



DRIPLINE



PNDU

Parenteral Nutrition Down Under

I hope you enjoy reading and learning about life on HPN from the people who live with it daily. In this issue we see members' HPNer children setting off for school for the first time – what a milestone! – and celebrating their birthday; We read some tips from Jodie on coping with life on HPN and - Emily, an HPNer all her life, addresses the need for Patient Centred Care; we read the story of an American woman who has been on HPN for 50 years; PNDU has been busy at a NIFS Conference in Auckland, as well as being represented at an Australian Parliament House meeting; Daniel encourages us to stay positive, and 2 of our members discover the gross build-up of fluff, hair and dust in our drip-stand wheels. All this and more,

Gillian Anderson
Editor, Dripline

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A Day in the Life of an HPNer – Caring for an HPN dependant Baby

Words by Amy

I am Amy, Mum to Evelyn. We are relatively new to HPN, but not PN. Evelyn has a genetic condition, a Filamin A deficiency, caused by a mutation to her FLNA gene. She has a number of health issues caused by her condition but as far as her gut goes, she suffers from a condition called intestinal pseudo obstruction which was first diagnosed when she was one, after she had been becoming progressively unwell over her first year of life. We had worked our way from breastfeeding, to elemental formula, to NG tube, then NJ, then GJ tube & finally onto hospital PN. By this time her gut had completely shut down and she was experiencing reverse motility.

She spent 4 months on complete gut rest in hospital while we waited patiently for her gut to decide to do something. She did eventually tolerate feeds again, and we were able to bring her home on G tube feeds. Fast forward 5 months and Evelyn's health had declined considerably again. She was admitted to hospital where she was again placed on hospital PN and gut rest. It was a stressful time for all involved, Evelyn has become extremely malnourished and it was discovered that her ability to store glycogen was impaired. She would become hyperketotic and hypoglycaemic even with jejunal feeds running and at one point ending up in metabolic shock in the ICU. She ultimately went on to spend 8 months in hospital, where the decision was made that HPN was going to be our only safe option for the long term.

We haven't had the easiest start to our HPN experience, with Evelyn's gut function declining further leading to issues with her metabolic stability, three line fractures and three bouts of sepsis, the latest of which leading to septic shock. Evelyn lost 3 central, and more than 15 mid and peripheral lines to this one infection, leaving us with very limited access as she has already lost complete access in both her arms one 1 leg due to clots and her abnormal venous system.

Evelyn's health has had a huge impact on our family, as I am sure is echoed throughout the HPN community. Evelyn is the youngest of 3 girls, with sisters Lillian (7) and Isla (5) having to deal with more than their fair share of heartache and disappointment because of Evelyn's frequent and lengthy hospital admissions. Lillian also has a Filamin A deficiency, and suffers from epilepsy and cardiac abnormalities, which will require open heart surgery in the coming years as a result.

I am always at the bedside when Evelyn is admitted, as we run our own business and my husband going to work every day is essential for our livelihood, and our mortgage payments!! So, our girls spend a lot of time with my parents, sometimes for months on end. We are incredibly blessed to have such a supportive family. Our hospital required 2 carers to be trained in HPN and central line cares – without question my sister stepped up to train with me when my husband could not due to work commitments.

Like any HPNer, Evelyn's cares at home take up several hours each day. It is not only her PN and line cares that require my attention, but a multitude of IV, subcut and enteral medications throughout each day. She has bloods taken several times each week for her INR, blood counts and liver function, due to interacting medications. We also do daily physical and occupational therapy with Evelyn in an attempt to close the gap between her and her peers.

Evelyn's PN cycle is currently 23 hours a day, and she is too young to understand the importance of staying close to her PN bag, so I always need to be within arms' reach when Evelyn is awake. My big girls are a great help, and love to be involved in Evelyn's cares. They love wearing her PN backpack and taking Evelyn on adventures down the paddock to see the chooks.

This all on top of all the 'regular Mum' stuff. I do not currently work, though I am a qualified nurse in my other life – my nursing skills are now reserved exclusively for my girls. It is exhausting to say the least, but we are grateful for PN, particularly HPN for allowing Evelyn to not only survive, but thrive at home with her family – right where she belongs!



First Day (Back) at School



Editor's Note: Seeing your HPN dependant child able to attend school is an amazing feeling for our parents and carers. Here they share this happy moment with us.



Mum Hayley: To say we are proud is an understatement. Noah is now in year 2! Where has the time gone? He's been on HPN since he was 4 months old due to complications with his small bowel from Filamin A Mutation and for him to come this far is incredible, to say the least, thanks to HPN. Yes, I may have bawled like a baby.

Mum Mel: Emily is now in grade 4 and about to turn 10. In her words "well I guess that shows all those doctors!"



Mum Susie: "Feeling blessed to share a photo of our son Thomas, who is home PN dependant. What an achievement for him to be starting pre-primary at mainstream school."



Mum Clare: Our HPN daughter since birth is off to our local primary school for Kindy. Couldn't be more proud of a "normal" milestone and achievement for her.

Grandma and carer Eileen: Well the time has finally arrived! Mayana has started big school. Such an amazing milestone for her! So proud of her - she is beautiful, strong, smart and amazes me every day. Love you to the moon and back my beautiful girl.



Pop and carer Chris: Dylan (right), Jordan (HPNer) and Logan (HPNer) back to school.

Mum Nicole: "I thought I'd share a photo of James on his first day of high school. I love seeing all the photos of the little ones either starting school or going back to school. They are all amazing little troopers with the most amazing smiles. James is loving high school so far.



Mum Sonya: What a smile. What a milestone. Our super kids on HPN starting school is an incredible achievement. It's taken a lot of navigating to get Milla there but I'm in awe of you all as we share in this journey. Congratulations!

Staying Positive



Words by Daniel

I'm writing this to fill in time on my way to Nhill, on the 7MA8 - The Overland train from Southern Cross, Melbourne, to Adelaide. I'm visiting a police friend at Rainbow.

On the email forum group there is always a mention how kids are good at being positive and adjusting well to being on HPN

Adults are just as good at doing this, but you need a good mind set on how to cope with things.

Being positive and having a good attitude will make dealing with issues a little easier.

Unfortunately, a lot of people get angry and upset with their illness, which is okay, but is this going to achieve anything good or constructive? I doubt it.

It's better to be positive and happy. Try to keep up with your interests and hobbies. I've always enjoyed photography, be it trains or in general. My passion for sports and Supercars has been since I was a kid. The first supercar event I went to was Craig Lowndes roll-over at Calder Park. People need passions, whether it's art or music or anything else.

Enjoy the life you've got. Share enjoyable things with family or great friends.

True friends will be always there for you.



Daniel, front and centre, with some of his 'true friends'.

The value of member surveys – this time 'retraining in central line care'



Words by Karen

Late last year PNDU conducted its latest member survey – this time on whether any retraining of HPNers and carers in competency to care for a central line (and in updated protocols) happens on a regular basis, or only if there are recurring line infections. PNDU believes this is an important issue considering the often long-term nature of HPN.

We were very blessed once again with the wonderful analysis skills of PNDU member, Sharyn, in addition this time to the very helpful feedback and suggestions from our friends at [AVATAR](#) (Alliance for Vascular Access Teaching and Research).





The abstract of this observational member survey has been accepted for poster presentation at the Australian Vascular Access Society's (AVAS) National Scientific Meeting in Sydney in May and we'll have more about that in the next issue of Dripline.

Just what is a poster presentation, you ask? At scientific and medical conferences, there is often opportunity to present research information in the form of a large poster (a bit like a school assignment!). Posters are viewed by delegates at the conference, and during a dedicated poster session, there is opportunity for authors to explain the research to anyone interested.

So watch this space!

In the meantime, while recently seeking PNDU member input on its draft document for HPN standards of care, AuSPEN (Australasian Society of Parenteral & Enteral Nutrition) has readily agreed to include in that document regular re-training of HPNers and consumers in HPN protocols at planned intervals. Woohoo! Thank you AuSPEN! This is very encouraging, and a great outcome already for our member survey.

Birthday Corner



Mum Melinda: Thank you so much for Molly's birthday card - she loves it! Although I am super glad I noticed the stream of glitter leaking from the envelope into my mailbox before I had opened it over the carpet, and thought it was a better idea to open it over the sink!

From mum Amy: We celebrated Evelyn's 3rd birthday on Sunday in hospital. We had the best day we possibly could with plenty of cheeky smiles, despite her feeling pretty awful.

Here is a happy picture from her big day.





From mum Clare: Thank you PNDU for Bertie's birthday card and balloons. He had a wonderful party and was spoilt rotten!



Poppy Chris says: Thank you for all Logan's birthday wishes. Logan had a great day, starting with an iron infusion, X-rays and a patch change at the hospital. The staff made him feel special with birthday gifts. The evening was spent with a family dinner and a Spiderman cake. Saturday will be a picnic in the park with friends.



Mum Melanie says: Thank you everyone! Especially for Emily's beautiful card from PNDU! A very special birthday for our girl on her 10th birthday.

Certificate presentation pictures



Editor's note: As part of PNDU's 10th birthday celebrations, it was decided to give all members a laminated certificate of appreciation, for presentation to their hospital team from PNDU, for all the good care given by hospital teams to PNDU's HPNer members.

Team Jordan and Logan presented their HPN team with a PNDU Certificate of appreciation at today's clinic appointment, nurse, gastroenterologist and dietitian, were overwhelmed to receive the certificate, all stating it meant a lot to them and appreciate the efforts of PNDU."



Logan and Jordan's team at John Hunter.
L to R: CNS Lee, Gastroenterologist Dr Scott, dietitian Dierdre



Gillian with her nurses, Irena (left) and Kate, Krystle, Nurse, Rachel, dietician, and Andrew, Intensivist, unavailable for the presentation.

Mum Hayley: Presented Noah's team at Queensland Children's Hospital with their 10 year PNDU certificate. Noah was impressed by the photo as you can clearly see!



Karen's HPN team (minus intensivist) – Steph, Suzie, Karen, Dr Kurtovic, Mark and Declan (inset) with PNDU's 10th Birthday Certificate of Appreciation. "Thanks so much for your great work team!"

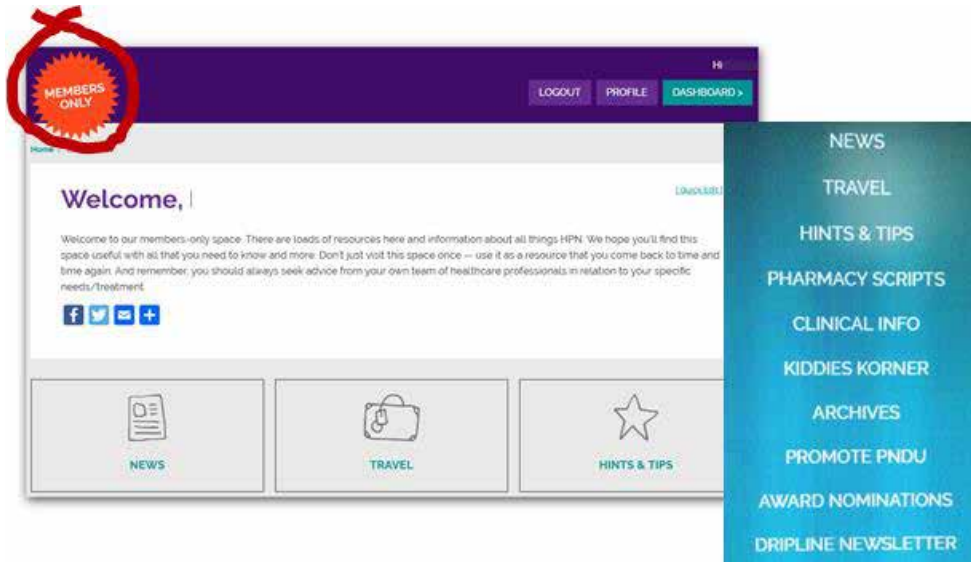
More to PNDU's website than meets the eye!



Words by Karen

Did you know there's a Members-Only section on PNDU's website with lots more pages and resources to access?

Don't miss out! Sign up to PNDU membership today at pndu.org. It's free. Anyone can become a member. And you can access all these Members-only pages.



PART 2 of 3: Coping with a Life of Intestinal Failure on HPN



Words by Jodie

Coping with a life of chronic illness and long-term parental nutrition is difficult. It has taken me many years to learn how to cope in healthy ways.

Living in a sick body is never easy. Here are some tools I've adopted to accept intestinal failure and its long-term treatments. I hope this list will give you ideas and in turn, help you cope too. things are just as important as the big achievements.

1. When my head is a big tangled ball of wool, I acknowledge the big things I'm feeling, try to work out why I feel them and validate myself.
2. I remember that loss of good health involves grieving, the same as if a loved one has died. Grieving is important and has its place – it's how our mind deals with significant changes of circumstance. I let grieving come and go as it needs to.
3. I 'cope ahead' by making plans for how I will physically and mentally get through challenging events as they present themselves. I also give myself extra grace to rest and recover after these challenges.
4. I try to have a flexible standard of success that is achievable for where I'm at on any given day.
5. I play to my strengths and try to forgive myself for my weaknesses. All I expect from myself is to do the best I can. Sometimes just surviving is a huge accomplishment so I give myself credit for making it through a hard day.

(I make surviving my success and my 'enough' on bad days. On good days, I challenge myself to stretch and achieve a little more. But stretching is for good days only, not for bad days.)

6. I make a list each day and check tasks off. This gives me a sense of accomplishment. On my bad days, I even list things like 'get out of bed'. Sounds silly but it really helps because the small, taken-for-granted things are just as important as the big achievements.
7. I set realistic monthly goals with the proviso that I may not reach them. I set these goals within a vision. For example, my monthly goal might be to write 5000 words on my novel but my vision is to become a published author. Goals and vision keep me motivated and help me to move toward my future in a positive way.
8. I stop when I catch myself comparing my achievements to healthy people's achievements. The reality is, we don't live on the same sliding scale as healthy people when it comes to success.
9. I try to keep anxiety about my future health where it belongs (in my mental lockbox) and forbid myself from dwelling on the 'what if's' outside of Drs appointments.
10. I try to not spend time dwelling on the better health I once had but am not currently experiencing. Ruminating on all the wonderful things I'm missing out on because of illness is also unhelpful.

Medical Play Toys Happily Received



A big thank you for our president – her own medical play toy



Mum Rania: This is a photo of Johnny with his medical play toy. He calls it baby Joe. Thank you for this Just Like You toy!



Nicholas with Superman



Mum Rebecca: Cierra is extremely happy with her Just like you doll!!



Bertie with Batman!



Nicholas with Superman

Personal Essay on Patient-Centred Care



By Emily

Editor's note: Emily is a young American woman who regularly contributes articles to Dripline. Emily studied for a semester in Sydney a few years ago and attended a PNDU social gathering.

I was born and bred in the healthcare system. At an early age, it was discovered that I was born with an extremely rare condition called Myopathic Intestinal Pseudo-Obstruction. Wikipedia does an alright job of discussing what it is, but if you're lazy like me I can sum it up now. Myopathic means muscle. Add in the intestinal and you have an illness that is centered in the muscular wall of the intestine. Pseudo-Obstruction is a nice way of saying it don't work no good. If there is a doctor reading this that has a major issue with my description, my apologies. Basically, I was born with an intestine that is as confused about navigating the world as a teenager. I infuse roughly four litres of HPN nightly and have a rocky history with line sepsis, acute kidney failure, hydration maintenance problems, and choosing a cute bathing suit. It has always been like this, I've always been this ill. I've learned to thread myself through schools, friends, and sleepovers with this, I've gone to college, and lived abroad, but most importantly, I've developed an in-depth knowledge of the healthcare systems, warts and all. For much of my life I never considered, or more accurately, never allowed myself the time to emotionally acknowledge that there are other people in the world on HPN. I was young, isolated, and with no connection to a PN expert in rural Missouri. My team was comprised of a GI surgeon, the director of infectious disease, my dad, countless hours of research and dedication, and special guest appearances from a professional who begrudgingly updated my formula once every five years or so. Their level of personal and emotional involvement in my health taught me what patient centered care feels like and that I am forever grateful for.

Like many young adults, I moved away from home to attend college. I moved to the healthcare mecca of Boston and began a relationship with a team of leading experts in HPN at Boston Children's Hospital. The team was incredibly diligent, knowledgeable, and organised; however, early on I began a habit of ghosting them. It wasn't that I thought, "oh, I'm in big bad Boston, away from my parents, I'm not really that sick." No, no. I knew I was sick and I knew I needed to continue maintaining my health. What I noticed was that while the level of research, innovative medicine, and access to resources skyrocketed, the level of patient centered care did a free fall. The clinic saw patients exclusively on Monday afternoons, and because I did not know this (at home, I could see my doctor whenever I wanted), I had scheduled classes then. I was consistently pressured by my own team to skip class to come see them; I was simply told what to do without much scientific reasoning besides "well it's what we think is best", and had an overwhelming feeling that every word that came out of my mouth went into their ears as cute toddler babble. And I get it, I mean, it IS a children's hospital, and the patients ARE children....but....do I really get it? I mean, one day, all of these children will grow up and become adults, right? And hopefully, by then, they become informed and educated members of their own healthcare team, somewhere down the road...but where and exactly how

in a system that doesn't directly and intentionally make efforts to teach those skills? If not in the children's hospital, then exactly where? And what are the consequences if it doesn't happen? This about the time in my life I realised how incredibly lucky I am to have my father. He's a psychiatrist, but he went through medical school so he knew the system, how it is set up and runs itself. He knew the jargon, and most importantly, he took the time to teach it to me. I remember him drawing pictures of the GI tract or central venous access, explaining electrolytes to me, and what a resident is compared to an attending. He taught me everything I know and it is from him that I can navigate the system myself as a critical thinker who can, even in scary and emotional times, weigh my options and make informed decisions. But what if he wasn't a doctor? What if he was an accountant? Or a sculptor? And more importantly, what about children living with chronic illness at this very hospital whose parents aren't doctors themselves? How will they learn and who will teach them?

This is what I accredit as my first tiny little step into my current career goal into patient advocacy. However, I've always been taking little steps towards changing healthcare simply by advocating for myself as a patient. Whether this is with my home health company, my outpatient medical team, or during impatient hospitalisations. Most recently, during a hospital admission, I persuaded MedStar Georgetown University Hospital to change their policy on line dedication to PN by persistently arguing a combination of patient-centered care, published evidence, and physiology reasons all the way up to the Vice President of Patient Care. I'm currently a contributing writer for the PNDUnder (PNDU) newsletter, Dripline, written for HPNers living in Australia and New Zealand, an HPN Ambassador for The Oley Foundation, I've provided one-on-one counselling for families with newly diagnosed children on PN, have presented a poster on paediatric health literacy* at the Institute for Healthcare Improvement's National Forum, and am currently working a self-exploratory article on how ballroom dancing helped me cope with hospital related PTSD. My interests span across increased access to healthcare, improved healthcare policy, employment obstacles for the chronically ill, inspiring others by my stories of both living independently domestically and internationally on HPN, but my focus is on increasing paediatric patient engagement. Of course, the goal is always "Until every child is well", but another critical goal is to equip chronically ill paediatrics with the knowledge and skills necessary, through true and authentic patient-centered care and shared decision making, so that they may become experts in themselves. Entering the healthcare system as a paediatric can evoke feelings of fear, learned helplessness, and dependency that can follow into adulthood. As a well-equipped expert in oneself, this gives the patient the freedom and confidence to move from team to team throughout their adult life as they see fit, allowing them to live a fuller and fulfilled lives despite chronic illness.

* Emily's poster "Health Literacy in Paediatrics" is on PNDU's members-only [Kiddies Korner page](#).

Cleaning the Drip Stand



[Editor's note: As if the HPNer/carer doesn't have enough to do...2 of our members discovered the reason that their drip stand wasn't tracking well was the build-up of dust/hair/stuff pulled up from the floor into the wheels, so decided to clean them, with amazing results!](#)

Belinda: in August last year, I decided to clean the wheels of my son's IV pole. Now I know why they wouldn't roll properly!! This is 2 years' worth of junk built up in the wheels - and I clean the floors every 2 days, so I was surprised it was this bad.

I watched a great [YouTube tutorial](#) on separating the wheels, which made cleaning them so much easier. It took us 30 mins for the 5 wheels, but 1 hour of searching online for an easy way to do it! I found this worked best for us.



Lara: A while ago, someone posted a handy YouTube video on [PNDU's FaceBook group] about how to clean out castors. Today, we did the ones on my pole and below is the result! VERY SATISFYING! She's rolling like a dream now! I recommend getting someone to help. It took a lot of elbow grease and sometimes three hands/screw drivers to pop the wheels apart.



PNDU's neat and nifty day with NIFS



Words by Karen

New Zealand's National Intestinal Failure Service's (NIFS) annual Education & Networking Day was held again in Auckland in late March, and this year PNDU was there! Both Chris, PNDU's Treasurer and President-in-waiting, and I, PNDU's President, attended on behalf of PNDU and enjoyed the opportunity to represent our members, and meet with and learn from HPN clinicians, both local and international, and from all faculties. What a great program for the 85 Kiwi HPN clinicians who came from across the country! – from lipids; to motility; a medical App to overcome distances; calories and protein; central line infections; and a number of clinical scenarios. Well done NIFS!

We were very grateful for the opportunity to also exhibit for PNDU alongside our industry friends. In addition, together with PNDU members' Shirley and T's wonderful presentations of their own journeys with HPN as carer and HPNer, I was given the opportunity and privilege to speak about what hospital is really like for those of us living with HPN. Three presentations by consumers and carers in a one-day program. How encouraging!

Furthermore, as a very nice feather in NIFS' cap – it was announced on the day that Auckland will be hosting the 2021 International Congress of the Intestinal Rehabilitation & Transplant Association (CIRTA). The dates are already confirmed – 30th June to 3rd July 2021. Congratulations NIFS and best wishes now for the planning of this event!

Lastly, a word of thanks to NIFS – PNDU has been really encouraged by the opportunity for Chris and I to play a part and meet with many Kiwi HPN clinicians. We look forward to continuing to grow PNDU's relationship with NIFS and working together for the benefit of HPN consumers and carers.



Karen and Chris at the PNDU exhibit



T, Shirley and Karen presenting the consumer/carer story and perspective at NIFS



Some of the NIFS team – Kim Herbison, UK invited speaker – Peter Austin, Briar McLeod, Karen, Cate Fraser-Irwin, Lisa Guest

PNDU's Social Gatherings – Perth and Auckland



Words by Karen

1. Perth

A fantastic PNDU gathering at Mike and Clare's home in Perth this afternoon [9 February 2019]. So nice to be in the cool and catching up with others who totally get life on HPN. Thanks so much Clare, Mike, Elsie and Bertie for opening your beautiful home for us, and to nearly all our WA members who were able to come. It was a tricky time of year with the heat, and school having only started this week, so we really appreciate it, but also understand it wasn't going to be possible for everyone.

Thanks again,
Karen



Back row: Jacqueline, Ada, Jodie, Kelly, Daryl, Steve, Sharyn
Front row: Karen, Alex, Elsie, Mike, Bertie, Clare, Anna

2. Auckland

Our numbers were smaller than expected, as sadly hospital called away two HPN families on the day. But it was still a great opportunity to meet and touch base with a couple of our Auckland members at one of the city's beautiful beaches on a stunning autumn afternoon. Food was nowhere to be seen, and we had a wonderful couple of hours catching up, and talking all things HPN. Thanks so much to our Auckland members – those who were able to make it and those called away by hospital – we love your contribution to the PNDU family, and celebrate growth in numbers on the Kiwi side of the ditch.



Beautiful scenery for our Auckland gathering



Fur baby Tuco also enjoyed the afternoon.



All three HPNers, although one has recently transitioned off – hooray!! We're so happy for you T.

PNDU 10th Birthday Celebration Caps – Where in the world have they been?



Editor's note: As part of PNDU's 10th birthday celebrations, all current HPN members over the age of 10 who wanted a free cap were given one. (HPNers under 10 are eligible for a free medical play toy on request). Below are some of the places that our caps have visited already.

And if you don't yet have a PNDU cap, get one today (email contactpndu@gmail.com)!

Eligible members (ie current HPNers, or carers of current HPNers, over 10yrs old - one per family) receive them free. Everyone else, they are cost price and just \$14 + postage - <https://pndu.org/resources/merchandise/>

Karen



Some close ups of PNDU's caps



front



...and back



Daniel on his recent trip to Muswellbrook, NSW



Lara (back right), her dad (with cap) and family at the Grampians Music Festival, SA



Jodie and Karen on Busselton Pier, WA



The cap at Milford Sound, NZ



A millinery of PNDU caps: Wendy, Karen and Chris on Auckland Harbour, NZ



The cap, visiting one of the many vineyards in SA



Sal wearing the cap with her 'new' Clipper bus at Crows Nest, near Toowoomba, Qld



Can adult HPNers work?

Words by Karen

In February, one of our members ran a short Facebook poll within PNDU on the employment situation of adult HPNers. The poll was then extended to the PNDU private email group, and here are the results:

There were 25 participants, and participants could tick more than one answer.

11 (44%) are unable to work due to illness

5 (20%) are retired

6 (24%) work part-time or casually

2 (8%) work full time

8 (32%) study

7 (28%) are homemakers or volunteers

An interesting snapshot of the work situation of some of our adult HPNers!

While it's not surprising that a little under half are not employed due to illness, interestingly there is still significant active involvement in life by our adult HPNer members, including study, homemaking/volunteering, and part-time/casual work. We are also aware of some of the amazing hobbies, talents and artistic abilities of some of our HPNer members – other ways of finding meaning and purpose, as well as being able to give to others. And remarkably two PNDU HPNers are in full-time employment! When we consider the demands, challenges, restrictions and complexities of HPN, Intestinal Failure and of the underlying cause of Intestinal Failure, all of this is quite amazing.

Thank you, Jodie for this interesting survey.

We celebrate however HPNers are making the most of life, even if that means simply reaching the end of the day in one piece. A wonderful achievement in itself!



PNDU at Parliament House Canberra, Australia

Words by Chris

I had the opportunity to represent PNDU during the 2019 Australian Rare Disease Day event at Parliament House in Canberra, 20th February 2019. The event was organised by Rare Voices Australia (RVA) and co-hosted by Hon Trent Zimmerman MP and Hon Steve Georganas MP- co-Chairs of the Parliamentary standing committee on health.

The Rare Disease Day event provided an opportunity for PNDU and other RVA Partner organisations, to come together under the RVA Banner and raise awareness with policy makers about rare diseases and their impact on the lives of patients, families and carers. This year's Rare Disease day theme is "bridging health and social care" highlighting coordinated care and access to services (including NDIS), focusing attention on the everyday struggles faced by people living with a rare disease and their battles with the very systems and processes that are supposed to be there to help them.

I was able to talk for a considerable time with the Minister for Health, Hon Greg Hunt MP, with regards to Intestinal Failure, Parenteral Nutrition and PNDU. I also had the opportunity to speak with co-hosts Hon Trent Zimmerman MP and Hon Steve Georganas MP. During their speeches on the day, it was wonderful to hear all three ministers (Greg, Trent and Steve) acknowledge they were talking with me, and how Intestinal Failure requiring Parenteral Nutrition, fitted with the theme of this year's Rare Disease Day event.

I would like to thank the Hon Ministers who took the time to attend the Parliamentary event and speak with

me, along with the ministers mentioned above, I was able to speak with my local MP Meryl Swanson, The Hon John Alexander MP and Hon Mike Freeland MP (chairs of Parliamentary friends of Medicine), Hon Kevin Andrews MP (joint standing committee NDIS)

PNDU is pleased to be an RVA Partner Organisation and have the opportunity to attend events like this. To find out more about RVA and the "Fair for Rare" campaign, click the "Fair for Rare" link on the [PNDU website](#).



Chris talking with Meryl Swanson



Chris talking with Hon Greg Hunt MP, Federal Minister for Health

Fifty Years on Nutrition Support: Yesterday, Today, and All of My Tomorrows



Words by Sharon Rose

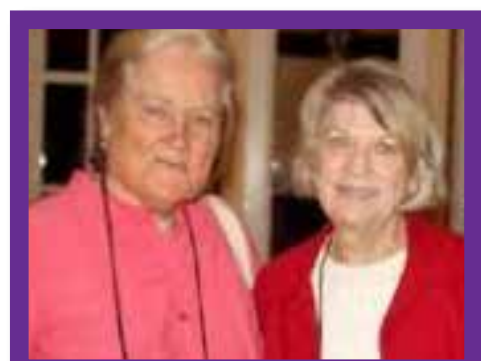
Reprinted, with permission, and PNDU's thanks, from Oley's LifelineLetter newsletter.

Based on a presentation Sharon gave at the annual Oley Consumer/Clinician Conference in June 2018, in Memphis, Tennessee. Find a link to Sharon's moving presentation at www.oley.org/2018confdoc (under "Videos," choose "Monday Main Session"). At the end of the talk, the audience fittingly honoured Sharon with a standing ovation.

In 1968, I had just graduated from nursing school. I had my first apartment, my first job, and things were wonderful. Then I developed abdominal pain. I ignored it until one day the pain came and didn't go away. To make a long story short, blood clots had blocked the flow of blood to my small bowel. My small bowel became gangrenous, then ruptured, and, in the end, most of the bowel was removed

surgically. I was young and healthy and I recovered from this surgery quite rapidly. I was home in nothing flat. The only instruction I was given on discharge was to eat a bland diet. I ate a peanut butter sandwich, which I loved. It, however, didn't love me. I became horribly ill—nausea, vomiting, steatorrhea. After I'd purged everything out of my body, though, I'd feel good. Then I'd eat another peanut butter sandwich—or something else—and the cycle would begin again. I steadily lost weight and eventually ended up back in the hospital.

This was a good-sized city hospital, but they didn't know what to do with me. They gave me IVs—the usual sugar, water, and electrolytes—and they gave me an occasional bag of plasma, but that wasn't enough. I was going downhill when one of the doctors told me a doctor at the university centre who had some



Oley Co-founder, Dr. Lyn Howard, with Sharon at the 2018 conference.

expertise in nutrition had agreed to take over my care. I moved to Cincinnati University Medical Centre under the care of Dr. Richard Bozian. Dr. Bozian was, and still is, a wonderful human being. He is currently in his mid-nineties, but is still very active in the community. The first thing my new doctor did was absorption studies, to see how much I actually could absorb. It wasn't much. Then he sat on my bed and talked to me about this new therapy called hyperalimentation (which is what total parenteral nutrition—TPN—was called in those days). From the very beginning he told me he'd never used TPN on anybody, but that he had read about it and there was a doctor in Texas who had successfully treated several patients with it. He felt it was what I needed. I agreed.

The Process

My doctor explained that TPN had to be rapidly diluted in a large vein, so I got my first central line. It was placed at the bedside. They placed a large-bore needle into the subclavian vein. Through the centre of that needle they threaded a little, thin, hard, plastic catheter. After the catheter was in the vein, they took the needle out, but they couldn't get rid of it because it was all one piece. The needle was taped to my chest and the catheter stayed in the vein. The catheter never got soft or compliant with my body. It was rigid, and when you moved, like if you moved your arm, it would ride in and out of the skin. Consequently, it became infected rather easily. To add insult to injury, we didn't have nice clear occlusive dressings like we do now. I just had gauze and tape. Thus, I had my central line.

The TPN

Making the TPN was a problem. My doctor couldn't call the pharmacy and say he wanted it. Nobody knew what it was. Luckily, my doctor had been a pharmacist before he got his MD. He went down to the pharmacy and together, he and the pharmacist figured out how they were going to compound this solution that would give me everything I needed. In those days, the TPN came from the pharmacy in glass bottles. Luckily, my doctor was familiar with 0.2 micron filters, and he wanted a filter on my IV because he recognized that it had great potential for growing bacteria. However, you couldn't infuse fluid through the filter without it being pumped, and there were no IV infusion pumps back then. That afternoon Dr. Bozian came into my room pushing a cart, and on it was a heavy metal box, about 10 to 12 inches square. It was a Harvard infusion pump. This pump was meant for laboratory use, not for patient care. It had no safety features, no bells and whistles. It had an on and off switch and a rheostat. You turned the dial up, the pump went faster; you turned it down, the pump went slower. That was the extent of it. The sterile tubing that went with the pump was not IV tubing, so I had to create something that would work. I would take sterile IV tubing, clean the outside with betadine, and cut it with sterile scissors. I would do the same thing with the pump tubing, then I'd take the two and tape them together. That was my IV tubing. I did not change my tubing every day. I kept using it until, well, usually it exploded. With no safety features, the pump pumped regardless. If something was blocked, like maybe the tubing was kinked or the filter was clogged with precipitate, it kept pumping anyway, and the pressure would get so great that the tubing would pop apart and there would be TPN in every corner of the room. The 0.2 micron filter was a lifesaver. Once it was wet, air could not go through it. There were no alarms on the pump, and if a bottle ran dry and I wasn't paying attention, it would pump air. The filter prevented that air from being pumped into me. Pressure would build up behind the filter and there were times when I would look over and see the latex part of the tubing blowing up like a balloon before it would come apart.

Going Home on TPN

This was basically my life for two years. I more or less lived at the university centre. I did occasionally get out. If a line went bad, for example, I could go home for a few days. In those days, we still hoped that if I really, really pushed oral feedings—eating small amounts constantly of the appropriate stuff—that I maybe could make it orally. But it didn't work and I would end up back in the hospital. After about two years, my doctor started talking about me going home and doing this. That set up a roar among his colleagues because they felt it was entirely too dangerous to let a patient go home with a central line. Thank goodness my doctor never gave up. He started brainstorming with some of the surgeons and they came up with the idea of creating AV fistulas for me to infuse my TPN through. An AV fistula is the same thing a dialysis patient has in their arm. They surgically connect the artery and the vein in the arm. Having the arterial flow pushed through this vein causes the vein to become engorged and have a very rapid blood flow. And that's what they did. I would put a little needle in my arm every night, and infuse my TPN during the night, then

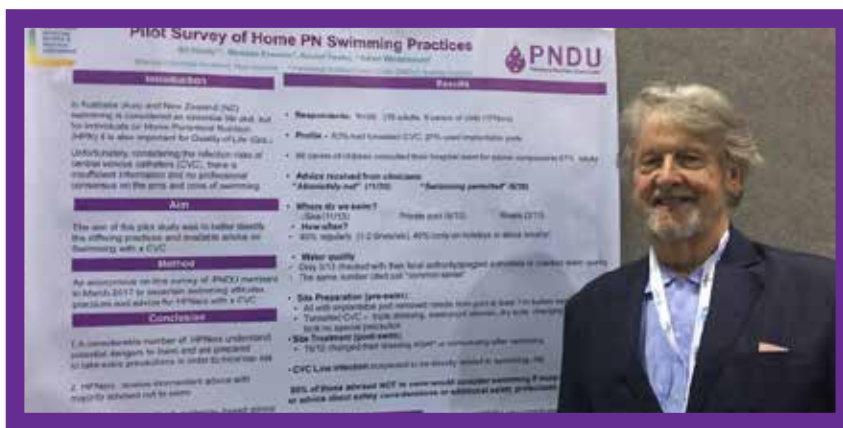
take the needle out in the morning and be free. I infused TPN using a fistula for six years, but it involved many, many, many surgeries, because although this vein had rapid blood flow, it still couldn't really handle the TPN. Over time the vein would become irritated and clot off. They would go in and remove the clot and put in an artificial vein graft. They did this consistently, going up both arms until they could go no further. Finally, I got my first silastic catheter. It wasn't cuffed; it was just a thin, soft, little catheter. They had to open my chest and managed to thread it through a small intercostal vein to get it up to where it should be. And it worked! Because it was a very soft catheter and because the route was so convoluted, at night I had to lay flat with my arms at my sides. I could not move my arms, or tilt my head, my shoulder, or even a hip. If I moved, the catheter would kink off. Believe it or not, I was kind of happy two years later when that catheter went bad. I did eventually get the type of catheter we are all familiar with today. I now have a Hickman. Getting a catheter in me can be challenging, as all the major vessels in my chest have clotted off. Throughout my body, small vessels have taken over the flow of the large veins that have been blocked off through the years. With our advances, however, it has become easier. Interventional radiologists can get a catheter into a turnip. They are wonderful. So life has gotten easier. We encountered a lot of problems through the early years. For example, it took me six years to get any lipids, and then I only got them as a research patient, because although lipids were being used in Europe with no problems, the FDA would not approve them. By the time I got lipids, my essential fatty acid levels were very low. I'd lost all my hair and the musoca in my mouth, nose, and vagina was like raw meat. Everything was "learn as you go." When I was home doing it myself, I used to reuse my tubing. I'd pack it in formaldehyde, then rinse it out and use it again. In those early days, I didn't get TPN already premixed. I mixed it from scratch, and I did it in my bathroom. Doesn't that make you cringe?

A Blessed Life

After I'd been on TPN about five years, my doctor told me Dr. Wretlind, a Swedish MD who was one of the pioneers in IV nutrition, was visiting from Europe and would like to meet me. Intralipid was his formula. Dr. Wretlind and I had a nice lunch together, during which he kept asking me rather everyday questions about what it was like living on TPN. I was surprised and said, "Certainly you know the answers, as one of the fathers of TPN." He looked at me and said, "I've never talked to anybody who has lived on TPN. In Europe, we only use it as a temporary measure while people are recovering from surgery." That was a real moment for me. I wondered, why am I so lucky? Why am I so blessed? I didn't know the answer then, and I still don't know the answer, but I'm thankful. I have led a full life. I was married, I have twin boys and five grandchildren, and I worked full-time as a critical care nurse. I have seen a lot of changes in the fifty years I have been on TPN and have seen many improvements. We improve so much every year. I want us all to have hope that it's only going to get better.



PNDU's Swimming Survey Poster at ASPEN conference



PNDU's lifetime member and supporter, Prof Gil Hardy, presented PNDU's Swimming Practices Survey at the ASPEN (American Society for Parenteral and Enteral Nutrition) held in Arizona, USA in March this year.

Upcoming Events



2-3 May	Australian Patient Organisation Network Conference (PNDU is attending)
12-14 May	Australian Vascular Access Society's 2019 Scientific Meeting, Sydney (PNDU is presenting and exhibiting)
1-21 July	Nominations open for PNDU Annual Awards
19 August	PNDU's Annual General Meeting and announcement of PNDU Annual Awards
13-19 October	HPN Awareness Week

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.

In addition, on its website, PACIFHAN provides an electronic **Dictionary** of Home Artificial Nutrition (HPN and HEN) words, in 8 different member languages, that you may need when in another country.



Thank You



PNDU wishes to thank the following HPN people and companies for their generous donations totalling \$8518.25.

- **The Book Depository** [thanks to the many who purchase books through The Book Depository link on PNDU's [homepage!](#)]
- **Anne Miehs**
- **Rob Stallard**
- **Takeda (Shire Australia)**
- **Fresenius Kabi Australia Pty Ltd**



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 acknowledgment/receipt of your donation, please email us at contactpndu@gmail.com.



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