



DRIPLINE



PNDU

Parenteral Nutrition Down Under

In this issue, read about the many ways that HPN Awareness Week 2023 was celebrated, by members, hospitals and our pharmaceutical HPN providers. Read member, Sarah's, story about the difficulties that some members have when trying to socialise at food venues. And, if you didn't know about it, request a PNDU restaurant card. Sadly, though, we have had to add 2 more names to PNDU's In Memoriam honour roll this issue. Our sincere condolences go to these families.

Gillian
Editor

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When: 12th November 2023

Time: 10:00am – 3:00pm

Where: Outhwaite Hall

1A Outhwaite Lane, Grafton, Auckland NZ

BYO food and drink

The PNDU annual social gathering is held alongside the AuSPEN conference each year. This year we are visiting Auckland, New Zealand and would like to meet as many HPNers, family and carers as possible. The annual gathering is a great opportunity to meet other HPNers who share a similar journey of HPN Our Life, share stories, make new friendships, and learn more about PNDU and what we do.



We hope to welcome as many HPNers their Families and Carers as possible at this wonderful 'Free of Charge' event.

PNDU gatherings are open to all HPNers, Family and Carers.

To register for the gathering. Please contact pndu@gmail.com

Outhwaite Hall is located opposite Auckland Domain and situated on Outhwaite Park.

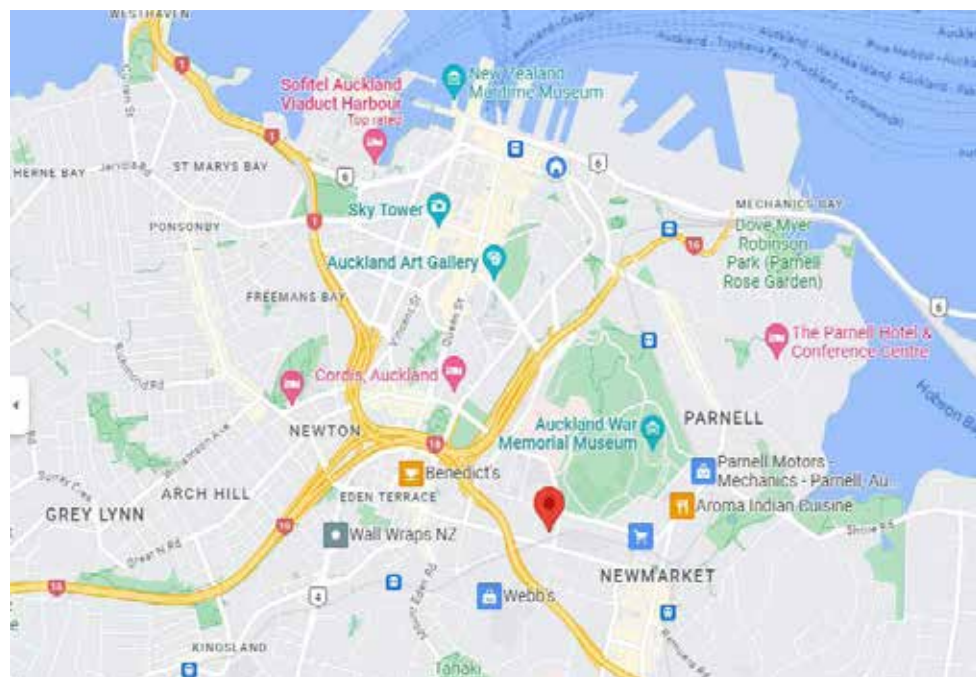
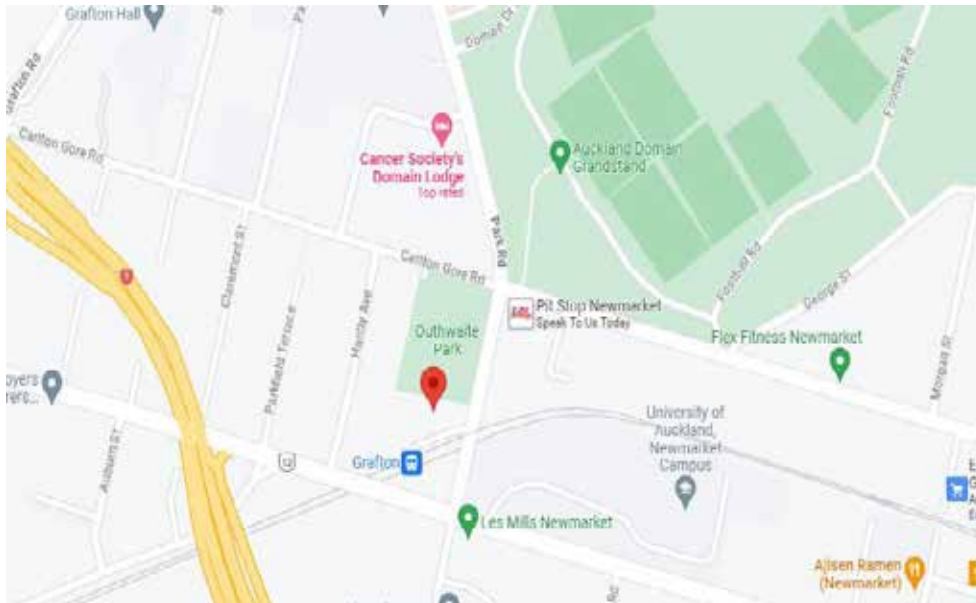
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<https://www.google.com/maps/place/36%C2%B051'54.5%22S+174%C2%B046'12.9%22E/@-36.8582275,174.757617,14z/data=!4m4!3m3!8m2!3d-36.86513!4d174.77026?hl=en-US&entry=ttu>

[Or see map below](#)

36°51'54.5"S 174°46'12.9"E

-36.865130, 174.770260





The PNDU Awards are a way of recognising the great work of members in their efforts for PNDU, as well as health professionals and industry in their dedication to providing high quality care for those living with Home Parenteral Nutrition in Australia and New Zealand.

It's wonderful to see the PNDU Awards return after a 3 year break due to covid restrictions. I would like to thank all of our PNDU members who voted for your special team members, a true reflection of the love, care and appreciation within the HPN community.

Congratulations to all of the 2023 PNDU Winners.

Lifetime Membership Award: Renee Koonin

Life Membership is a special award for any member who, as an HPN consumer, parent or carer, has given their time "over and above" for PNDU. It is the highest accolade that the group can bestow as a token of appreciation for the individual's exceptional contribution to development and growth of the group's support for people on HPN.

Renee was nominated by the PNDU Management Committee, a unanimous decision for Renee's dedication to PNDU. Renee has been a member of PNDU since January 2012 and one of the administrators of the PNDU Facebook page since its launch in 2014. A very active and supportive member, Renee has attended PNDU gatherings, regularly posts on the PNDU forums and is the first point of contact for most of our new members.

Congratulations, Renee.

PNDU Professional Awards

The PNDU Professional Awards are a recognition of positive efforts by health professionals and industry to provide good quality service to HPN consumers in Australia and New Zealand.

Adult Parenteral Nutrition Professional of the Year: Emma Osland

This award is for a nutrition professional who has gone above and beyond what is expected of them in their day-to-day role. This could include taking on additional duties, running a special project or charitable work related to IF and/or HPN.

Emma is a Dietitian at Royal Brisbane and Women's Hospital QLD. Emma has been nominated for this award several times in the past for her support of PNDU and working closely with the Specialist Nutrition Support Team at RBWH to deliver outstanding HPN Awareness week engagement activities. In 2023, Emma was nominated by the PNDU Management Committee for her ongoing support of HPNers across Australia and New Zealand. Emma has presented at the AuSPEN HPN Consumer workshop and is an active member of the AuSPEN HPN Model of Care working group, and the QLD HPN Steering committee, Emma is dedicated to improving the lives of all HPNers and establishing a national model of care for HPN in Australia.

Congratulations, Emma.

Paediatric Parenteral Nutrition Professional of the Year: Katrina Robertson

This Award is for a paediatric nutrition professional who has gone above and beyond what is expected of them in their day-to-day role. This could include taking on additional duties, running a special project or charitable work related to IF and/or HPN.



Photo: L – R Steve C., Katie (Katrina) Robertson, Lucy C. Photo: Katie (Katrina) with Harper (HPNer)

Katrina is a Clinical Nurse Consultant at Monash Children’s Hospital, nominated by PNDU Member Lucy who wrote, “Katie stepped into the role of home TPN nurse at the beginning of our HPN journey with our then 3-month-old. Katie jumped right in the deep end and has been an absolute blessing in our lives in a crazy time. Full of knowledge, a fantastic teacher, easy to communicate with and most importantly a brilliant supportive nurse. Katie goes above and beyond at ensuring our family has everything required, that we know and understand what is going on, and showing excellent patience and understanding when we just need someone to listen. I wholeheartedly appreciate this lady beyond words and she deserves the recognition.”

Congratulations, Katrina

Commitment to Patient Care – Company Employee of the Year: Andrew Nguyen

This Award is in recognition of an individual company employee who has shown exceptional dedication and compassion above and beyond their day-to-day role. This could include taking on additional duties, providing excellent service or charitable work in support of PNDU members.

Andrew is Product & Education Specialist – Nutrition, NSW North Baxter Healthcare

Nominated by PNDU members Katie and Brooke. Andrew also received mentions for this award from other PNDU members, all who spoke highly of Andrew’s support and dedication to training PNDU members during the changeover to the new Micrel HPN Pumps.

Congratulations, Andrew.



Photo: Andrew Nguyen, Chris Walker (PNDU President), Claudine Daniel (Product Manager, Nutrition at Baxter)



By Sarah

In 2016, I was lucky to survive Meningococcal Disease. But not 'lucky enough' to not be left disabled, having experienced multi organ failure, amputations, over 65 operations and a kidney transplant. Now I live with a range of newly acquired disabilities and chronic illnesses, including gastroparesis and intestinal failure, and as a result I have been on Home Parenteral Nutrition (HPN) for many years.

PN is a complex mix of intravenous nutrition via a central line that sits in the opening to my heart. It provides my body with everything it needs to survive. I am hooked up to this for 15 hours, 6 nights a week. It is rare with only approximately 320 people in Australia living on PN.

This is how I "eat". This is how I stay alive.

Lately I have been eating scrambled eggs orally - not because I am better in any way, but because I want to and for my mental health. I had to have clearance from my medical team that this was ok to do. This is one of the easiest and only foods for me to enjoy.

Yes, this gives me a lot of pain and discomfort, but that brief moment of eating is something I enjoy (until the pain starts that is!)

How would you feel if you literally could not eat at all? No sharing a meal with friends, or catching up for lunch, or Christmas dinners. Think of the mental and social impact that this would have on a person's life.

I have now discovered (the hard way) the lack of accessibility and inclusion in cafes/restaurants for someone with a disability and chronic illness.

Recently I went with my mother to an eatery. I usually sit there and watch other people eat, which I have done for well over four years, and this doesn't get easier. I always study the menu as it distracts me from everything going on around me. In this instance when studying the menu, I noticed that they served a fried egg on a burger.

Feeling very hesitant about asking, mum decided she would go and ask the wait staff if it were possible to have a scrambled egg (as they are already frying an egg to put on a burger). She explained my disability

and her reason for asking.

Immediately the chef said "No". I then became aware that all the wait staff were looking at me and I honestly wanted to melt away into my chair.

The feeling of shame, guilt, worthlessness and embarrassment consumed me.

I wondered why I put myself out there only to get shut down and reminded just how much people don't understand what accessibility means.

Would you ever feel you had to disclose your medical information in order to gain access to food? Menus usually mark food for allergies (eg gluten/dairy free) and dietary requirements (vegetarian, vegan) without people having to ask, but when someone with a disability is forced to ask for their needs to be met it goes unheard?

Another example I experienced is attempting to book a table at a restaurant. I have not sat at a restaurant table with my girlfriends and eaten a meal with them in countless years.

I searched and searched and found a place that does an all-day breakfast. Brilliant, I can have scrambled eggs! However, when it came time to book a table for 10 or more people, you were required to pay a \$100 deposit. And then on the day of your booking you are deducted per person who does not attend.

While I understand businesses needs for deposits, as they do have a business to run and Covid hurt most of the hospitality industry - but this feels like another layer of feeling excluded if allowances can't be made in special circumstances for the chronically ill or disabled.

Yes, they accept walk ins, but how can people expect those with a disability or chronic illness to stand and wait for a table for who knows how long. Living with chronic illnesses and disability can make your life extremely unpredictable, so there could be a chance of myself or other guests not being able to attend last minute.

This cancellation policy is like being fined for trying to be included in society, when your body can unexpectedly prevent you.

It's not about the eggs... It's about accessibility and inclusion.



PNDU's Management Committee developed a restaurant card several years ago. It is useful for members such as Sarah, who want to be in a restaurant or café with friends or family – or even by themselves – but feel awkward or unwelcome if not ordering food, or food from the adult's menu. It is not a legal requirement for people to follow the instructions on the card, but rather the card gives a bit more authority to a member's request as it has an official look and is from an incorporated, registered organisation, so hopefully restaurateurs are more likely to be cooperative. For members wishing to have a card, email your request to PNDU's email address, contactpndu@gmail.com.

Below is the front and back of the restaurant card.

Restaurant Card

For people who are fed intravenously
(Parenteral Nutrition)



contactpndu@gmail.com
www.pndu.org



I have a serious digestive disorder which limits my ability to eat.

Most or all of my nutrition is infused through an i.v. drip
(Parenteral Nutrition)

Please allow me to order a smaller portion, share a plate, order from
the children's menu, or not order anything at all.

Thank you for your consideration.
PNDU Member
www.pndu.org

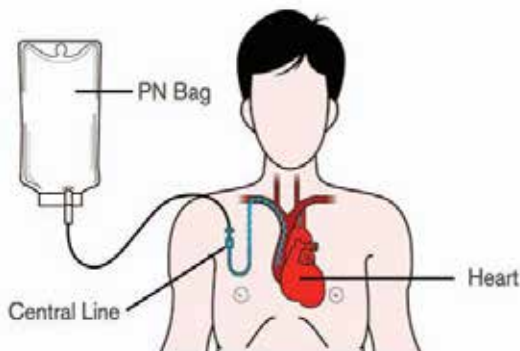


HPN Awareness Week is a wonderful time for HPNers to connect with the wider community and help to bring about a better understand of what life is really like living with the rare and complex condition Chronic Intestinal failure requiring Home Parenteral Nutrition.

What is HPN?

HPN stands for Home Parenteral Nutrition. It is a highly complex life support therapy performed at home by those who cannot get enough nutrition from food to live. This happens as a result of a serious problem with the digestive system (Intestinal Failure).

Parenteral Nutrition (PN) is food in a liquid form which is pumped into the body via a tube in a major vein close to the heart. This liquid food contains all the essential nutrients our bodies need to live, but because it's pumped directly into the bloodstream, it must be kept completely sterile and all setup connections and procedures must be kept sterile (aseptic). This is to minimise infection risk from bacteria entering the bloodstream (sepsis).



When this is done at home - usually overnight – it is called Home Parenteral Nutrition (HPN).

Various diseases and medical conditions can cause Intestinal Failure and the need for someone to be

on HPN, a number of these diseases being quite rare. They include: Gastroparesis, Chronic Intestinal Pseudo Obstruction, Hirschsprung Disease, Hollow Viscous Myopathy, Malrotation Volvulus, Short Bowel Syndrome, Crohn's Disease and intestinal cancers.

HPN is highly complex and there are serious risks and possible complications, but it allows approximately 320 adults and children across Australia and New Zealand to live at home and be involved in life.

HPN Awareness Week Video

The release of the PNDU video was a fantastic way to kick off HPN awareness week. The video is produced by PNDU Secretary Miranda and her team, a light-hearted look at what can happen when you ask AI a question about "Living with a Drip". With over 5000 views on social media on the first day, the PNDU video was shared around the world, helping to raise awareness for this small group of Aussies and Kiwis who rely on HPN in order to survive.

To watch the PNDU AW23 Video visit our website pndu.org

Here is the link to the PNDU AW23 video <https://youtu.be/w8sViq72Hjl>

To watch & share on YouTube: <https://www.youtube.com/watch?v=w8sViq72Hjl>

To watch & share on Instagram: https://www.instagram.com/reel/CyZWU8HJUbk/?utm_source=ig_web_copy_link&igshid=MzRIODBiNWFZA==

Show us your AW23 Stickers

PNDU invites all of our members to join in the celebrations during HPN Awareness Week; we ask them to reach out and connect with others, be ready to start a conversation about what HPN is and how it keeps a very rare and special little group of Kiwi's and Aussies alive. To help start up conversations, PNDU posts AW23 stickers to all members on our mailing list. We asked you to wear them with pride during the week and be ready to talk to others about what being on HPN really means to us.



HPN: Life is Good" Together we can increase awareness and understanding

Thank you for sharing your awareness week photos and stories with PNDU.

Logan (HPNer) helped to put more than 2000 HPN Awareness Week Stickers in more than 200 envelopes, seal, stamp and post them out to our PNDU members.

Our PNDU Members proudly wore the colour purple, their stickers and T-shirts and were ready to start up conversations - it was wonderful to see the confidence shown.

PNDU Member Anna shares with us what awareness week means and how connecting with others can inspire all of us.

Words from Anna.

I know that home PN looks different for everyone, and we all have different hills and valleys. I know my life was absolute hell before HPN and many times I didn't think I'd make it. I have an amazing team that look after me so well and I'm so grateful. For PNDU week, my awareness and celebration look like being well enough to be busy (Omg I have a job now, and study, art commissions, and I'll hopefully be able to start uni next year!). All of these things seem "minor" and "normal" but for me they've never happened because of severe gastroparesis. I feel a bit behind everyone my age starting uni at 30, but I also felt compelled to share because for me, these are HUGE accomplishments. I still have constant symptoms and complications, but my life is so much better than it's ever been.



So whatever levels of independence and quality of life HPN brings you, celebrate them. And if it's hard right now, we're all standing with you.

(Also, I never, ever want to come across as insensitive to those who are suffering. I know how traumatic intestinal failure can be. My purpose in sharing was to encourage everyone no matter where they are. I plan to dedicate my life to those that are suffering, so for me, having a quality of life means I can do just that).



PNDU's latest Lifetime Member Renee (front left) enjoying her birthday with friends proudly wearing their HPN AW stickers

HPN: Life is Good



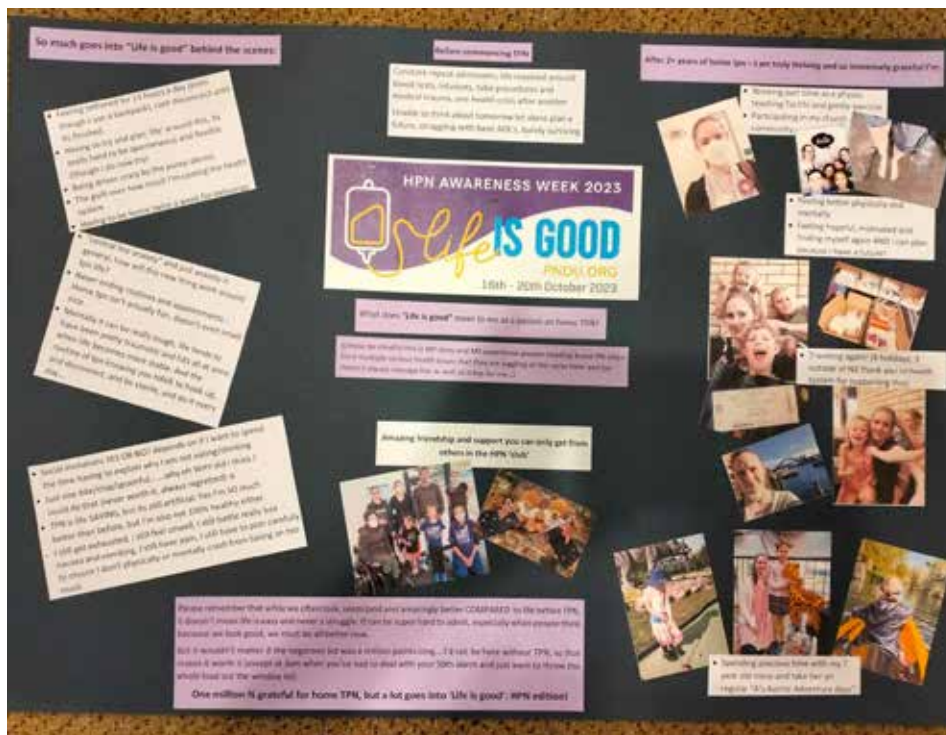
Despite the many challenges, NZ PNDU member Paea, showing us HPN: Life is Good

Words from Felicia

Such a funny day at work today, I went in wearing my shirt and a sticker (I work in a retirement village) and we ended up finding the awareness 2023 banner and printing 50 stickers for everyone to wear, staff and residents. It was quite neat, as a lot of them have walked my health journey with me and seen the amazing gift that HPN has been for me. So, it was actually really special that they wanted to be a part of it (we did take a photo with a bunch of staff, but they were all facing side on and hiding most of their stickers lol)

Also, I made this infographic for the infusion clinic who look after all the HPN clients in my city. The nurse doing my dressing and bloods said she learned something at the end of my session - ha-ha. And said they are always getting student nurses, so the poster would be really useful.

This is the poster I put together



Hospitals

Royal Brisbane Women's Hospital QLD

A big shout out to Emma Osland and the Specialist Nutrition Support Team at RBWH, who started the week with a "Snack and Learn" morning tea for the dietetics and gastro staff with examples of food appropriate on a short gut diet, complete with St Marks solution tasting. The Specialist Nutrition Support Team are wonderful supporters of HPN Awareness Week every year.



John Hunter Hospital & John Hunter Children's Hospital



The Children's Hospital at Westmead

Claudia Borg CNC, organised a group of HPN families and Clinicians to attend the Baxter Tour in Sydney. Claudia shared a few words about the AW23 Tour.

"Thanks again for an excellent day. It is so special to take our patients through Baxter HQ. The magic never gets old. Seeing the faces of the kids, the parents and the technicians at the window of the PN room is just priceless. Not a dry eye in the house. It is just gorgeous seeing how excited the staff get, putting faces to the names. It makes the work we all do even more special.

Thank you, Chris, for PNDU's ongoing support. It really does help to keep the families going!"

A special thank you to Queensland Children's Hospital, Princess Alexandra Hospital, Royal Melbourne Hospital, Monash Childrens Hospital, AuSPEN, NZ NIFRS and Rare Voices Australia for your support of PNDU and HPN Awareness Week 2023.





Across Australia and New Zealand there are 3 providers of HPN: Biomed, Fresenius Kabi and Baxter. During HPN Awareness Week, they generously open the doors of their HPN compounding facilities for guided tours and welcome HPNers, family, carers and clinicians. PNDU would like to thank our industry friends for this wonderful opportunity to see how our HPN is manufactured and the attention to detail that ensures the safe delivery of our life-saving solution that is HPN.

Baxter Healthcare HPN Compounding Facility Tours – HPN Awareness week 2023



It was wonderful to see our HPNers, family and carers connect with each other and share their stories of #HPNLife, with the dedicated staff who manufacture and supply our HPN. Thank you to all our HPNers, family, carers and clinicians who attended the pharmacy tours. You have all contributed to bring about a better understanding of HPN and help ensure HPN: Life is Good.

Baxter Toongabbie NSW

Organised by the amazing people at Baxter, Katie Barovs and Claudine Daniel, the pharmacy tours are big hit during HPN Awareness Week with every Baxter site across Australia and New Zealand represented.

Baxter Sydney AW 2023 Pharmacy Visit By Miranda (carer for daughter Ariel)

Having a tour of Baxter's sterile pharmacy is a wonderful opportunity to learn and be reminded of the amazing thing called parenteral nutrition, as well to meet some of the people who make it possible. Ariel (HPNer) and I joined the tour this year - what better way to celebrate HPN Awareness Week!

There were over 20 of us attending the tour, so after gathering for some short introductions and also greeting old friends, we started the tour with a fun challenge of getting gowned up - just as a pharmacy staff would in order to enter the compounding room. Emily and I stepped up to the task, and with quite a bit of help, managed to complete the mission (sort of). Suffice to say the procedure - involving full sterile jumpsuit, masks, goggles and double gloves - gave us a profound respect for the meticulous care that goes into keeping the pharmacy sterile (as well as a deep appreciation of air-conditioning).

We went off next to view the three different compounding rooms dedicated to the creation of parenteral nutrition. These rooms are where the magic happens, where expert pharmacists and



staff meticulously prepare intravenous solutions containing essential nutrients for all of us who are unable to eat or digest food.

Approaching the compounding rooms is like seeing another world. The rooms are walled by glass with stations of pharmacy staff in sterile suits, masks, and gloves working with utmost precision to mix the necessary components that would sustain someone's life. We watched the staff at their various stations, carefully adding medications and vitamins to the base solutions, to tailor each mixture to meet the unique needs of each patient. Other stations were dedicated to quality control, where staff put each batch through rigorous testing and scrutiny to guarantee the safety and efficacy of the solution.

A beautiful moment was caught, also, when at one point, some of our little HPNers came to the window and the gowned pharmacy staff, aware of our

presence, approached the large glass window that separated us from their world. Peering from behind their masks and goggles, they smiled and waved as they read and clearly recognised the names of the HPNers present - and the kids waved happily back to the people who make the "food" they have every day- I don't think I was the only one tearing up then! After the tour of the compounding rooms, we had some time to gather and mingle with some of the pharmacy staff and other HPN families in the lunchroom cafe. We heard from Katie Barovs, who joined in giving us a very warm welcome and in celebrating HPN Awareness Week with us, and then Chris took the opportunity to present the PNDU Company Professional Award 2023 to Andrew Nguyen in person. It was a truly lovely way to end our tour. As Ariel and I walked back to our car, I realised just how connected all of us involved in the tour, pharmacy staff and the HPN community, were to each other. I think Ariel felt it too as she asked whether we can come back again to visit next year.



Brunswick Victoria



Auckland, New Zealand



Christchurch, New Zealand



Baxter Australia New Zealand

Words by Claudine Daniel

During Home PN Awareness Week 2023, Baxter ANZ celebrated with activities and events all through the week. Our teams celebrated in different ways but particularly enjoyed the bingo activity and quiz put together by PNDU!

PNDU members and friends were welcomed on site to tour our compounding facilities across ANZ and we were thrilled to have visitors at all 7 sites across ANZ again this year.

The Baxter teams across ANZ really love getting involved with Home PN Awareness Week, it's a fantastic opportunity for those who make HPN to meet the wonderful people who use HPN and have an opportunity to share stories and experiences. We are already thinking of activities for next year!

Words by Michael Doyle

Last week we welcomed members and friends of Parenteral Nutrition Down Under (PNDU) to visit our network of TGA-licensed pharmaceutical compounding facilities across Australia and New Zealand, as part of Home Parenteral Nutrition (HPN) Awareness Week.

At Baxter, we are proud of our partnership with PNDU – a non-profit group supporting carers, and the 300+ adults, teens, and children across Australia and New Zealand living with chronic illnesses that affect their digestive system, who require parenteral nutrition.

Each year, we proudly host a series of tours and activities with PNDU, designed to bring people together and demonstrate our HPN production process.

According to PNDU President, Chris Walker, these tours are what HPN Awareness Week is all about. "It's more than just learning how our HPN is manufactured. It's also about meeting the wonderfully dedicated Baxter staff, each of whom know our HPNers by name, and enjoy catching up with us, in person, every year," said Chris.

"HPN Awareness Week is about connecting people who share a similar journey of living with intestinal failure and HPN, and exchanging stories of what it is like to live with a drip," he said.

Check out some of our 2023 Baxter tour highlights, including a gowning demonstration, in which PNDU members were invited to try on the many layers of Personal Protective Equipment (PPE) worn by our teams of compounding technicians.

Gowning Up Exercise

Every day the compounding staff gown up for their 4-hour shifts inside the climate controlled HPN compounding rooms. Gowning up is done as a sterile procedure and isn't as easy as it looks. A great interactive part of the Baxter tours for our HPN families is to have a go at gowning up under the expert direction of the Baxter staff. Thank you to everyone who accepted the challenge - great fun!





Words from Baxter

In support of Home Parenteral Nutrition Awareness Week (15th – 21st October) in Australia and New Zealand, our senior leaders Belinda Campbell, Richard McNamee and Glenn Cullen at Baxter ANZ are experiencing a small part of what it means to be a Home Parenteral Nutrition patient. They participated in a “day in the life” challenge by wearing a backpack filled with parental nutrition solution and infusion pump similar to that of a patient. (For a total of 3 days)

Supporting people on Home Parenteral Nutrition (HPN) with the products and services they need is a significant part of Baxter’s 50-year history in Australia and New Zealand and we are proud to continue this for the next 50 years and beyond as part of our Mission to Save and Sustain Lives.

More than 300 adults, teenagers and children across Aus/NZ require Home PN due to chronic illnesses affecting their digestive system. This often means wearing a backpack containing a bag of specialised medical fluids (nutrition formula) and a small infusion pump that administers the nutrition fluids over the course of the day or night via a venous/vein (parenteral) access.

Thank you to @PNDU (Parenteral Nutrition Down Under) for advocating for HPN patients across Australia and New Zealand.

#ThisIsWhere #LifeAtBaxter #50years
#HPNAwarenessWeek #HPNLife



Glenn Cullen, Belinda Campbell, Richard McNamee’s Experiences of HPN

This year Belinda Campbell (Compounding and Nutrition Director), Richard McNamee (Associate General Counsel, Legal) and Glenn Cullen (Healthcare Solutions Director) participated in the Challenge between Tuesday–Thursday during Home PN Awareness Week. We aimed to give the three a small insight into what it means to be connected to HPN and utilised a range of simulated alerts and commands received by all three simultaneously during this time. For example, they were alerted to connect to a power point for several hours because they had forgotten to charge their pump, to drop everything and deal with simulated air in line alarms and to take regular simulated bathroom breaks which meant they needed to go and buy a coffee for a colleague and have a chat about the challenge they were undertaking and help to educate about Home PN Awareness Week! All three were really invested in the Challenge and took it all very seriously.

When asked about the experience they all were keen to share their thoughts:

Belinda said “I took part in the challenge last year; however, I had my backpack confiscated by airport security, so I was a little more prepared this year! I found that lots of people were really interested in why I was wearing the backpack with a line attached to me.

It was trickier than normal to move around, and I certainly felt that there were a lot of additional factors I had to consider when going about my daily life. I have a 9-month-old at home and think that the carers and parents of our little Home PNers do an absolutely incredible job.

Before the challenge I wouldn’t have spoken about the infusion happening in front of me if I saw it, after the challenge I would recognise it and have a

chat about it if the person was willing to. It needs to be recognised and is something to be proud about... the people who receive HPN really do know how to do it all!"

Richard mentioned "I felt a bit daunted before the challenge as I wasn't sure what to expect; my 9-year-old son was very interested in what I was doing and very happy that Baxter could make the Home PN products that it does. I found it surprising how relentless the simulated activities in the challenge felt and the impact that they had in terms of time and effort. Although this was just a simulation, I really feel such admiration for Home Pners."

And finally, **Glenn added** "I was surprised that on more than one occasion I forgot I was connected and jumped up from my desk only to get caught by my tube, it was a reminder that you are in partnership with your pump and HPN. The requirement for cleanliness to avoid infection was also made very clear to me.

I can imagine that being on HPN would certainly be challenging but hearing the inspiring stories from our patients, it provides the opportunity to be at home with friends and family. Thanks for getting me involved and it was nice to be able to close the loop and share my thoughts with some of our home Pners at the pharmacy tour in Brunswick."

Fresenius Kabi, Australia and New Zealand



Words by Michele Pink

This week, together with Parenteral Nutrition Down Under (PNDU), we celebrate HPN Awareness Week, and we would love your help to spread the word. Living with Home Parenteral Nutrition can be complex, but with continued support from clinicians, carers, family and friends, many people on long-term PN can stay at home, which helps to ensure "HPN: Life is Good"

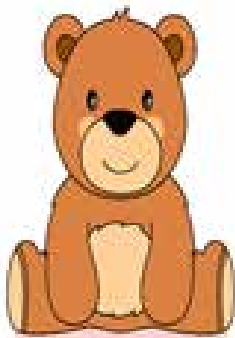
Being part of HPN Awareness Week is important to us, as it helps to recognise the dedicated work done by PNDU, helps to raise awareness of the needs of individuals at home on PN, and for us to stop and recognise how our products can make a difference and why it is important for us to continue to strive to provide better services and support. Unfortunately, not many people know what happens when someone transitions from the hospital to the home on long-term PN. For us, raising awareness is one of the ways we can support PNDU and HPNers.



Sadly, a PNDU member, Lily Thai, 23, passed away peacefully, on Wednesday 21 June 2023. Lily was diagnosed with Ehlers Danlos Syndrome and Autoimmune autonomic ganglionopathy and was terminally ill. Lily spent her final moments at the Laurel Hospice in the Flinders Medical Centre, SA. Lily's name has been added to our In Memoriam roll.

PNDU remembers past HPNers

Over the years, PNDU has been reminded of the fragility of life, especially for those with Intestinal Failure. Sadly, PNDU has shared with family and friends in saying good-bye to these precious loved ones who have passed away, but who have also left wonderful memories of love, strength and courage.



Rosie Crosland - 30th August, 2023, aged 70
Fay Boyd - 23rd August 2023, aged 76
Lily - 21 June 2023, aged 23 years
Lynden - 14 July 2022, aged 68 years
Tracie - 5 February 2022, aged 47 years
Aidan - 21 May 2020, aged 14 1/2 years
Lara - 24 April 2020, aged 37 years
James - 9 November 2019, aged 28 years
Elise - 19 August 2019, aged 43 years
Ross - 23 January 2019, aged 67 years
Celena - 27 November 2017, aged 43 years
Emma - 9 April 2017, aged 35 years
Lara - 16 February 2017, aged 7 years
Teresa - 15 February 2017, aged 58 years
Natalie - 18 September 2016, aged 27 years
Sam - 13 September 2016, aged 14 years
Carol - 2 September 2016, aged 67 years
Jessica - 24 January 2014, aged 20 years
Tynasha Rose - 29 October 2012, aged 5 years
Aria - 20 June 2011, aged 5 years
Pauline - 29 April 2011, aged 38 years
Hebe - 3 January 2008, aged 2½ years



May the cherished memories of these dear ones
never fade

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 \$12,115.46

A. Howard-Bath

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C. Walker

S. Lynne

Upcoming Events



- **Exhibit at AuSPEN's annual convention in Auckland**
10th November
- **PNDU Annual Social Gathering Auckland NZ**
12th November 2023

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

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

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