overseas (UK, USA, Czech Republic, Denmark, Italy, France, Poland and Sweden) which may be able to assist with any HPN travel questions in those countries. Just ask us at contactpndu@gmail.com.



Membership for Aussie and Kiwi HPNers and carers:



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

Benefits:

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



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



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



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

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

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

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