

DRIPLINE

PNDU
Parenteral Nutrition Down Under

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2020

Dripline's last issue, in January, was written during our country's severe drought and dreadful, wide-spread bushfires. This issue is being written during an international crisis, and our hearts go out to all those who are suffering in many and various ways due to the effects of Covid19. We join with the world in giving special thanks to all front-line workers, including doctors, nurses, paramedics, cleaners etc who are doing such wonderful and necessary work.

In this issue, we read about Sarah's story of how Meningococcal led to her need for HPN; we hear about Sal's family's outback trip to provide help for a farming family; we learn of the response of both New Zealand's and Australia's Parliaments to rare diseases; we find out what some of our HPNers are doing with themselves during self-isolation; and we read about Baxter's filming of a video to assist new HPNers for transitioning from hospital to home. I hope you enjoy the read,

Gillian

Editor

CONTENT

Coronavirus and the HPNer

Words by Gillian

Who would have guessed that since the last issue of Dripline, the world could have changed so drastically, with our everyday activities and work curtailed for at least the next 3 months? Coronavirus and the associated changes in our routine has impacted all of society, of course, not just HPNers, but because we all obtain our nutrition through a CVAD (Central Venous Access Device), we are always very cautious about the possibility of line sepsis, which can lead to death in some circumstances.

This is why HPNers are trained in aseptic technique, and its importance, in setting up our PN bags each night. But as well as this, we need to be vigilant in handwashing and general cleanliness at all times, to prevent, as much as possible, introducing germs, bacteria and viruses into our systems.

The one concern that some HPNers have is the difficulty of sourcing sufficient anti-bacterial solutions. These are members who are particularly prone to infection and have a very prolonged cleaning regime. They have found that the number of bottles they are usually able to obtain from their supplier or hospital has been limited, and can't find any to buy at pharmacies or the shops, or, indeed, find some. Hopefully their hospital teams will be able to negotiate sufficient cleanser for them.

PNDU's President, Chris, has been in contact with the companies which supply our bags of PN, and has been reassured the supply of our HPN remains unthreatened and the supply of consumables should continue as usual, if normal monthly ordering patterns are followed. The supply of high demand items (anti-bacterial solutions, handwash and surface wipes etc) may become difficult as hospitals will have first priority from suppliers and some items may have restrictions and limitations placed on them. If you are unable to obtain the products that you normally use, please contact your HPN Hospital Team for an alternative product.

I hope that all of our members come safely through the Coronavirus pandemic unscathed, being able to stay out of hospital for the duration.

PNDU Events 2020

Words by Chris

Sadly, due to the outbreak of the novel corona virus COVID 19 and the restrictions placed on travel and gatherings, PNDU, along with many of our friends and associates, have had to cancel/postpone events planned for 2020. We hope that by adhering to the advice given by our governments and healthcare professionals, working together we will all safely come through this pandemic and return to a normal world in the not too distant future.

For all our friends in New Zealand, we wish you all the very best until we meet again.
Intravenous Nursing New Zealand (IVNNZ) March 2020 Conference Christchurch NZ (Postponed)
National Intestinal Failure Service New Zealand (NIFS NZ) April 2020 Education and Network Day Wellington NZ (Postponed)
PNDU New Zealand Social Gathering March 2020 Christchurch NZ (Postponed)

Unfortunately, the following events planned for Melbourne in November 2020 have been cancelled and are now rescheduled for 2021
AuSPEN 2020 Melbourne (Cancelled)
AuSPEN HPN Consumer Workshop 2020 Melbourne (Cancelled)
PNDU Annual Social Gathering 2020 Melbourne (Cancelled)
We look forward to catching up with everyone from AuSPEN in Melbourne November 2021

The Annual PNDU Social Gathering will be held in Melbourne 2021 to coincide with the AuSPEN Conference. PNDU will be offering 2 travel sponsorships to help members attend the HPN Workshop and annual social gathering. We very much look forward to bringing HPNers, carers and families together again at these events.

Rare Voices Australia (RVA) 3rd National Rare Disease Summit 2020 scheduled for November, has been postponed until 2021
With the official launch of the National Strategic Action Plan for Rare Diseases in February this year, PNDU looks forward to continuing our association with RVA as the plan is implemented.

PNDU looks forward to the rescheduling of cancelled/postponed events and once again being able to catch up with everyone who helps make the extended PNDU Family, very special.

Despite the lockdown, PNDU remains open for business as usual and will continue to support, research and inform consumers, carers and providers of Parenteral Nutrition for Intestinal Failure across Australia and New Zealand.

The PNDU Management Committee is a small group of volunteers, dedicated to improving the quality of life and connecting HPNers, carers and their families down under.
If you have some time to spare and would like to help out. Please feel free to send us an email
contactpndu@gmail.com

***Editor's Note*: Because World Meningitis Day is this month, Sarah's story is particularly appropriate for this issue. Thank you, Sarah, for your courage and for sharing your story with our readers.**

Meningococcal Led to HPN

Words by Sarah

I was struck down by Meningococcal disease W strain with septicaemia in August 2016. I was 30 years old. I went from being a happy, independent woman working as a nurse educator, to fighting for my life within hours. After thinking I had the flu, I kept getting worse and after 12 hours I was on life support and my family were told to say goodbye. Waking up 8 days later from a coma, I had no idea the fight I still had ahead of me. I couldn't move my body and I was put back on life support a further four times. I lost four major organs; my spleen, gallbladder, and bowel were removed and my kidneys have failed.

I have had 64 admissions to hospital and 36 operations, including amputations of fingers and toes. There isn't much of me that Meningococcal hasn't impacted.

Life after Meningococcal for me is a constant battle. Nearly four years on, I am still dependent on dialysis and have been reliant on a feeding pump to keep me alive and I require a kidney transplant. I have tubes and attachments all over my body. I am in constant pain and I never know what the next day will bring.

My large bowel was removed due to a c diff infection that caused a toxic mega colon - I was taking regular antibiotics due to my spleen being removed and was given a medication that reacted to this. I now have an ileostomy for life.

Due to the multi organ loss and failure, the sepsis also caused my Intestinal Failure. I lost 20kgs, leaving me at a mere 43kgs. I have had multiple feeding tubes during this time. And then required HPN after a further 6 month's hospital admission. I have been on and off HPN for the last 3.5 years.

I was very depressed when I was constantly vomiting, losing weight, being in pain and being unable to eat. I found it was a topic that not many people know about or empathise with. And it made me feel very alone. Like it was my fault, or that I wasn't trying enough.

And because I had so many other conditions happening, I was constantly told how complex my case is.
When the decision was made to start me on a PEJ and TPN after the intralipid dialysis feeds, NG and NJ feeds failed, I felt scared.

I was lucky to have an extraordinary human involved in my care, not only as a professional, but as someone who knew exactly what I was going through. They sat with me and talked to me about everything and also gave me the contact details for a support group. The group being PNDU. I can't express how much this helped me. It makes me tear up thinking about it. And I am forever grateful for this person and this group.

I am currently eating and have been managing without HPN, I have lost 4kgs in the past month and I continue to have IV cyclizine at home, which is the only thing that manages my nausea and vomiting.

Meningococcal has taken a lot from me. It has taken my career, my independence and the ability to have children.
I have struggled a lot throughout this journey of not being able to do my career and feeling worthless.

I decided to raise awareness for the disease that changed my life. I set up The Sarah Joyce Project which raises awareness for Meningococcal. I share my story very publicly and, despite the occasional online bullying, I know I am making a difference. People tell me they have gotten themselves vaccinated or their children because of my story. Many people don't know they aren't fully protected because one of the vaccines is not on the immunisation plan and it seems no one talks about this. So I do.
I also have my vulnerable images of my showing the extent of what had happened to me on billboards and buses throughout WA, and Meningitis Centre Australia plan to make the campaign national.

I will continue to do all I can to prevent this from happening to others.

I wouldn't wish it upon anyone.

Meningococcal can happen to anyone any age at any time. It happened to me.
Don't let it happen to you.

Learn the signs and symptoms.

Stay protected, get vaccinated.

You can be vaccinated against all 5 strains of Meningococcal Disease with MenACWY & MenB.
I didn't know I wasn't fully protected, because you don't hear about Meningococcal until it happens to someone else.

World Meningitis Day is on the 24th April.
Visit: Sarah's Recovery and/or The Sarah Joyce Project on Facebook and Instagram to follow my Recovery and awareness resources.

"Meningitis is cruel and relentless. A world without meningitis is a world I want for everyone to live in. It means precious lives will not be destroyed or tragically taken. Meningococcal changed my life forever. And I wouldn't wish that upon anyone. Lets defeat Meningitis!"

- Sarah

Sarah's Recovery & Sarah Joyce Project,
Australia

HPNer Film Stars

Words by Gillian

Well, the title m-i-g-h-t be a bit of an exaggeration, but it is true that 3 HPNers and 3 carers were professionally filmed in October for a video that Baxter has organised for the benefit of HPNers transitioning from hospital to home. It is accessible via a link to a website that clinicians of Baxter HPNers will be given access to, and HPNers can join. This can be requested from the Baxter Homecare representatives.

All of the 'stars' are members of PNDU. Gillian (HPNer) and Miranda (carer) are on PNDU's Management Committee (MC). Gillian and Sal are adult HPNers, and Miranda and husband Dave are the carers for an HPN dependent child, Ariel, who also appears in the video, along with her sisters.

The film company, Tiny Giants, spent half a day with each person and this is what happened at my home. At 9:00am, two Baxter employees, including Katie Barovs, HPN Product Manager, Baxter, and 5 members of the film company arrived with equipment, including 2 huge lights and a camera on a tripod.

After showing the producer, Diane, around my home where they might want to film, I had make-up put on and my hair tweaked so that I was camera-ready. Katie then discussed how she planned to present questions to me, for me to respond as though I were just discussing the topic, as well as reading a few bits for a voice over. I then was filmed setting up, using a sample HPN bag, as it was the wrong time of day for me to actually set up. After that, we filmed some short clips showing some of my hobbies, so I was filmed entering our caravan, doing some gardening (probably some nice shots of my backside!) and relaxing with a coffee looking at a photo book of a trip to New Zealand. I then packed HPN supplies for a 2 week's holiday, which basically filled up a suitcase!

They then headed off to Miranda and Dave's house, followed by Sal's the next day. It was a really interesting experience and the finished product will hopefully achieve its purpose of helping new HPNers be ready for home.

Katie Barovs, second from left, with me beside her, along with members of Tiny Giants.

Editor's Note: IV Team provides intravenous information in their e-newsletters.

Intravenous catheter lock solutions in patients receiving home parenteral nutrition

BY IVTEAM ON FEBRUARY 13, 2020 INTRAVENOUS LITERATURE

"We suggest discussing with patients the benefits and risks when starting taurolidine, especially in patients who are considered to have a higher risk for CRBSIs" Wouters et al (2020).

Abstract:

BACKGROUND: Use of catheter lock solutions (CLSs) as a strategy to prevent catheter-related bloodstream infections (CRBSIs) has been evaluated in recent clinical trials. Our aim was to identify the most effective CLS formulation in patients receiving home parenteral nutrition (HPN). METHODS: We conducted a systematic review and individual-patient data meta-analysis (IPDMA). Prospective randomized clinical trials in adult HPN patients using CLS were identified from PubMed, EMBASE, Web of Science, CINAHL, Cochrane library, and ClinicalTrials.gov. Primary outcome was the number of CRBSIs per 1000 catheter days for each CLS. Other outcomes included time to CRBSI and identification of patients with a higher risk for CRBSIs. RESULTS: In total, 1107 studies were screened for eligibility, of which three studies comprising 162 HPN patients and 45,695 catheter days were included in the IPDMA. CRBSI rates were significantly decreased in patients using taurolidine (rate 0.13; 95% confidence interval, 0.05-0.32) when compared with saline (rate 0.74; 95% CI, 0.31-1.74; P = .002) or heparin (rate 2.01; 95% CI, 1.03-3.91; P < .001). The cumulative proportion of CRBSI-free patients using taurolidine, saline, and heparin after 1 year was 88%, 56%, and 14%, respectively. Three risk factors for CRBSIs were identified: type of CLS, intestinal dysmotility as underlying condition, and use of central venous catheters. CONCLUSIONS: Taurolidine was the most effective CLS formulation in HPN patients for the prevention of CRBSIs. We suggest discussing with patients the benefits and risks when starting taurolidine, especially in patients who are considered to have a higher risk for CRBSIs.

Full Text

Reference:
Wouters, Y., Causevic, E., Klek, S., Groenewoud, H. and Wanten, G.J.A. (2020) Use of Catheter Lock Solutions in Patients Receiving Home Parenteral Nutrition: A Systematic Review and Individual-Patient Data Meta-analysis. JPEN. January 27th. doi: 10.1002/jpen.1761.

Whacha Doin'? (During Self-Isolation)

Editor's Note: I asked this question on the forum so that we could share ideas that may inspire others to try new activities.

Gillian: I'm gardening, talking to friends on the phone (something I rarely do except to set up meeting them, usually), reading, learning to use 'Zoom' for church activities online, putting Dripline together and... I've become obsessed with a free colouring app called Happy colour, which has masses of pictures to colour- not at all creative, but addictive!

Daniel: I'm just going for walks and doing some weights. I've also got streaming services and I'm playing music (hopefully not annoying the neighbours, ha, ha).

Julia: I'm learning how to make sourdough bread. After three ghastly attempts, I'm now starting to get the hang of it. We are also thrilled with watching Pumpkin (HPNer) walking (staggering like a tiny drunk all around our lounge room). And she's eating, wanting to taste anything she sees us eating...maybe a taste of chocky egg for Easter!

Renee: Lots of reading, beach walks, meditation, cooking, baking... and my house is very clean! I even took my washing machine apart and cleaned the drum and agitator!

Carmel: This is my 5th week of isolation. Been cleaning, chatting on the phone, online yoga classes, exercises, reading, TV, music, online classes, baking, and on it goes. The best though has been FaceTime play dates with [my grandson] who is now 6 and in Year 1. We have checked out his menagerie of pets; played Lego; put our bunny ears on while he played "Hot Cross Buns" on the piano; found pieces in a 1000-piece jigsaw and tonight he was able to play scales on Mum's harp. Yep, online play dates are definitely the best. Isn't technology wonderful?

Miranda: We are baking!! Ariel (HPNer child) dusted off an old bread making book we've had for years and is reading it day and night. We had a quite in-depth discussion with her about the pros and cons of egg-wash! Funny, as she doesn't even like bread (too hard to chew and swallow) - she just loves all the measuring, floury mess and punching the dough down. I'll take that as her maths homework, reading and PE done for the day!

Jane: I'm gardening a lot, knitting, reading, doing jigsaw puzzles on my iPad, phoning friends, organising a conference call every Wednesday for my Bible study group - in fact, I am actually enjoying not going out... mostly.

Sal: In our home, my eldest son is working from home; my next son is doing uni from home; 'baby' son is doing year 12 and trying to keep him awake and motivated has been hard. My daughter got engaged! I already worked from home for [my husband's] business so that hasn't changed. I'm still working at the hearing clinic part time as well, as I'm just answering the phone really and the odd client pops in for batteries. We had a big Easter egg hunt around the house today. My dogs are getting extra walks and tummy rubs! My garden is thriving with all the rain. We have church with live streaming through Facebook and we zoom call Matt's parents.

Tracie: I have lost interest in food, so I'm trying to invent things that are interesting to eat. I have also been doing tapestries and started reading a book. I forgot how much I loved reading as for a long time I haven't had the concentration to follow a story. Tomorrow I'm planning to plant some bean seeds so I can share them with family, as I don't eat many veggies. I'll see what other veggie seeds I have, as I share with community as well, as my way of giving back to people.

Rare is Everywhere

Words by Gil

In late February, Gil Hardy represented PNDU at a **Fair for Rare** event, organised by **Rare Disorders NZ** at 'The Beehive', New Zealand's parliament, in Wellington, hosted by **Dr Liz Craig MP**.

Rare Disorders NZ represents more than 140 rare disease support groups (including PNDU) and is part of the global rare diseases community, aiming to amplify the collective voice of rare disorders in New Zealand.

The Vision of Rare Disorders NZ is that **'People living with a rare disorder will have improved healthcare and wellbeing through access to diagnostic medicines and services.'** This means implementing effective person-centred care which acknowledges their needs, has room to hear their voice and involves them in the structure of mechanisms for healthcare and social inclusion

Launching a petition with a collective call for a National Framework, supported by a White Paper, **Rare Disorders NZ, chief executive, Lisa Foster,** pointed out that rare disorders are not scarce, infrequent or remote, with 1 in 17 people (around 300,000 New Zealanders) affected. Data from a survey in 2019 demonstrates the impact of living with a rare disorder in NZ: 73% had to stop work due to their health; 38% had an emergency hospital visit in the previous six months; 37% often felt depressed and unhappy; 60% felt communication and information exchange between services was bad.

According to Lisa Foster, just because a disease is uncommon, it shouldn't be dismissed or lead to serious barriers and challenges to wellbeing. It's time for New Zealand to follow the lead of countries like Australia, to take rare diseases seriously and establish a National Rare Disorder Framework with a 7-point plan, that helps ensure equitable health outcomes for everyone:

- **Diagnosis:** early and accurate diagnosis of rare diseases
- **Planned Pathway for Clinical Care:** coordinated and integrated pathways for cohesive healthcare
- **Access to Disability and Social Support:** implement simple mechanisms to ensure appropriate access to disability and social supports
- **Rare Disorder Medicines:** equitable access to modern rare disorder medicines through a specific assessment pathway
- **Research:** coordinated and funded programme of research for rare disorders
- **National Rare Disease Registry:** capture relevant data on rare disorders in New Zealand
- **Workforce Development:** planned training on rare disorders for health professionals and support staff

"We want to work with the NZ government", Lisa concluded, "to co-design a framework that ensures people living with a rare disease are integrated into a society that leaves no one behind".

Officially Launched: The National Strategic Action Plan for Rare Diseases

It's not often you receive an invitation to attend an event like this, the launch of a plan that should for-ever change the lives of Australians living with a Rare Disease.

On the 26th February 2020, in the lead up to Rare Disease Day, Chris Walker represented PNDU, at such an event in Parliament House, Canberra. Organised by Rare Voices Australia (RVA) hosted by Dr Mike Freelander MP and Trent Zimmerman MP, the event was attended by RVA Partner Organisations and Rare Disease Stakeholders from across Australia.

The Australian Minister for Health, the Hon Greg Hunt MP, officially launched the National Strategic Action Plan for Rare Diseases. Minister Hunt stated "This is a transformative moment in Australian History"

Bipartisan support will ensure the Action plan will be implemented, despite who wins the next election. Shadow Health Minister, Chris Bowen MP, who also spoke at the event said "The National Strategic Action Plan will drive real change to extend and improve the lives of those with rare diseases."

Rare Voices Australia (RVA), Australia's peak organisation for Rare Diseases, in consultation and collaboration with rare disease stakeholders and partner organisations around Australia, led the way in the development of The National Strategic Action Plan for Rare Diseases.

RVA CEO Nicole Millis said,

"effective rare disease policy transforms people's lives. Developed by the rare disease sector, for the rare disease sector, I am very confident that the Action Plan provides a blueprint towards the best possible health and wellbeing outcomes for Australians living with a rare disease. "

PNDU would like to thank RVA and partner organisations for their contributions and dedication to the development of the National Strategic Action Plan for Rare Diseases and we look forward to working together on the implementation of the plan.To view a short video and read the National Strategic Action

Plan for Rare Diseases, please click this link.

https://rarevoices.us3.list-manage.com/track/click?u=2faa19dd1e6808d16ad363e83&id=1af4c1a9da&e=d-551fee712

Our Cowell Outback Links Adventure 2019/20

Words by Sal

Our outback adventure began on Boxing Day 2019, after spending Christmas at Tarana, on Matt's parents' farm near Bathurst. We headed off in "Bridget" the bus – Matt, Sal, our (not so young now) children Jolyon, Juliet and Bradden and Juliet's boyfriend Enoch. The day warmed up very quickly as we travelled along, and it wasn't long before Matt worked out the best way to keep the bus engine temperature under control was to drive about 85-90km/hr, so it was a slower journey. Our good mate Ian joined us at West Wyalong in his car (he found us cooling down in the 'Reject shop', as it was open), and I jumped ship to his car that had air conditioning. The bus doesn't have air conditioning when we are travelling at this point in time, and I don't cope with the heat very well. We stopped at Rankin Springs for a brief rendezvous with my sister and her sons, who live in Griffith, before heading to Hay for the night. Matt and I have the bus for accommodation, but the others stayed in a cabin. It was a long hot night and the next day was to be equally hot at 40 plus. Bradden is still on his learner's permit and took the chance to drive the car on the outback roads to get some hours of practice up. Stopping for lunch at Mildura, we melted in the shade by the Murray River. We also stopped at Morgan and dipped our legs in the mighty Murray to cool down. By then, I had retreated to the car again to get cool. We stopped at the South Australian town of Burra for the night. We headed off early to make most of the mornings when it was a bit cooler and the sun less intense. We arrived in Cowell, at our destination, that afternoon. We met our farmers Muriel and Alan (they are in their mid to late 70's) and got the tent set up before heading into town for the early New Year celebrations with the locals. A band played on the back tray of a semi, whilst some locals ran food stalls. We finished the night with 15 minutes of beautiful fireworks over the Franklin Harbour at Cowell. It was nice to have the breeze off the water to cool down.

The next day Bradden and Jolyon went out to learn the ropes for dropping off hay in the paddocks for the sheep. We were shown around the farm and the over 100 year-old stone homestead. We began work to prepare the shearing shed for the shearer. This entailed sweeping it out, repairing the floor in places, fixing gates and fences and creating a strong point in the old shed for the shearer to mount his equipment to. Matt also began looking at the 50 year-old tractor and their old Hilux farm vehicle that both desperately needed servicing and love. We explored town to get our bearings that afternoon and to find where the medical centre was, as Enoch was being a locum GP for 4 days that week and Juliet would assist and observe as a medical student. That night it blew a gale and the tent poles snapped and tore through the fly of the tent, even the bus rocked in the wind. Needless to say, not much sleep was had after the tent collapsed. Juliet and Enoch had to crawl into the collapsed tent to get their clothes out, and look presentable at the medical centre that morning. They then moved all their beds and bags into the homestead and stayed there for the rest of the trip. The boys got working on the Hilux and tractor and we finished sorting out the shearing shed. We also had to round up the sheep ready for shearing and bring them in from outlying paddocks. The next day it was New Year's Eve and it was forecast to be over 40 degrees again, so they opted to postpone the shearing for another day. I picked up my PN bags from the local hospital without any worries. That day, the northerly wind blew 45km/hr and it was 45 degrees, and in the afternoon the southerly came through and dropped the temperature by 20 degrees, yet the wind still blew at 45km/hr, just from the other direction! Matt joked that the dirt and sand that the wind had picked up and blown across in little dust storms that day, then got sent back from where it had come from!! We went to bed early for New Year's Eve; the heat was exhausting, especially for me. Shearing started at 7am and we helped to round up the sheep from one yard to the next, then helped to get them sorted by wool length and into the pens ready for shearing. I helped get the food sorted and made sure everyone was well fed and watered, as it was another warmish day. After about 200 sheep were shorn that day, they had to back line and brand them all, then round up the remaining sheep for the next day. They also had to remove 3 merino sheep belonging to a neighbour. This was no easy task, especially when the sheep dog was pretty good at splitting the flock and guarding the gate they were supposed to be entering!! Let's just say the sheep dog was observed to submit and roll over for the pet lamb… We didn't get all this done until after dark, around 9.30pm that night, and had another day of shearing to come.

The next day with Juliet and Enoch at the medical centre, we were down in numbers to help, but managed to get through the rest of the sheep. Apart from a snake going over Bradden's feet when he was trying to move a sheep in the run, it went well. It was another warm day and I just had to keep everyone fed and watered. It was exhausting work and weather. We went out and met the second farmer we were to help the next week the following day. We then headed down the coast to Tumby Bay to cool down as it was another 40 plus day. It was so refreshing to be by the sea and everyone enjoyed the local fish and chips! The next two days proved to be a lot cooler and we needed jumpers and trousers and were able to get the tractor and Hilux going again and Jolyon worked on our generator to see why it had seized. Turns out the glue holding the magnets had given up in the extreme heats! Jolyon had to then fly back to Sydney for work.

Come Monday, we were at the second farm and had not long begun work when our mate Ian unfortunately had a seizure. Lucky that Enoch was on hand and cared for him while I tried to arrange an ambulance in a poor phone zone with only a farm name, as there was no street number for the farm. They came eventually and Ian only spent a couple of hours at the hospital before being cleared, but was then not permitted to drive for 6 months. That day and the next, we repaired a shade shed and made a larger one. Matt weld repaired a tractor with a front-end loader attachment and they removed and replaced leaning posts and frames and roofing of a carport structure and got it all strong and sound again.

Our last day on the farm comprised of moving some fresh hay into the paddocks and putting wire around them to keep them upright for the sheep and to stop them leaving it on the ground where they won't eat it if it's soiled. We then went for a drive and explored a few other local spots. In the evenings during our stay, we would go and chat with Muriel and Alan or play a game with them. They even sourced a guitar from a neighbour so we could do a sing-along for their old favourite songs. The trip was just as much about listening and supporting them and being company as it was about the practical help on the farm.

We left early the next day as it was, of course, another 40 plus day. We took it in turns to drive the car. We arrived in Broken Hill that evening and, after dinner, went to the pool to cool down. I even ventured in as far as my chest and my Hickman position would allow me! We had another hot night but got up early to take a quick tour of Broken Hill and sit on the giant park bench for a photo before heading to Nyngan. Again, we took turns driving the car and Matt took it easy on the bus. It was 47 degrees and we were all not enjoying the trip. The odd goat and emu were seen along this straight stretch and we stopped at Cobar to fuel up and top up on ice creams that had to be eaten quickly before they melted! We arrived at Nyngan that evening and there was nowhere cool to sit; the bus was hot and so was the cabin accommodation. If you had a shower, there was no need for a towel, as you dried so quickly. We had a dust storm that night and again the wind blew wildly, and if you looked outside, the area under the streetlights was an eerie orange colour. You could smell the dirt. The next morning everything was orange, even the inside of the bus, which isn't completely draft proof.

We headed homeward for our final day of driving, which fortunately was much cooler and pleasant. We took a detour at Bathurst and the bus did a hot lap around Mount Panorama in a blistering 9 minutes (2 minutes faster than Matt's old side valve engined Morris Minor!) Okay, so we did have to stop at the top to let the engine cool down but all up it was only 9 minutes!! The bus always seems to draw attention and you get people coming and asking about it in the street or in the caravan parks. We have seen people taking photos as they overtake or you get a thumbs up or people shouting cool and the like as they drive past. This trip, we had a guy tailgating for a while, then they overtook us whilst filming and then they pulled over and filmed us driving past. We do wonder what people then do with the footage and photos, and if it's shown on social media or not. You just smile and wave!!

We arrived back to where we started at Matt's parent's farm and collected Enoch's car as well as sharing our adventures, before driving the fire-ravaged Bells Line of Road through Lithgow and Bilpin. Our dogs were very happy to see us and we were glad to be home. We felt incredibly blessed for our safe travels and being able to go and help the farmers in Cowell and bring some temporary companionship and love. We had fun despite the heat and dust and being together is always a joy.

Matt, Sal's husband, driving the bus.

Cooling off in the Murray R at Morgan. Sal (HPNer) on left.

Bradden moving hay with the repaired tractor and attachment.

Bridget, the bus.

The homestead at Cowell.

The dust storm.

The effects of the drought.

Birthday Corner

Editor's Note: It's lovely to see our young members growing up!

Emily, looking lovely on her 11th birthday.

Logan, looking very happy and daring on his 8th

A Day in the Life of an HPNer: Electricity and Water

Words by Gillian

These days, people are encouraged to conserve our countries' (Australia and New Zealand) resources, to minimise our water consumption and power usage. I'm sure that this general concept would be supported by most people as a good idea and something to aim for in our personal lives – if for no other reason that it should result in lower power and water bills!

However, for those of us dependent on HPN (Home Parenteral Nutrition), this isn't as easy as it sounds. Electricity is vital for us to run a refrigerator – and many of us need to run a second frig, just for storing our PN bags. We also have to charge our pumps, after running all night on battery mode, in the charging cradle during the day. Some HPNers run 2 pumps at a time, depending on their other treatments. If we are lucky, depending where we live, many of us are able to apply for a small rebate* from our electricity provider to offset the cost a little, although this doesn't help with our actual consumption figures. Our dependence on electricity can also make life difficult if we happen to live in areas prone to blackouts. For example, when I visit my sister-in-law on a property in the Dandenong Ranges in Victoria, I have to hope that they don't have a blackout, as these occur from time to time during the year and my relatives don't have a generator, as the power usually returns fairly soon – but if it didn't, it could make keeping my PN cold and my pump charged very difficult. If an HPNer lived in an area that experiences blackouts, they would need to have a generator as back up.

I am aware that I use more water than I used to, now that I live with HPN. One reason is that whilst scrubbing up my hands before setting up and connecting to my PN each night, I leave the tap running between getting my hands wet, soaping and washing and the final rinse. This is because once I start, I can't turn the tap off and then on again easily without compromising my sterility – knocking the mixer tap off is easily done with my forearm, but turning it back on is too difficult. Thus, water is wasted as it runs down the sink. If HPNers have a carer handy, they could stand by to do it for them, but otherwise it is too hard.

Secondly, although before my HPN days I used to drink some water during the day, once I developed Intestinal Failure, I was encouraged by my team to drink a couple of litres a day, which adds up to a great deal over time.

The last reason is flushing the toilet! During the night, when my (in my case) 3L bag of PN is infusing, my bladder needs emptying at least 3 times, sometimes 4, during the night, as well as the small amounts in my ileostomy bag – and each of these visits means a toilet flush. And in order to thoroughly flush the contents of my ileostomy bag, which many of our members also have, I need the full flush without a brick to minimise in the cistern, or else I find that bits are remaining. As I am one of the lucky HPNers who can eat and drink, I need to empty my high out-put ileostomy bag at least 6-8 times during the day so that I don't have a large protruding lump under my clothes, which may start to leak if not emptied. All these toilet flushes add up to a lot of waste-water.

This need to use so much water is especially hard for HPNers living in areas suffering severe drought with high level water restrictions, such as Tamworth, a NSW country town, currently on Level 5 - which means an (unenforceable) limit of 150L per person per day (including showering, food prep and washing up, washing etc - ie everything). In this situation, it's especially hard to feel you're doing your part – yet compromising on sterility could very easily lead to a line sepsis and hospital.

As everyone can only do what they are able to do, I think about how I would like to be more careful of my use of resources, but I know that I'm not being wasteful – simply living as I have to as part of the trade-off of life on HPN.

*Check with your electricity provider whether or not they give rebates for life-saving pump use.

Upcoming Events

PNDU will continue to stay in contact with all of our supporters and friends, such as AuSPEN, IVNNZ, NIFS NZ and RVA, as we prepare for Awareness Week 2020, we are eager to see an end to the COVID 19 restrictions and will make preparations to attend all the rescheduled 2020 events.

PNDU continues business as usual and have some exciting activities to look forward to.

Australian Patient Organisation Network (APON) with the support of the Centre for Community Driven Research (CCDR), will continue their webinar series, in preparation for the next APON Conference, patient organisations working together to design systems that work better for their patient communities. Health services/Health system and Navigation: Access to medicines and services: Research and Medical Research Futures Fund (MRFF): Clinical trials and registries: Digital health and emerging technology:

Patient Voice Initiative (PVI), in collaboration with the Consumer Evidence and Engagement Unit, Office of Health Technology- are hosting an informative Workshop- "Patient- Based Evidence, from insights to evidence", with a focus on PBAC submissions for patient organisations.

Thank You

PNDU gives thanks to our generous donors listed below.
Donations to PNDU January to April 2020: total $10 505.

- Baxter Healthcare
- C Walker
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- A Holmes

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.

Editor's Note: Although worldwide travel is currently banned, due to COVID 19, the world will eventually return to normal. If you are planning international travel in the future, now may be the time to make some enquiries.

Membership for Aussie and Kiwi HPNers and carers:

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

Benefits:

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

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

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

Donations

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

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

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

Donating via direct deposit

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

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