

DRIPLINE



PNDU
Parenteral Nutrition Down Under

It's wonderful to put together a newsletter that includes social gatherings; three of them over the past few months! Also read about Sal and Matt's tour of Tasmania in their bus; read about the benefits of having a filter in our lines; learn about PPIs, written for Dripline by a pharmacist; read about Jane's role in volunteering at her hospital; and learn of PNDU's participation at an Auckland and a Canberra conference. Also, importantly, have input into the next HPN Consumer Workshop topics. I hope you will learn something of interest re life on HPN.

Gillian
Editor

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By Gillian

Saturday 4th March marked the return of stand-alone in-person social gatherings. (This isn't counting the get-togethers that occur in conjunction with pharmacy tours in HPN Awareness Week and the annual AuSPEN conference and HPN consumer workshop). Our very first Sydney gathering was held in November 2012 at Blaxland Park, and the first New Zealand gathering in September 2013 in Auckland and were held, at least annually, until early 2019. After this, Covid stepped in and prevented our meetings for the next 3 years.

Miranda organised the venue, Redfern Park, in Redfern, with access to the Community room if the weather was nasty. Luckily it was a lovely autumnal day, sunny, with tables set up under the shade of a few large trees. In all, 19 people – 8 HPNers plus husbands, parents and a grandmother - and 2 dogs attended.

It was wonderful to catch up in person, to see how much our young HPNers have grown over the years, developing into lovely pre-teen and teenagers. It was lovely to see the interaction between them. Having met several times over the years, the relationship and friendship between young people who live with a rare disease and a rare treatment (HPN) helps them to see that others are in the same boat as them. The older ones can mentor the younger ones. Young Samuela (in preschool) was interested in seeing Logan's 'button' – he hadn't seen another boy with one before.

Jordan was particularly interested in watching the police working in a section of park that they had cordoned off due to a fight and stabbing that had occurred just about the time Jane and Neil were arriving. After the tape was removed, a few of our young would-be sleuths went to investigate.

It was terrific to catch up with the older HPNers and families, too, and see how we are faring. A few quick comments on the forum or Facebook can't begin to substitute for a real, meaningful conversation where questions can be asked and answered as they crop up.

Hopefully, we will attract more new faces to our next get-together, so that more families can support others and, in turn, be supported in living with HPN.



Our HPNers...
(L-R back) Jane, Gillian, Emily, Jordan
(Front) Samuela, Ariel, Logan



and Sal, who missed the group pic.





What would you like included in the HPN Consumer Workshop? How can we improve the Workshop experience for you?

The current workshop format is a 3-hour event planned for a Thursday morning 9:30am – 12:30pm. The workshop is run in person and also live streamed for those unable to attend. The workshop delivers an update on activities from AuSPEN and PNDU, followed by presentations by 4 guest speakers who are clinicians, on topics requested by our PNDU members.

As AuSPEN and PNDU start organising the HPN Workshop for Auckland in November 2023, we would like to hear ideas from our members on how we can improve the workshop experience for you.

- Does a 3-hour workshop on a Thursday morning 9:30-12:30 suit? Or would an afternoon or Saturday be a better option?
- The workshop will be at the Park-Hyatt in Auckland – will you be able to attend in person?
- The workshop will be live streamed – will you be able to log in to a live stream event?
- Does the current format suit?
- Would an alternative format be a better option – example 3 x pre-recorded webinars throughout the year?

Please let PNDU know what you would prefer as an opportunity to learn from the clinical professionals by sending an email to contactpndu@gmail.com. PNDU and AuSPEN would hate to see this specially organised annual event be discontinued due to a perceived lack of interest.

History

The wonderful team at AuSPEN, with the help of PNDU, organise and host this HPN Consumer Workshop as part of the AuSPEN annual conference. The HPN Consumer Workshop has been held in person each year since 2014, with live streaming made available since 2021. The workshop is exclusively for HPNers, their family and carers only (not clinicians). The workshop provides a unique opportunity for HPNers to learn from clinical professionals who specialise in Intestinal Failure and Parenteral Nutrition. The AuSPEN HPN Consumer Workshop is believed to be the only workshop of its type delivered by a professional society specifically for consumers anywhere in the world. We are truly lucky to have these workshops made available to us and would like to see them continue, but we need your support.

Please let PNDU know what you would prefer as an opportunity to learn from the clinical professionals by sending an email to contactpndu@gmail.com.

PPIs (Proton Pump Inhibitors) - Not all created equal



Stephanie Davies

Senior Pharmacist, Sydney Children's Hospital, Randwick

HPNer query:

"I've been on omeprazole for about 6 years now, and have always told my pharmacist I'm happy with the generic brand. A few months ago, they started giving me a different generic brand. These tablets are passing straight thru and come out intact in my stoma bag. I've also been getting indigestion in the evening and feeling very thirsty. Could there be a difference in different brands of omeprazole?"

Introduction

Gastric hypersecretion (excess production of gastric acid) is a common complication of short bowel syndrome (SBS). This is thought to occur due to the loss of certain hormones which would usually inhibit these secretions. The increased volume and lowered pH of secretions entering the small bowel leads to fluid losses (high stool or ostomy output) and causes complications such as erosive esophagitis and peptic ulcer disease as well as impairment of the function of digestive enzymes and fat malabsorption.

Management of Gastric Hypersecretion

Most patients with gastric hypersecretion can be managed using histamine-2-receptors blockers (H2RB) or proton pump inhibitors (PPI). PPIs are considered more potent and effective than H2RBs and are more commonly prescribed. PPIs work by inhibiting acid secretions. Examples of PPIs include omeprazole, lansoprazole, pantoprazole, rabeprazole and esomeprazole.

All oral PPI products are formulated with an enteric coating (either on the outer shell of the tablet or the cover of the granules inside the capsule) to delay disintegration (breakdown) and dissolution (dissolving into a solution) until the tablet has passed through the stomach. The active ingredient is destroyed by the acidic environment of the stomach, so the enteric coating is used to protect the drug until it reaches the duodenum (this is why PPIs should never be crushed). PPIs are absorbed in the proximal small bowel, so for patients with SBS the amount of drug that is absorbed can be limited.

Are all PPIs the same?

Although all PPIs are considered to be equally effective with a similar side effect profile, they differ in what other medications they interact with. This may lead to higher or lower concentrations of medications in the body and an increased risk of adverse effects. They are also available in different dose forms. Omeprazole, pantoprazole, and esomeprazole are available as both an injection (for intravenous therapy) and oral formulation. Intravenous PPI therapy may be used for hospitalized patients unable to use the oral form.

To maximise the efficacy of PPIs in patients with SBS, it is important to consider the dose, frequency, timing of dose and formulation.

Using a dispersible tablet (one that can be suspended in water) rather than a capsule

may be preferable for some patients as the dissolution time is minimised (ie it dissolves quicker, and therefore is able to be absorbed quicker).

Different brands of the same generic drug may not be equivalent when it comes to dissolution. An example of this is Omeprazole 20mg enteric tablet: Acimax, Losec and Omepral can all be dispersed in water, however Maxor, Ozmep and other generic brands are NOT dispersible. So, although the active ingredient is the same, the different dose forms mean they are not interchangeable. It is also worth noting that if prescribed omeprazole dispersible tablets, there is an additional \$7.15 surcharge on the PBS for the Losec brand.

Summary

PPIs are commonly prescribed for patients with SBS to improve symptoms of gastric hypersecretion.

Although all PPIs have similar efficacy, the difference in dose forms should be considered when prescribing. Even if the active ingredient is the same, absorption of the medication can be affected by the dose form.

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By Gillian

One of my father's favourite sayings was 'a volunteer is worth 10 pressed [press-ganged] men', meaning that a volunteer is committed to the task, enthusiastic, and reliable, as opposed to someone who is forced to do something. When talking to Jane at the PNDU Sydney social gathering held on March 4th, I discovered that she spends her Fridays volunteering at the San hospital in Wahroongah, where Jane once worked as a nurse.

Jane has been HPN dependent for 24 years and lives with several health problems, but nothing stops this loving, caring, softly-spoken individual from giving her time, expertise and understanding to patients in the surgery ward. In the past she has helped as a volunteer in different ways, but has now been given 'her' own ward, so that she is able to develop better relationships with long-time patients. She begins early at 8:30, hoping to catch people before they are in the shower or off having tests etc. Those she has met previous weeks are pleased to talk with her again. She finds that many are happy to have someone's undivided attention, something she couldn't give when

nursing, due to demands on her time. But now, she is able to listen to patients' concerns and problems, and if they wish, she prays with them.

I'm sure that volunteering brings satisfaction to Jane, knowing that she provides an important service. Maybe volunteering to help with an organisation is something more of our members could consider if feeling well enough.

Filtering PN At Home



*Filtering the evidence in Home Parenteral Nutrition: a recommended practice change from ASPEN**

Summarised by Prof Gil Hardy, March 2023

Parenteral Nutrition (PN) at home (HPN) has been lifesaving therapy for many years. An important safety measure when administering PN is the use of an in-line filter to prevent particulate matter from entering the circulation. In the past, a 0.22micron (μm) filter has been recommended for the lipid free amino acid-dextrose solutions and a 1.2 μm filter for lipid emulsions (ILE) or All-in-One (AIO) regimens containing ILE. Over the years, several guidelines for filter use have been published by societies and manufacturers. Despite this guidance, filter use remains controversial and is not widespread. The 2008 AuSPEN guidelines [1] state that "in-line filtration can be an option" following the earlier recommendations of the UK BPNG expert group, largely based on the work of long-time friend of PNDU, Prof Patrick Ball and others. The BPNG 2001 paper [2] actually stated "appropriate filters should be used during the administration of PN to.... patients receiving home PN because of the large volume of potentially particulate-contaminated fluid administered and their increased susceptibility to the detrimental effects of particulate contamination""1.2 μm filters should be used for the administration of lipid-containing AIO admixtures and changed every 24h" and " when used, in-line filters should be placed as close to the patient as possible"

Now, 20 years later, the American Society for Parenteral and Enteral Nutrition (ASPEN) has produced a new position paper that reviews past guidance, examines the consequences of infusing particulate matter, discusses the challenges and issues related to filtration and simplifies recommendations for filter use with PN [3]. A summary of ASPEN recommended Best PN Practices is shown in Table 1.

The most important ASPEN recommendation is to routinely use a 1.2 µm inline filter for all PN administrations.

Particles in PN

The ASPEN paper eloquently summarised recently in a shorter review by two of the lead authors; Pat Worthington and Peggi Guenter [4], emphasise the most important and often overlooked risk is from infusing particles, that are always present in PN systems. In their comprehensive literature review, the ASPEN experts found many articles erroneously implying that the primary purpose of filters is to protect against infection, whilst not fully appreciating the danger of particulate matter. Particles in PN can vary in size from 1-10µm, but the greatest risk is from particles larger than 5µm that can be trapped in the lungs leading to pulmonary complications. Particles smaller than this can pass through the capillaries to be deposited into the liver and/or spleen but will then mostly be eliminated.

The experts note that inline filters can also “block microbes, air and enlarged lipid droplets from reaching the circulation” but reiterate that the US Centers for Disease Control advise against using an inline filter for infection control purposes, because in most reported cases, infection has usually occurred after the solution as passed through the filter. This has led to many health professionals incorrectly believing that filters are not needed for PN [5]. Nevertheless, although 1.2µm filters are not recommended for routine infection control, ASPEN confirms that these devices are effective in blocking *Candida albicans*, a pathogen frequently associated with PN therapy.



Table 1. ASPEN Best Practices for Using Filters for PN Administration

1. Use a 1.2 µm filter for all PN
2. Connect the filter to the catheter hub. Visually inspect the PN for evidence of particles or instability, including emulsion cracking.
3. Observe the manufacturer’s directions for priming the filter before connecting
4. Do not invert filter during priming
5. If administering the dextrose-amino acid part of the PN and the ILE separately:
 - a. Attach the filter below the Y-site where the two infusions meet
 - b. Programme the pump for the first infusion before setting up the ILE
6. Avoid co-administration of medications with PN.
7. When co-administration of medications with PN cannot be avoided:
 - a. Attach the medication tubing below the filter.
 - b. Flush all tubing before and after the medication
8. To avoid filter clogging during set up:
 - a. run a small volume of ILE or AIO through the tubing into the filter
 - b. close the clamp on the ILE administration set. (if separate)
9. Release all clamps and initiate the PN infusion.
10. Schedule filter changes to coincide with the initiation of a new PN bag and set.

Clogging Filters

If filters block or clog during PN administration, this means that they are doing their job! However, because it's then tempting to simply remove a clogged filter, ASPEN stresses that "PN admixtures should never be allowed to infuse without an inline filter" and provides a list of steps to follow if a filter clogs: Table 2. [adapted from ref 4]



Table 2. Trouble Shooting Steps for Potentially Blocked Filter

- 1.** Verify that appropriate pressure setting has been used on the infusion pump
- 2.** Rule out mechanical or thrombotic causes of infusion pump alarm, as follows:
 - a.** Trace the administration tubing from the pump to your catheter, checking for kinks
 - b.** Confirm that all clamps are open
 - c.** Assess the patency of the catheter according to your Nutrition Support Team's instructions
 - d.** Inspect your catheter to ensure that the tubing is not kinked or twisted under the dressing
- 3.** Verify that the correct 1.2 µm size filter has been used
- 4.** If correct size filter is in place, assume that particulate matter is the cause.
- 5.** Remember that precipitates can occur hours after your PN bag has been prepared and delivered
 - a.** Remove clogged filter and replace it with a new 1.2µm filter
 - b.** Be alert for repeated episodes of occlusion/blockage
 - c.** Never allow an unfiltered admixture to continue to infuse.
- 6.** Inform your NST/PN provider so they can prevent further occurrences.

In conclusion, the risks of particulate contamination and the safety of using a single 1.2µm filter for PN as a preventative measure is supported by decades of experience in both hospitals and the home. ASPEN now recommends routine use of a 1.2 µm inline filter for all PN administrations.

References

1. Gillanders L et al Nutrition 2008;24;998
2. Bethune K et al Nutrition 2001: 17;403
3. Worthington P et al. NCP 2021;36;29
4. Worthington P and Guenter P. Infusion 2022: Sep;39
5. O'Grady NP et al. Clin. Infect. Dis.2011;52;e162

*NB. The ASPEN recommendations may not necessarily be the same as AuSPEN or your own NST are



By Rebecca Coggins - Adult Nurse Specialist Co-coordinator

In 2015, the National Intestinal Failure and rehabilitation service (NIFRS) was developed in New Zealand as an initiative by the Ministry of Health to improve outcomes and provide equitable care to patients of all ages with Intestinal Failure. The NIFRS team is a multidisciplinary team that includes a paediatric and adult team, including Surgeons, Gastroenterologists, Nurse Specialists, Dietitian's and a Pharmacist. NIFRS aim is to provide a nationally coordinated service to work with local and regional centre's providers to achieve optimum clinical outcomes for patients with Intestinal Failure (IF). Included in this support is the provision of recommendations to assist clinicians across NZ to care for patients and whānau (Family), close to home whenever possible.

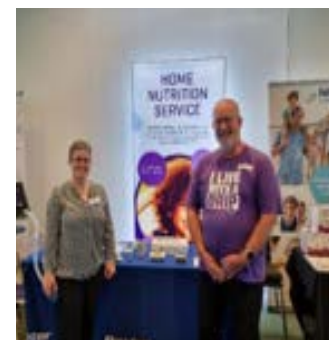


In 2022, the NIFRS team published a National Guidance Document that is available as a resource online to provide up to date information and educational resources for clinicians in management of Intestinal Failure patients of all ages. At the end of March 2023, they presented a National Network Educations Day in Auckland for clinicians. There were 112 attendees from across New Zealand and for the first time, some colleagues joined in from Australia. The team presented the guidance documents and had a wide variety of speakers including Surgeons, Gastroenterologists, Nurse Specialists, Dietitians, Neonatologists and Psychiatrists. The feedback from the day has been overwhelmingly positive. Chris, president of PNDU, was there, which was a fantastic addition to a truly multidisciplinary and patient- focused day. As part of delivering the 2023 workplan the NIFRS team will continue to offer Educational webinars and will focus on maintaining and updating the NIFRS guidance and also intends to develop new resources to assist with training and education for IF patients and whānau (Family).



By Chris, PNDU president

On behalf of PNDU I would like to thank Rebecca Coggins and Ian Bissett for the invitation to attend the NZ NIFRS Education and Network Day in Auckland, an amazing event and a credit to the NIFRS Team. The presentations from all speakers were very informative and the event provided a great opportunity for PNDU to connect with clinicians in New Zealand who specialise in the field of Intestinal Failure. I was kept very busy by the numerous attendees who visited the PNDU stand during the day. It was wonderful to see so much interest in PNDU and what we do. I happily shared a wealth of information and PNDU printed resources for the clinicians to pass on to their HPNers. PNDU welcomes all Kiwi HPNers, their family, carers and clinicians who wish to become members of PNDU to visit our website



Catching up with NZ Industry friends, Donal - Fresenius Kabi, Claudine – Baxter and Jessica – Biomed.

PNDU President Chris – NZ NIFRS 2023 Auckland – PNDU Information stand.



Chris Walker PNDU President.

It was wonderful to catch up with long time PNDU members Lisa and her mum Anne while I was in Auckland for the NZ NIFRS Education and Network Day. Anne and Lisa graciously hosted PNDU founder Emeritus Professor Gil Hardy and myself for afternoon tea. While it would have been great to have other HPNers join us for the afternoon, we understand how quickly plans can change for HPNers. There will be another get together in November and I look forward to meeting you in Auckland.

Chris Walker PNDU President.



Chris, Lisa and Gil

Rare Voices Australia



Rare Disease Day Parliamentary Event March 8th 2023

By Chris, PNDU's president

I had the privilege to represent PNDU at the Rare Voices Australia (RVA) Rare Disease Day Parliamentary Event in Canberra on Wednesday 8th March 2023, hosted by Dr Mike Freelander MP (Chair, Standing Committee on Health, Aged Care and Sport and Co-Chair, Parliamentary Friends of Rare Diseases). The theme this year was, 'Ensuring Equity for Australians Living with a Rare Disease.'

RVA CEO, Nicole Millis, provided an update on the implementation of the National Strategic Action Plan for Rare Diseases.

RVA Ambassador, Renae Wood, shared her heartfelt personal story of living with epidermolysis bullosa.

The following Parliamentarians also spoke at the event.

Dr Freelander, Member for Macarthur, Hon Mark Butler MP, Minister for Health and Aged Care, Senator Anne Ruston, Shadow Minister for Health and Aged Care, Senator Wendy Askew, Senator for Tasmania and Co-Chair, Parliamentary Friends of Rare Diseases, Dr Monique Ryan, Member for Kooyong and Co-Chair, Parliamentary Friends of Rare Diseases

These rare disease day parliamentary events provide the opportunity to raise awareness of the issues faced by the estimated two million Australians living with a rare disease. I was able to speak with a number of Members of Parliament, including Dr Freelander, Dr Monique Ryan, Hon Mark Butler MP. A wonderful chance to highlight some of the difficulties faced by our small PNDU patient population living with intestinal failure requiring parenteral nutrition. I was able to speak with RVA board members, geneticist Emma Palmer and other support group leaders, strengthening the network connections of PNDU.

On behalf of PNDU I thank Rare Voices Australia for providing this opportunity to engage with our Parliamentarians.



Photo - Hon Mark Butler MP, Minister for Health and Aged Care; Dr Mike Freelander, Member for Macarthur, Chair Standing Committee on Health, Aged Care and Sport and Co-Chair Parliamentary Friends of Rare Diseases; Nicole Millis, CEO Rare Voices Australia; Senator Wendy Askew, Senator for Tasmania and Co-Chair Parliamentary Friends of Rare Diseases; Dr Monique Ryan, Member for Kooyong and Co-Chair Parliamentary Friends of Rare Disease.

Photo courtesy of Rare Voices Australia.



By Sal

Our Tassie adventure started after a day at work, and a lead up of us squeezing in family gatherings for Christmas, birthdays and our daughter's university graduation. This trip was a much-anticipated time for us to stop and rest, just Matt and I for a belated 25th Wedding Anniversary gift to each other. We headed off in 'Bridget', our 1956 Flexible Clipper Coach, and we made it to Gundagai, before we retired for the night. We were awoken at dawn by the chattering and screeching of Corellas, who called the surrounding trees home. I peered through the windscreen and was greeted with the picture of a light mist over the old, rickety wooden rail bridge traversing across the recently flooded flood plains. Rays of the early morning sun filtered through the



Western wilderness area

lifting fog. We didn't stop long to admire the scenic night stop location, as we had a long day of driving ahead. Bridget cruised down the Hume Highway, and after a few hours, we were at the border and into Victoria, and before we knew it, Matt was navigating the web of motorways leading in and around Melbourne. We wove our way through the heavy lunchtime traffic and headed south before we stopped at a berry farm near Bunyip, to meet our Clipper Club president and his wife, and their new puppy. After a late lunch for Matt, and lots of catching up, we collected the air tanks that we were freighting to Tasmania to install in another Clipper and were back on the road via Melbourne to Geelong, where the new berth for the Spirit of Tasmania is located. Entertaining the fellow motorists along the way, seeing our motoring relic, always bringing smiles, and cameras on phones snapping up our images, we often wonder where these images get shared. A brief stop for dinner for Matt and for me to connect to my PN for the night, before queueing up at the terminal to go through quarantine and onto the boat. We again provided enjoyment to those queueing in cars, who most likely would never have seen a Clipper before and may never again. It was a tight fit in the narrow lane for us to park inside the hull, but slowly Matt was able to get us parked so we were able to open the door, before we found our cabin and enjoyed watching the sunset as we left Port Phillip Bay and headed towards the Bass Strait.

We had smooth sailing overnight and were woken by a text message at 6.30am from our Clipper Club mate Adrian -we had been spotted and we hadn't even reached Devonport! Adrian had spotted the Spirit as a smudge on the horizon, from Boat Harbour and sent us the photo to prove it. After disembarking, we found a nearby beach for Matt to enjoy breakfast and to disconnect me from my PN. We grabbed some fresh fruit and veggies, as we hadn't been able to bring any from mainland due to quarantine restrictions and no sooner had we left Devonport, and I was receiving a phonecall from Adrian's wife Pam, who had spotted us as well. Matt said, 'oh so that was the woman madly waving at us in a car coming from the other direction'! We felt the love, as about half an hour later we had another 'welcome to Tasmania' message from our Clipper Club friend Narelle. We hadn't been able to see our Tassie Clipper club friends for a few years, because of Covid restrictions.

Although we had a vague itinerary for this trip for my Baxter PN delivery locations, we were open to exploring and stopping wherever we wanted. We headed inland to the high, alpine region that we hadn't explored before. We found the Honeycomb caves and creeks near Mole Creek and had a good walk around them and then were back on board and we were winding our way up to the top and drove around the Great Lake and Arthur's Lake, before we found the free camp area by Arthur's Lake. No one else was around and we had the secluded waterfront spot to ourselves. We went for a late afternoon stroll before setting up the BBQ for dinner and a campfire to warm us in the chilly alpine evening. After dinner, we went for another explore, as the sun didn't go down until well after 9pm. This time we spotted a wallaby, and we were then enthralled by watching this wallaby wag its tail like a dog, as another wallaby came bounding over to it. Upon reaching each other, both wallabies were wagging their tails and were playing fisty cuffs with each other. Who knew that wallabies wagged their tails?! After this delightful scene played out by nature, we headed back to



Sunset at Bay of Fires

our campfire and enjoyed the warmth; the stars starting to emerge, twinkling between the canopy of trees above, and we watched the flames dance, before the embers

cooled and we called it a night.

The next day we headed south back down from the alpine area and explored the mid highland town of Bothwell. We walked around the streets, checking out

made it to Campbell Town for dinner and had time for an evening stroll around town and found some interesting headstones in the local cemetery. I always find it fascinating but sad, as you read the tombstones and



Sal and the Bay of Fires



the quaint and historic buildings lining the local streets. Bothwell originally had a lot of Scots move to the town and they had the street signs in different tartan patterns representing the clans. Bothwell's claim to fame is that the guy that brought golf to Australia lived here and so, in honour, they had a golf museum. From Bothwell, we headed to the history filled town of Oatlands, where I had arranged to collect my Baxter PN delivery from the medical facility. While we waited, we meandered along the main street, admiring all the colonial buildings. After my delivery arrived, we headed to Ross, and as it was getting late, we did a quick tour of the parts of town that we had missed when we had spent a day there on our previous tour in 2015 with our children in our 1967 coach. There had been a female convict facility at Ross, and some amazing buildings and tragic history. We

see how young some of the children were. My heart felt heavy, I did miss our own now adult kids, as I remembered they had been teens aping around when we stayed here with them on our last trip, treasured memories for me.

Exhausted, we then slept for the next couple of hours after lunch. It was delightful being so close to the beach and being able to come and go, depending on our whim and the time of day. The sounds of the waves gently crashing made a lullaby to sleep to. We spent the next couple of days, being Christmas Eve and Christmas Day, exploring, relaxing, strolling the beach, literally chilling our feet in the crystal-clear Antarctic waters, reading, sleeping in and celebrating Christmas together.



Happy Christmas – Sal and Matt



Cosy Corner Beach, Christmas site at Bay of Fires

We called our family on Facetime, as they celebrated Christmas dinner at my parents' home with the rest of my family. While we were camped there, we did find out we had been spotted by a Tassie bus nut, and Bridget's photo was put up on the Aussie Clippers Facebook page, couldn't even hide without being found. But as always, it was over too soon, and it was time to move on. We drove around the rest of the Bay of Fires, before heading inland, and back up the pass and over a dirt road through

the forests, to the outskirts of Launceston, for a quick food shop. We were shocked to discover vegemite and cheese flavoured hot cross buns selling at Coles. It was only Boxing Day!

We arrived late afternoon at our planned destination with our Clipper club friends Pam and Adrian, who had spotted us on our arrival to the island. Here at their property at Merseylea, we would spend the next week, with Matt working with Adrian to construct new tailgate doors for his tipper trucks for an upcoming pyrethrum and poppy harvest that Adrian would be hauling. I was able to rest and catch up on some reading, and eventually Pam relented and let me do some gardening for her, while she did night duty. It wasn't all hard work for Matt and Adrian; we did go on a 2 Clipper convoy drive one afternoon and on other days, Adrian played tour guide and showed us around the region.

We spent New Years' Eve at a large gathering of Pam's wider family, on a rural property. We must be getting old, as we headed to bed before it was midnight! Most evenings we spent chatting with Adrian and Pam and before long our week was up, and we had to say farewell to our dear friends, and we headed to Deloraine. We were able to spend the evening there with one of my former classmates from Avondale College, and we had a great night reminiscing and sharing stories. Despite getting caught up in conversation, we still made it to our next destination of Longford before midnight. The next few days we would be here with our Clipper club friends Narelle and Geoff and their children Jack and Evelyn.

The next morning, we were greeted by their kelpie dog Jess, and were playing ball with her, when Evelyn, aged 10, showed us around and how she could drive around the farm. Later that day, we went and inflated all the tyres on an irrigator that had been out of action since the floods, a few months earlier. That afternoon, Matt helped Geoff reinstall the water pumps by the riverside, while I was employed as chief ball thrower for dog Jess. Jack aged 14 would mow with a tractor, as you do at that age, an area by the river for us to park on for the night. The family came and joined us for dinner and a campfire. It was lovely to catch up with this beautiful family. We heard about the floods that had filled the cropping paddocks multiple times over the year and that had meant they had reduced capacity to grow for the season.

The next day I had arranged to meet up with the PNDU

Tassie members Jacqueline and Susan. (See separate 'A Tasmanian Get-Together' about this meeting). Meanwhile, Matt helped Geoff finish off the pipe works for the river water pumps and got them going again. Geoff had had to remove the water pumps, so they didn't disappear down the river when it flooded. We had a lovely dinner with the family and another opportunity for good conversations and catch up after not seeing them for a few years.



Clipper convoy



By the river at Longford

As my PN delivery had arrived at 8 am the previous week, we were up early to receive it, but the courier didn't arrive till lunchtime. That gave me time to continue reading Jane Eyre, as I waited for the courier. Matt went and installed the air tanks that we had brought over from mainland. I later went and did some gardening for Geoff's Mum, as she was unwell from chemotherapy and had ended up in hospital the day before. She has the most delightful garden, very English. That evening Matt moved Bridget to be in one of the top paddocks and we enjoyed watching the sunset over the distant mountain ranges. We had been spoiled for views here. The next day Matt was able to finish the installation of the air tanks and Geoff's Clipper was ready to drive again. I did more weeding in the garden and we had a quiet evening enjoying the views.

After a slow morning, Geoff finally got to drive his Clipper after being off the road for several months and we headed off in a Clipper convoy to the Bridestowe Lavender farm near Lilydale.

We wandered through the rows of lavender that were in full flower and buzzing with bees. Everyone enjoyed lavender infused ice cream and lunch at the café before we headed off to the coastal town of Bridport for a wander and we found a park just for food trucks and everyone all had Tassie style international cuisine, and



Sal and Matt at the Lavender farm

we made it home in time for another spectacular Tassie sunset. Neighbouring Geoff's farm was the historic Woolmer Estate, a World Heritage Listed site because

it had once had convicts as servants. Matt and I enjoyed the tour of the old homestead and wandered around the various buildings that had kept this estate functional and in business. I loved the rose garden that now features on this property. Matt went and helped Geoff repair one of the pivot irrigators, and I was able to make a batch of my famous triple choc brownies that I knew would be food for the soul for Geoff. In fact, Geoff managed to keep the brownies secret for a few days before the rest of the family found the stash and he had to share the love. The next day it was time to say goodbye to Geoff and we followed Narelle and Evelyn in their car, to the old 1930's wooden home in Queenstown, that they had purchased to slowly restore and bring back to life. On the way, we visited the famous Wall at Derwent Bridge, which had the most amazing Huon pine carvings telling the story of early Tasmania. These life-sized carvings were so detailed and intricately carved, they looked real. We then drove the 99 bends road to Queenstown and wound our way through the most spectacular mountains and ranges of the western wilderness and world heritage area of Tasmania. Once in Queenstown, Evelyn gave us a very detailed tour of the house and we were able to appreciate the potential in all the original features, when it will be loved once again. Narelle and Evelyn were joined by some friends, as they were going to do a hike together the next day. At the last minute, we were able to arrange a 4WD tour to the world heritage wilderness area, where the Franklin Dam had been proposed and where the years' long battle was fought to stop it. Again, the views were breathtaking as we drove through this pristine and untouched forest and mountain ranges. It's hard to comprehend how this area could ever been considered to be flooded for a hydroelectricity scheme. It would have ruined such a huge area of rugged mountains and habitat for the flora and fauna and Indigenous cultural sites. I am glad that all the years of arrests, blockades and protests were successful. Our guide gave us a bonus tour and extra time and took us to a hidden Huon pine believed to be thousands of years old and it was next to a King Billy pine. It was easy to feel close to God in these most amazing settings.

After this tour, we headed north to a campground east of Stanley, called Black River, and again we scored a beachside spot for the night in this national park. The next morning, we took a stroll along the beach, spotting a few Pademelons hopping about. The beach was incredibly windy and if it was not for the amazing views, it was actually most unpleasant. We had to hike back through the coastal scrub back to Bridget before we drove on to Stanley. We took the chairlift up 'The Nut' at Stanley, and did the circuit walk around the top, enjoying the views of the sea, a few Pademelons hidden in the bush, and we were trying not to get blown away. It was sad to see how bad the weeds were up there, and they seemed to be taking over too. We took the chairlift back down and did a quick tour of town before it was time to head east and return to Devonport and get ready to head home. We stopped at Latrobe and met up with Pam and Adrian for coffee at the quirky shop 'Reliquaire'. We had been to the original Reliquaire with the kids in 2015 and learned it had burned down 10 days after that visit. This was the new version, filled with all sorts of knick-knacks, toys, unusual or novelty items and games. Then it



Huon pine in the western wilderness area

was time to head to the port and get ready to board the Spirit of Tasmania and head back to mainland. Neither of us wanted to leave after 3 weeks of rest and time with friends and touring the most amazing landscapes.

Unfortunately, it wasn't a smooth sail back, and I suffered greatly from seasickness. Meanwhile, Matt went out on the deck and enjoyed watching the waves crashing against the boat as it rolled and went up and down. Lucky for some! You could tell when the boat made it to the heads of Port Phillip Bay and the sea was calm again. We arrived at a foggy, dismal Geelong and we disembarked without any problems. We paused nearby for my PN disconnection and for Matt to have breakfast and to fill up with fuel. We opted to take the scenic route after we drove the motorways in peak hour around Melbourne and headed via Mansfield to Mount Beauty, where we were to collect my Baxter delivery and stay with Clipper club friends Greg and Carol. The day may have started cold and foggy, but it soon cleared and was 35 degrees and very hot. We had got used to liking the mild Tasmanian Summer of low to mid 20's, though we were amused as the Tasmanians were struggling in those temperatures, while we still almost felt cold! We had a wonderful and blessed time with Greg and Carol. We parked Bridget next to the golf course, opposite their house and were able to enjoy catching up with them that evening. The next morning after a walk with Greg and their dog Lucy, we decided it was time to face the inevitable and head north, and in the direction of home. It was another hot day, and Matt did well to drive in the heat. We stopped for dinner at Holbrook and then parked up at the same spot at Gundagai, as we had on the first night of this adventure. The Corellas were coming home to roost as we arrived, and while they made all their noise, we had a walk around the site while the stars gradually came out, but so did the mozzies and we quickly abandoned our walk and got the generator running to be able to use the air conditioning and cool Bridget down. We were both tired and had a good sleep before we headed home to Sydney. Our adventure was over, and we were home before long, to find our son madly cleaning the house! We feel incredibly blessed that we had such a good time away from it all and that we could help our friends in the process. We love Tasmania and look forward to returning there one day.

Weathertex Fundraiser



A big shout out to Donna Duncan and your wonderful team; an amazing show of support from Weathertex and your employees. Thank you for your fund-raising efforts for PNDU, the HPN community.

On the 5th April, Weathertex held a fundraiser for a community close to ours. Weathertex has team members whose families suffer from a rare disease that requires constant care and medical attention. We are proud to raise funds for this amazing team assisting others to live with this rare medical condition. Fundraising Total \$3,875.40

PNDU is a support group created specifically by and for Australian and New Zealand Home Parenteral Nutrition (HPN) consumers and their families' and carers.

"Our aim is to Support, Research and Inform Consumers, Carers, and Providers of Parenteral Nutrition for Intestinal Failure"

To learn more or offer your support visit <https://pndu.org/>



Upcoming Events



- National Patient Organisation Network (APON) Australia, Conference 15th - 16th May 2023 Sydney

Thank You



PNDU is very grateful for the support given by the donors listed below. We wish to thank the following for their generous gift. Total donations \$3,875.40

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- Opportunity to contribute to PNDU Inc.'s work in raising awareness of HPN and supporting HPN research.



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