



DRIPLINE



PNDU

Parenteral Nutrition Down Under

Welcome to our Awareness Week 2020 issue! This year has been difficult for everyone in many ways; for the Management Committee of PNDU, it has meant a challenge to involve hospitals, pharmaceutical companies and members in awareness raising activities, while still following rules about social distancing. Our president, Chris, has done a magnificent job in encouraging and instigating activities to involve all of these people – read about some of the activities happening in Australia and New Zealand. Find out who won PNDU's Professional Awards, 2020; read about the progress that 'Pumpkin', one of our PNDU toddlers, has made; read about three Baxter executives accepting PNDU's challenge in 'A Day in the Life of THESE 'HPNers''. Read the third instalment of 'What's in Your Bag?' about the importance of Iodine in our diet; and more. I hope you enjoy the read and learn about various aspects of living life with HPN,

Gillian
Editor

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Our little 'Pumpkin'

Words by Julia

On April 10, 2019, our lives turned upside down and we didn't even realise it.

I'd received a call asking if we could care for a baby girl in hospital. Of course we could. I mean, we'd taken so many similar calls in the past and had cared for 47 babies and children in many years as foster carers, and raised 14 kids as permanent members of our family.

So yes, I'd head in to hospital in the morning to meet our little one, nicknamed "Pumpkin". I was told she was tube-fed. Okay, no biggie. We've had maybe six or seven foster babies on tube feeds before, including premature identical twins born with Down Syndrome and gastric reflux. I remembered how to test pH levels and work the Infinity pump. We had no idea how long she would need our care, but typically babies are with us for six to twelve months before they are restored to birth family or placed in a long-term foster family.

Our girl was the darling of the High Care ward. Of all the long stayers, she was particularly beloved by nurses who had stood in as pseudo parents during her first nine months of life. They told me stories of how sick she had been with line infection after infection, how many surgeries she had gone through, of how they moved her baby swing out to the nurses' station so they could talk to her through their shift and how they would hold her through the long nights that she was unwell.

I immediately saw how undemanding and smiley our baby girl was, and also how developmentally delayed. She couldn't crawl or sit. She could barely roll over. She didn't babble at all. Pumpkin was always happy and always smiling. She held her arm out without protest for blood tests. She lay for hour after hour alone. She smiled at everyone who passed her open door. She had learned how to smile to pull people in, whether they were cleaners, nursing staff or parents of other little ones. Everybody knew Pumpkin. Her behaviour, though endearing, was quite worrying. Babies should protest painful procedures. They should fight and howl. By nine months, babies should be showing some discrimination, favouring familiar family members over strangers. My saddest moment was reading the assessment of a doctor who specialises in children experiencing abuse and neglect, in which she said that Pumpkin was starting to show attachment behaviour towards the one consistent thing in her life ... her IV pole!

Within a couple of days, I realised this placement was going to be different. It wasn't going to be sufficient to just visit for several hours during the day. I packed a case and moved into hospital. I stayed with Pumpkin day and night, coming home to sleep and catch up with family two nights per week when she was well, and staying 24/7 when she was ill. She was often ill.



1st week home and she learns to crawl - 15 months



1st steps using a posterior walker - 19 months



A total of 15 months in hospital - she just loves being outside



Weekly bath time before dressing change



The Wiggles are her absolute favourite

Pumpkin was born with Gastroschisis and lost most of her bowel at birth. She had an NG tube, ostomy bag and a central line. She couldn't suck from a baby bottle and barely ate anything (soon becoming totally oral averse). Her TPN and gastric feeds ran 22 hours a day.

Quite quickly, I started understanding that tubes ain't tubes! Her NG tube was no issue. Her central line, however, was a whole new world.

And so, we started our daily lessons. At first, it felt overwhelming. I thought I knew how to wash my hands, having done it all my life. Now, I learned how to really wash my hands. We learned what it meant to create a sterile field, what key components are and how everything fits together. I learned how to maintain sterility; how to scrub, glove up and then manage my glasses sliding down my damn nose. I spent forever learning how to confidently open sterile packets without touching the contents. To drop lines, swabs and syringes on to my sterile field and not the floor. Then, we had to learn the process of hooking up and coming off TPN. Wowsers! I had flashbacks to the teen anxiety of learning how to drive and of thinking to myself "I will never be able to do this without feeling utterly stressed!"

In the meantime, I was falling in love with this little girl. Several weeks after meeting her, she suddenly became very seriously ill with Klebsiella Variicola sepsis. Her central line and peripheral blood tests came back positive in just 3 hours. One of her paediatricians came to see me early in the morning after I'd spent a sleepless night holding her febrile little body, moaning and thrashing, in an armchair. Sepsis had been causing such severe pain that they'd given her endone. The doctor's eyes welled up as she told me "This is serious", and she then apologised for being emotional. I thanked her and told her how much it meant to know that the medicos loved Pumpkin. We prepared to airlift her to Sydney when she took a small turn for the better. Turns out that two of the three potent antibiotics pumping into her happened to be the right ones.

It also turned out that this little one already had a firm grasp on my heart.

The week of her first birthday, Pumpkin came home. Her birth parents joined doctors, nurses and me in having a lovely party to farewell our girl. Her room and the ward were decorated with streamers and balloons, and nurses provided a lovely morning tea. Then, off we headed to begin our next adventure.

In the following few months, we were in and out of hospital. At a case conference before discharge, her paediatrician said she expected Pumpkin to be back in hospital every six weeks or so, given how many infections and lines she had in her first year (I counted 8 but could be more). We didn't even make it to six weeks between trips back to Club Med. On a month-long stay in September (Staph A and yet another central line), I started doing research. I realised I had to become Pumpkin's advocate. I found evidence and pushed the hospital to put her on Taurolock, an antimicrobial solution for locking central lines. Our hospital hadn't used it before and weren't keen to start, but I found studies backing up my request and it was eventually approved. In late September 2019, Pumpkin started using Taurolock. To date, she's had no further infections!

Once home and on slightly reduced HPN hours, Pumpkin made the best of her 4 hours of freedom each day to start exploring. Within a week of arriving home, she learned to crawl. By 17 months, she started weight-bearing on her legs if we held her arms. Within a few more weeks she could walk with a posterior walker. She was fitted with orthotics and orthopaedic boots. She had weekly physiotherapy, occupational therapy and speech therapy. Mostly, she had a home, family and a floor to play on all day long. Pumpkin took off...

In November 2019, the court granted long-term care orders to age 18 years. Much to our delight and relief, we were asked if we were happy to be her permanent family. She has loving birth parents who are still involved in her life but unable to meet her needs, and we are glad to involve them and keep them updated on our little warrior.

We are honestly thrilled to now be dealing with the "terrible twos". Our withdrawn, overly-compliant little girl has become a tantruming banshee, and I couldn't be happier. She's discovered her strong will. She protests medical procedures, refuses to lie still and constantly steals our mobile phones and remotes. Although her speech is delayed, she has caught up in all other areas.

And I've now got this medical stuff down pat. I no longer stress about hooking lines up or taking them down. I can manage most situations and know where to call for help when things go pear-shaped.

Mostly, we are just delighted to be parenting this wonderful little girl.

HPN Awareness Week October 11th – 17th 2020



Words by Chris

Due to Covid 19 restrictions, Home Parenteral Nutrition Awareness Week 2020 took on a new look this year. PNDU entered the world of virtual online meetings to help raise awareness and better understanding for Aussies and Kiwis living with the rare and complex life support treatment, Home Parenteral Nutrition (HPN). It went something like this:

PNDU is inviting you to a scheduled HPN Awareness Week update meeting.

Join AW 2020 Update

AW20 URL: <https://pndu.org/resources/dripline-newsletter/>

AW20 ID: "HPN: Pumped for Life"

Passcode: #HPNlife

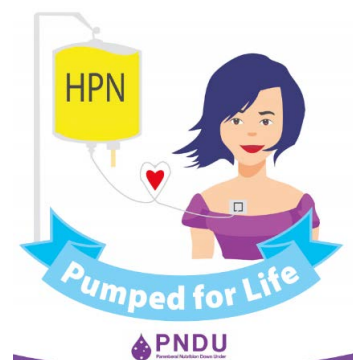
Update:

2,500 AW stickers were posted to over 200 PNDU members who proudly wore their stickers and shared their photos and stories on social media.

21 Hospitals and 4 Pharmaceutical companies received the PNDU HPN AW20 Video link with 11 able to utilise PNDU AW20 resources and host events during the week.

PNDU would like to thank everyone for your support of HPN awareness Week, (the biggest fundraising event on the PNDU calendar) - your time and effort, hosting online events, morning teas, lunches, education sessions and sharing HPN AW20 with your friends and colleagues, is very much appreciated.

Below is a snapshot of the week that was HPN AW20.





This year's AW Video piggybacks off the theme of 2020 – COVID 19, specifically leveraging the public health focus on handwashing as a link to shine some light on HPN and HPNers – for whom thorough handwashing carries a specific meaning – "Before, during and long after covid-19 passes.... For someone on Parenteral Nutrition, handwashing can be the difference between life or death in more ways than one."

To view the official PNDU HPN AW20 Video, please visit our website www.pndu.org or subscribe to the Parenteral Nutrition Down Under YouTube channel. <https://www.youtube.com/watch?v=ONB09iACHAw>
During HPN AW20 PNDU is pleased to bring you a special 2-part series of video messages.

Message 1: reflects on the challenging year for HPNers and a special thank you to all frontline healthcare workers who support us – Thank you Daniel for sharing.

To view the HPN AW20 Video Message 1: <https://www.youtube.com/watch?v=a86GmTvc52g>

Message 2: Do we really understand what it is like to live with HPN? Isolation and the need for support! – Thank You Sal for sharing.

To view the HPN AW20 Video Message 2: <https://www.youtube.com/watch?v=NRUeCiNRHQo>

A very big thank you to Miranda and her team for producing this series of fantastic AW20 Videos.

Show us your Stickers:

Once again it was wonderful to see our PNDU members and friends proudly wearing AW20 Stickers, a wonderful way to start a conversation with others about what HPN is and how it keeps our rare and special little group of Aussies and Kiwis alive. Thank you for sharing.





It's always wonderful to see our hospital teams joining in awareness week celebrations and sharing photos and stories.

John Hunter Hospital



JHH TPN team
Patrick Nay - Pharmacist, Justin Singleton -
dietitian, Peter Cocking - CNC, Ed Martinez
- ICU consultant

John Hunter Children's Hospital

Shared a HPN Patient story on their facebook page

Princess Alexandra Hospital

Azmat - organised an online meeting session, presenting a HPN case study, a guest speaker HPN patient telling their story and Dr Martin speaking about Revestive.

Royal Brisbane & Women's Hospital

Emma - @speacialistnutritionsupportteam were instagramming and tweeting all week, sharing videos and photos, helping to spread awareness for HPNers. Email – Bingo proved educational



Queensland Children's Hospital (Below)

I wore my shirt (except today) and we had a morning tea with the Gastroenterology team this morning. Posters and stickers were about everywhere at QCH and I rounded up our PN team faithful for this photo for you – we have other exceptional Dietitians and Pharmacists who support our patients who are not listed. Blessed to be a part of a brilliant team but more importantly care for a wonderful group of children and families who show us true resilience and optimism every day. (Katie)



From the Left of the photo, we have:

Pharmacist Lana Steward-Harrison, Gastroenterologist and HPN consultant Dr Looi Ee, Dietitian Julia Fox, and Katie Zajac.

PNDU resources – Playing HPN Bingo



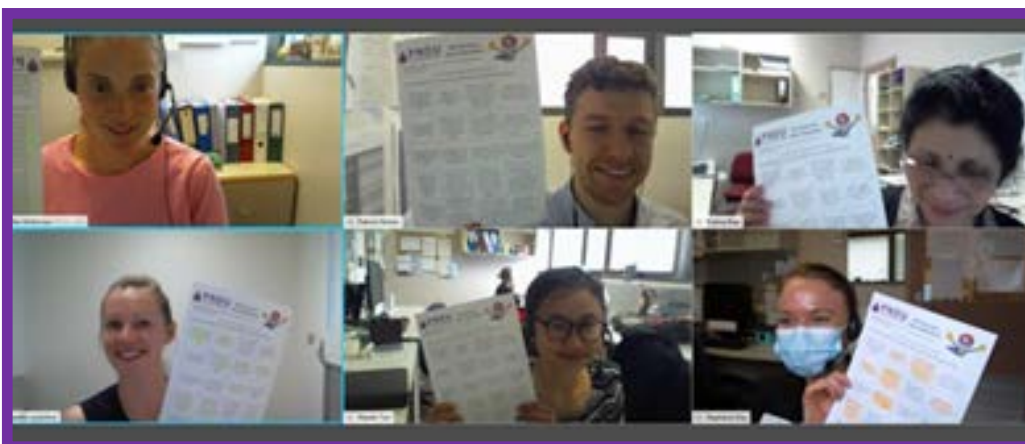
Utilising PNDU Awareness Week resources helps bring about a better understanding of what it is like to live with HPN – Monash Medical Centre and Royal Brisbane Hospital enjoyed playing HPN Bingo.

"It was great fun, and good to think about so many things that face our HPNers every day."

"A massive thanks to @pndownunder for the great opportunity to learn about #HPNlife from those living it"

"The resounding comments back from those playing this year's bingo was how much they learned about life on HPN."

"Playing HPN bingo provided an educational diversion that helped brighten a very busy week, very much appreciated"



Monash Medical Centre



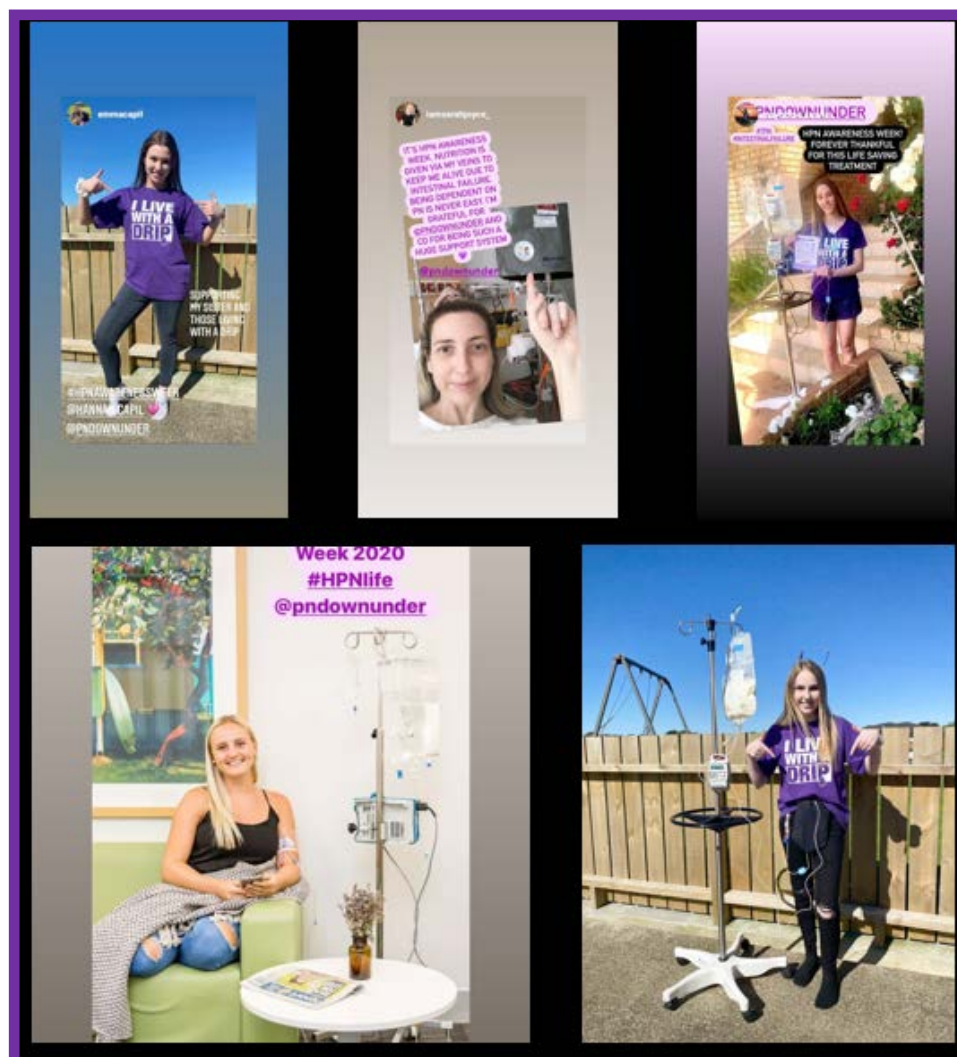
Royal Brisbane and Women's Hospital

Instagram – pndownunder



With pndownunder Instagram followers climbing to 100 during AW20 – PNDU members, friends and supporters were able to share the awareness week message HPN: Pumped for Life

#HPNlife @pndownunder





Takeda organised an online education session during AW – Miranda shared what it is like being a parent of a HPNer:-

A quick report on the presentation to Takeda - informal Parent of an HPNer talk. It went well and was very well received! Had a good turn out- over 70% of Takeda staff. Q&A was lively, too - questions about daily life routine, views on disability, outlook for future etc.

Always strange...for me, articulating to others what is normal for us, snaps me out of my usual "normal" and for a fleeting moment, you can see your life through their eyes.

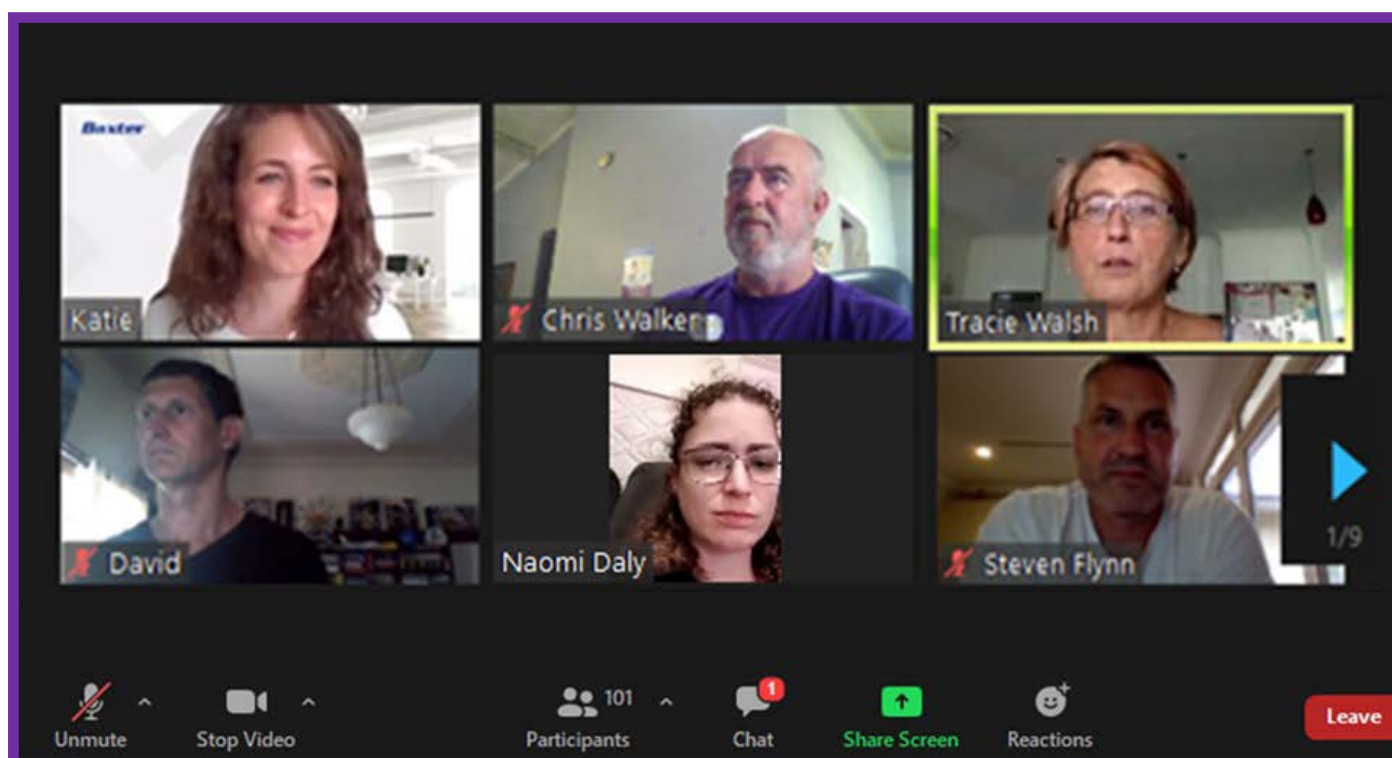
Miranda

Baxter online "Living with HPN" Session:



(Words by Katie on behalf of Baxter)

Prior to COVID, we would have had members from PNDU in each state and NZ Islands present to individual Baxter teams. We would have had a lot less faith that the virtual presentation would reach enough people. I am blown away by the support of the Baxter team; we had over 100 staff members from all different areas of the business dial in to listen to Tracie and Naomi present. We had a constant stream of engaging questions throughout the presentation and I am still getting comments and questions today, a week later, from colleagues who were touched by the conversations we were having in raising awareness for Intestinal Failure and HPN. Tracie and Naomi spoke so well about both the challenges and positives of living with HPN. I can't thank them enough for sharing their stories on behalf of the HPN community. It has really inspired Baxter to think about what else we could do to support HPN. (Katie)





Although it's not always possible to organise events or share your photos, PNDU is very grateful to all the companies and hospitals who in some way have contributed to AW20 without your support it would be difficult to share the HPN message throughout the wider community – thank you for sharing our message on social media – in newsletters and on your websites. We look forward to sharing your involvement in the future.

New Zealand National Intestinal failure Service (NZ NIFS)

Australasian Society for Parenteral and Enteral Nutrition (AuSPEN)

Fresenius Kabi

Children's Hospital Westmead

Gold Coast University Hospital

Sydney Children's Hospital

2020 certainly has presented many challenges for everyone. PNDU would like to thank you for being part of HPN Awareness Week 2020. PNDU's mission is to support, research and inform consumers, carers and providers of Parenteral Nutrition for Intestinal Failure across Australia and New Zealand. To help PNDU achieve this, we rely on your support and generosity. To find out more about HPN, or to make a tax-deductible donation, please visit our website www.pndu.org

Thank you
Chris Walker
PNDU President

A Day in the Life of these 'HPNers' – the Baxter Executive Challenge



Background:

During 2020's HPN Awareness Week, Baxter executives accepted the PNDU challenge to simulate a day in the life of a HPNer.

Our Baxter Challengers were:

Steve: General Manager ANZ; Phil: Director of Quality and Country Manager NZ; and David: Director Nutrition and Medication Delivery

Each wore a backpack with pump and 2.8L bag of HPN (activated and primed, then clamped off) to get a glimpse of what a day with HPN is like.

It was hopefully a very valuable experience in raising awareness for HPN use at home and just how amazing HPNers and carers really are.

During the day, PNDU president Chris organised with Baxter product manager Katie, to send them text messages to simulate pump alarms, including low battery and having to find a power point for a couple of hours.

PNDU very much appreciate the time and commitment Baxter put in to make this challenge as realistic as possible, thank you for participating.



The HPN Challenge:

What did you think of the processes when you were learning to set up for the challenge?

- David: I was amazed at how many boxes were arriving at my house and each was full of equipment that somehow had to be integrated to each other.
- Phil: Wow, how easy my normal mornings are and how much HPNers need to be on the ball every day to avoid infection.
- Steve: The challenge provided great insight into what it takes to be a HPNer. The hygiene requirement and preparation for connecting and disconnecting to the therapy are far more demanding and important than I had previously appreciated.

How did wearing/carrying the backpack make travelling to and from work different?

- David: I was working from home, but I did have a lower back complaint by the mid-afternoon. I did walk with the backpack in my lunch break around the block which was slightly uncomfortable.
- Phil: The packs are heavier than expected and it would take time to feel comfortable having people look at you and ask why are you wearing a backpack?
- Steve: During this COVID period, I was working from home and on Zoom calls most of the day. I did continuously forget that I was connected which is something that would be very difficult to get use to and is a real eye opener, especially when you get up quickly to make a coffee in between calls and the feeding line pulls at you and abruptly reminds you that you are connected to this life saving therapy for 12 hours.

How would you explain to others why you are wearing the backpack and having the line connected to you? (Especially at the shops or airport or even to police or in the theatre when they ask you to check your bag into the cloakroom)

- David: I would say it was complex medication I need to live and show them the line with PN in it if it was connected.
- Phil: I explained the Day In The Life initiative but then explained that our patients have this every day to keep them alive. I did use the old 'Big Mac' in a Bag once or twice. I was just open and honest about what it was, but also understand from a security perspective people might have questions.
- Steve: Other than explaining to my family and a few colleagues on video calls I did not have to explain the situation to anyone. Everyone that I spoke to was very supportive of the challenge and wished me and the team well in helping to raise awareness of HPN.

Comment on having to wear the backpack all day. What is the most unexpected aspect of this challenge? What part of your daily life did this experience have the most impact on?

- David: The most unexpected aspect was that you are connected to something and can't move around impulsively. The most impacted parts of my day were the increased planning required when moving around the house or going for a walk, it would be even greater if I was travelling or very active during the day.
- Phil: Most unexpected was the prep time and the weight of the pack on my shoulders. The biggest impact was my inability to freely move around, having to think and prepare for even moving rooms in the house.
- Steve: Due to constantly forgetting that I was connected, I reverted to wearing the backpack which required me to stand up during my virtual meetings. After a few hours the backpack weight did make it a little uncomfortable. You certainly need to be more prepared and think ahead as a HPNer. I got up earlier to fit in my run knowing that I needed to prepare for connection at 7:30am. Having to change my shirt mid virtual meeting was made easier, given I was home but if I was out and about or in the office, I would have needed to remember to pack a change of clothes. *(Editor: the 'HPNers' had an ostomy bag 'accident', requiring a change of shirt.)*

How did the interruptions – pump alarm, low battery requiring connecting to power for at least 2 hours, stoma accident requiring change of clothes – affect your day? How did you feel when they occurred?

- David: I felt it was important to address these as it would affect my health, even though for the day mine weren't for real, but I felt a lot of empathy for people who had to have these interruptions "for real". Out of respect for HPNers, I treated the "alarms" and the challenges seriously and addressed all the interruptions.
- Phil: The interruptions were an eye opener to the fact that they need to be addressed with urgency and stop what you're doing. It puts perspective into what I classed as critical in a normal day.
- Steve: These were all made a lot easier given I was working from home. For example, during the low battery recharging I was on a virtual call so it was not a major inconvenience to recharge the pump. However, I can appreciate that if you are on the move this would be a major inconvenience.

Did work colleagues respond to you differently? If so, in what way?

- David: I was on Zoom calls so I explained what I was doing with a backpack on and explained the set up I had for the day to everyone I spoke to.
- Phil: They all asked about the pack and I'd explain what it was for. They all thought it was an excellent initiative and cool that we were doing it to raise awareness for HPN.

Consider what HPN is like for babies, toddlers and children. Imagine tethering your toddler to a pole with about 1.5 metres of space to move, for 20 hours every day. How would you manage an active toddler who wants to crawl, climb, run and jump but is too little to carry their backpack or push around an IV pole?

- David: I can't imagine it. I have nothing but admiration for parents/carers of these kids, it will drive me to improve every aspect of Baxter's service to the HPN community.
- Phil: I honestly couldn't imagine. I had trouble with myself. Absolutely hats off to the parents of HPN children - they are absolute superstars.
- Steve: I can only imagine. I felt a bit like a child every time I forgot I was connected. I personally commend all the parents and caregivers of babies, toddlers and children on HPN. You are the everyday heroes.

Do you think that being an HPNer for the day has helped you to empathise with Baxter's HPN patients/clients/recipients/consumers? Imagine you were told you would have to do HPN every night/day for the rest of your life...how would you react? What would have to change in your life?

- David: 100% It was a humbling experience. I would like to make this an annual experience for Baxter staff. It would be a huge challenge to be connected for the rest of my life and it would change everything; job, family time and activity levels.
- Phil: For sure! I'm happy that Baxter was looking after me and that we have a team, like Katie was for me on the day, looking out for HPNers. I would adapt as I would have to, but wow, gosh, I really don't know how I would react. Priorities in life would have to change significantly, work, travel, leisure and family time would all be affected. I would have to be more organised.
- Steve: Absolutely. Putting yourself in the shoes of others even if it is only for a day really helps your understanding and empathy. Initially I would be overwhelmed and scared. I would have many questions. For this very reason the work done by PNDU of supporting, connecting and advocating for patients is so critical. I would need to be far more diligent and prepared. It would affect my life significantly. It is life changing and I would certainly need to make the necessary adjustments to my routine.

From your experience in undertaking this challenge, do you have any ideas for improving the patient experience?

- David: Not yet, but we will continue to listen to HPNers and improve. Biodegradable tape was a great idea I gleaned from the presentation by Naomi and Tracie on Friday. Also exploring other pumps, backpacks and lines so patients can choose what best suits them.
- Phil: Power cords are too short; ensuring pump battery life is good; maybe reviewing backpack sizes.
- Steve: The experience has helped me gain a glimpse of life on Home PN. I have a greater appreciation of the therapy and how all the components (backpack, pump, line, bag of Parenteral Nutrition, Training, etc) need to work for the patient. Personally, I would improve the look and comfort of the backpack to start with.

What's in your Bag? [Part 3] Iodine



Words by Prof Gil Hardy

Editor's note: This article is written by Prof Gil Hardy for Dripline. Prof Hardy is a retired Professor of Clinical Nutrition, who helped found PNDU and is a Life Member. Together with colleagues at St Mark's hospital in London, he invented the first 3 litre bag for PN in the 1970's and has collaborated with Nutrition Support Teams in UK and New Zealand ever since. He has published over 250 papers on parenteral nutrition and has written several articles, and adapted others, for Dripline. He is a past chairman of the international clinical nutrition section (ICNS) of the American Society of Parenteral and Enteral Nutrition (ASPEN) and has just been appointed, as the first director from outside North America, to the ASPEN Board of Directors.

Iodine (I) is an essential trace element that occurs in soil, plants and sea water. There are consequently traces of iodine in all foods, but ocean fish are the best natural source.

Unfortunately, in many parts of the world, such as Australia, New Zealand and UK, soils and crops are iodine deficient resulting in inadequate intakes. Since the only known function of iodine is for thyroid hormone synthesis, iodine deficiency (ID) will lead to inadequate thyroid function. Thyroid enlargement (goitre) is the classical sign of chronic ID, which was common in the early settlers 'Down Under' until table salt was fortified with iodine. Chronic intestinal failure (CIF) patients with a normal duodenum, who are able to eat, may absorb dietary iodine but this quantity may be reduced in short bowel syndrome (SBS) patients.

The recommended daily iodine intake for adults is 150 mcg, with extra needed during pregnancy for the lactating breast. In healthy adults about 90% of dietary iodine is absorbed in the stomach and duodenum and then about half is transferred to the thyroid (a process which is inhibited by cigarette smoking). A high dietary intake of iodine (up to 1mg/day) is well tolerated by most healthy adults, but some adverse reactions, such as headache, fever, metallic taste, gastrointestinal irritation and acne have been reported.

It is therefore important for your NST and/or GP to assess iodine nutrition status using several complementary tests:

- Urinary iodine (UI) is a measure of recent iodine intake. Low UI indicates insufficient iodine intake and suggests a high risk of developing thyroid dysfunction
- Thyroid function tests for Thyroxine (T4) Triiodothyronine (T3), Thyroid stimulating hormone (TSH) and Thyroxine binding globulin (TBG) which is synthesised in the liver, provide an index of iodine intake over past weeks to months. TSH is a good marker of iodine intake in newborns, but in older children and adults, TSH is relatively insensitive, so serum concentration alone is not a good marker of ID
- Thyroid size is related to long-term iodine intake.

It always used to be assumed that ID was unlikely to occur in CIF adults on HPN. Iodine absorption from iodine-containing antiseptics, radiographic contrast dyes and absorption of dietary iodine by patients with a functioning duodenum, were thought to be sufficient. However, there is no iodine absorption in CIF patients totally fed by PN, and some patients who are exclusively fed by enteral nutrition (EN), may still have inadequate iodine intake, depending on the amount of iodine in the enteral formula. For these reasons, AuSPEN advocates routine supply of 100-130mcg/day iodine in their HPN guidelines for adults. For children a daily PN dose of at least 1mcg/kg/day has been recommended. The most recent ESPEN/ESPGHAN guidelines on paediatric PN published in 2018, draw attention to the potential for ID, especially in older children, for whom they recommend up to 10 mcg/kg/d, with regular monitoring of TSH for long term/HPN. Supplementary iodine is included in the PN bag, usually as part of a multi-trace element additive, in the compounding unit.

A recent publication by a leading European HPN expert, questions some of the earlier assumptions about the adequacy of iodine in PN patients and concludes that HPNers may have an increased risk of ID. Italian researchers examined the amount of iodine supplied in the PN bag to CIF patients on long term PN. Only 26% of patients received iodine in the range recommended by ESPEN. 19% patients received less, while 55% received no iodine at all. Even those patients who received a PN iodine supply according to ESPEN guidelines had a low UI. SBS-patients had lower UI than non-SBS, but TSH was low only in 22% of patients. Interestingly, all subjects used chlorhexidine instead of povidone-iodine antiseptics for their lines, and this fact, coupled with low oral intake, seem to be the predisposing factors to low iodine levels.

Iodine requirements for CIF patients may therefore have been underestimated and more research needs to be conducted in large cohorts of patients to better define iodine requirements in long term HPN. Nevertheless, these results would suggest a need for more frequent monitoring of HPNers iodine status to prevent iodine deficiency occurring.

Congratulations to our 2020 PNDU Award winners



During PNDU's 2020 AGM in August, we had the great pleasure of announcing this year's PNDU Professional Award winners. The PNDU Awards provide an opportunity for PNDU and our members to recognise the many dedicated people who work tirelessly to improve the quality of life of Aussies and Kiwis living with Home Parenteral Nutrition Down Under.

On behalf of all PNDU HPNers and carers, congratulations to all our Award winners and thank you for your hard work and dedication.

All PNDU Award winners receive a special award certificate and their names are included on PNDU's Roll of Honour. To view the list of PNDU Award winners visit our website: - <https://pndu.org/resources/pndu-awards/>

Thank you to everyone who nominated someone special for an award.

PNDU's Professional Award winners

(judged by our PNDU Professional Awards judges Dr Sharon Carey & Prof. Gil Hardy).

Outstanding Achievement Award: - Jane Gillard, Assistant Director of Pharmacy – John Hunter Hospital

Adult PN Professional of the Year: - Terry Tremain, Clinical Nurse – Fiona Stanley Hospital

Paediatric PN Professional of the Year: - Michael Purcell, CNC – Sydney Children's Hospital

Commitment to Care - Company Employee of the Year: - Katie Barovs, Senior Product Manager – Nutrition – Baxter Healthcare

PNDU Lifetime Membership Award: - Chris Walker HPN Carer – PNDU President.

Award Presentations

Paediatric PN Professional of the Year: - Michael Purcell

Michael was nominated by Miranda (Carer of child) and Belinda (Carer of child):

'Michael works as a CNC at SCHN, he goes above and beyond for his patients. In a recent stay in hospital he went out of his way to check on our son and advocate for us when we felt that the teams weren't listening. He would take our son for walks up the street and play games with him, often spending a few hours several times a week making sure that Aidan was cared for and had support. He would ring or email us daily as well to make sure that things were ok, including on weekends when it was his day off.'

'Michael is an outstanding CNC who not only provides exceptional care and professional advice but does so in the most caring and family-centric way. Michael consistently goes over-and-above his duties –Michael is exceptionally thorough, reliable and professional in everything that he does - he never fails to follow through on anything that he undertakes to do. He really listens and is genuinely, absolutely committed to supporting Ariel and us (her family) to provide the best quality of life for her.'



Michael receiving his Award from Ariel (HPNer)

Adult PN Professional of the Year: - Terry Tremain

Terry was nominated by Kelly (HPNer)

'Terry is the point of call for all of us on TPN who attend Fiona Stanley Hospital. She is a friendly, kind and beautiful person who strives to help her patients in every way possible. She researches new treatments, procedures, formulas and takes the time to know the specific needs of all those under her care. Terry is also there for every appointment, advocating for my needs. She isn't afraid to voice her opinion about my treatment plan, seeking alternatives to put to my specialist that suits my medical requirements better. She speaks a normal 'unmedicalised' language I, as a patient, can understand, whilst being respectful and accurate. When I am admitted into the hospital, she is one of the first people from all my teams to pop in and see if I need anything and to ensure all my TPN needs have been addressed. Terry is the meaning of patient-centred care, and I feel extremely fortunate to have her on my team. Being on HPN can be very isolating and frightening at times, especially given many of us have serious health conditions that put us onto TPN in the first place, but Terry is always there to give assistance where she can and a listening ear when things aren't going so well. It is a comfort to know she is there to guide my care and ensure I get to enjoy my life despite TPN being necessary.'



Terry receiving her award from Kelly

Commitment to Care - Company Employee of the Year: - Katie Barovs

Katie was nominated by Sal (HPNer), Chris and Brooke (Carers of children)

'Katie has always provided support with PN pump problems, organising replacement pumps on overnight transport and follow up phone calls to ensure our problem was resolved.'

During the summer bushfires when we were holidaying on the NSW north coast our PN deliveries were disrupted when fires closed the highways, Katie went over and above to ensure we had spare PN bags on hand and rang daily to keep us updated on the delivery situation. This was very comforting for us, as we were very unsure what to do during the time we were cut off.'

'I have always found Katie very helpful, planning holidays in remote outback Australia. My PN would always arrive at the pre-planned destination without complications. Katie would always ring me to let me know the progress of my PN deliveries.'

'Katie Barovs has always gone above and beyond her normal duties as a Parenteral Nutrition Product Manager. Katie will liaise with Baxter Home Care services and Home Parenteral Nutrition patients to help rectify any problems with HPN and consumable supplies, along with any issues concerning HPN pumps. Katie organises annual Baxter Pharmacy tours during HPN Awareness Week, always ensuring the tours are interactive, informative and enjoyable to attend. Katie has also been very supportive of PNDU activities, especially during Awareness Week, helping to circulate PNDU printed resources. Katie produced a video and developed a new website for HPN patients, to help with the transition from Hospital to Home. Katie is always quick to follow up on any problem and always replies in a positive way, wanting to do everything possible to support the HPN community.'



Katie receiving her award from PNDU President Chris

Outstanding Achievement Award: - Jane Gillard

Editor's note: Unfortunately, there is no picture available of Jane receiving her award.

Jane was nominated by Fay (HPNer) and Brooke (Carer of Children)

'Jane has always been very positive and supportive during difficult hospital admissions. Jane has always gone over and above to resolve issues with the supply of our Parenteral Nutrition. When we have encountered problems with leaking PN bags and Baxter have been unable to deliver a new bag until the next day, having a bag of PN ready for us to pick up at the hospital and avoid an overnight admission is exceptional.'

'Jane has been looking after my TPN and medications for about 18 years and is always available on the phone. Over these years I have observed and been amazed by her vast knowledge of drugs and their uses etc. I have come to consider her a friend. In fact, she was the one who introduced me to PNDU in the first place by inviting me to attend a workshop on the Gold Coast, which led to a meeting of the PNDU members in a hotel room on the Gold Coast.'

Lifetime Membership award – Chris Walker, PNDU president

Chris was nominated by Gillian (HPNer) and Katie (Carer of children).

'Working hard for PNDU on the Management Committee; attending conferences and speaking on behalf of PNDU; lobbying politicians and telling members how to do the same; speaking at Parliament House on behalf of Rare Voices Australia and PNDU; attending meetings with pharmaceutical representatives and AuSPEN representatives; etc'.

'Chris has been caring for 3 family members on Parenteral Nutrition for 20 years. He joined PNDU in 2013 and became a member of the Management Committee in 2014.

Chris has helped link PNDU with many organisations to help raise awareness and support for Chronic Intestinal Failure as a rare disease.

Chris gives generously of his time as a public speaker attending Parliament House in Canberra, AuSPEN, AVAS, IVNNZ, NZNIFS conferences and as a member of working groups, lobbying politicians to implement a National Plan for rare diseases in both AUS and NZ.

Chris works tirelessly for many hours each week to help improve the quality of life for everyone living with chronic Intestinal Failure requiring Home Parenteral Nutrition across Australia and New Zealand.'



Chris with his lifetime membership award



Words by Sal

Hi all, thought I would share a funny story to make you smile:

On Friday I went and caught up with some good friends. They have a pet bunny named Barbara. Barbara gets to play out of her hutch when they are home. So, Barbara was out exploring the lounge room. We were warned that she likes to chew things, especially power cords, so we were watching her all night. She was very cute, like a puppy, coming up to you for rubs. Near the end of our evening I happened to wind up my tubing as I often do as a fidgeting habit. And lo and behold, PN was spurting out of several little holes. And you can guess how they got there!!! It turns out that Barbara is a stealthy bunny, too. I had to disconnect immediately, of course.

All I could think of afterwards was images of a scene from Monty Python's Holy Grail, where Tim the Enchanter, played by John Cleese, describes the killer bunny that guards a cave as having 'nasty sharp teeth'. But they ignore the warnings of the enchanter and go to the cave, only to get massacred by the bunny! So, at this point, I'm hoping Barbara isn't the killer bunny and so far, so good. Hoping the final score is Taurolock 1 and Bunny Bugs 0 (not to be confused with Bugs Bunny...and hoping I can avoid saying 'What's up Doc!!')

Upcoming Events



No events scheduled for November to January, due to Covid 19 restrictions.

Thank You



PNDU is very grateful for the generous support given by the donors listed below. We wish to thank the following for their generous gift. Total Donations, \$3,509

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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.)

Donating via direct deposit

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Management Committee Members

President - Chris
Vice-President - Gillian
Secretary/Public Officer - Miranda
Treasurer - Belinda
Editor - Gillian
Committee Member - Fay and Ryan

Contact Us

Parenteral Nutrition Down Under Inc. ABN 49742201085
contactpndu@gmail.com | www.pndu.org
Registered address: 128 Rainbow Street, Randwick NSW 2031, AUSTRALIA
 PNDU Inc.'s privacy policy is available on our website www.pndu.org

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Designer: MBE Hurstville