



DRIPLINE



PNDU

Parenteral Nutrition Down Under

Welcome to another edition of Dripline. Sadly, we begin another issue with a farewell to three of our precious members. We then continue with the positive aspects of being an HPNer: we share members' holidays, outings and birthdays; we learn about research with Biofilm and muscle cramps; we read HPNers comments about their CVADs (central venous access devices) and some feelings on well-meant, but frustrating, comments about our appearance; and about one aspect of life on HPN: weight change. We learn about PNDU's involvement in 2 different forums to advocate for improvement to living with HPN. I hope you read, enjoy and learn!

Gillian - Editor

In this issue:

- [We say good bye to three of our precious members](#)
- [CVADs \(Central Venous Access Devices\): Members' Thoughts](#)
- [Fun in the Water](#)
- [Camping \(Glamping\) Patonga Style with HPN- Justine](#)
- [Molecular chameleons can help track formation of bacterial biofilms](#)
- [A Great Day Out](#)
- [PNDU invited to Parliament House Canberra](#)
- [Birthday Corner](#)
- [Out Yonder \(Again\) – an HPN travel story – Sal](#)
- [Surveys, Studies and Data – HPN down Under](#)
- [Muscle Cramps and HPN](#)
- [A Day in the Life of an HPNer – Weight For Me!](#)
- [PNDU participates in a QLD Home Therapy Ideas Forum.](#)
- [The Great HPN Family Holiday Road Trip - Chris](#)
- [PNDU in Perth – May 2017](#)
- [Brisbane events for HPNers and carers – May 2017](#)
- [Please Don't Tell me I'm Looking Well](#)
- [Lunch With Bev](#)
- [PNDU's New Website Launch](#)
- [HPN Line – a new toy](#)
- [Planning Overseas Travel with HPN?](#)
- [Upcoming Events](#)
- [Thank You](#)
- [PNDU information: membership, donating, contact details](#)
- [In Memoriam](#)

ISSUE 19
FEB-APR
2017



We say good bye to three of our precious members

LARA

WORDS BY KAREN

It is with great sadness that we recently said goodbye to little Lara. After putting up an amazing fight through recent hurdles, in February little Lara passed away at home surrounded by her family.

Lara celebrated her 7th Birthday last November, and those who attended the PNDU Brisbane social gathering in September 2015, and the Brisbane Baxter pharmacy tour last August remember her well, and the amazing and beautiful impact she had on those around her.

Our hearts go out to mum Sarah, Lara's sisters – Lourdess and Madeline, and the whole family as they grieve Lara's passing. Thank you for sharing your beautiful girl with us, and for being part of this special little community. May the cherished memories of your dear little one never fade.



Lara with big sister, Lourdess

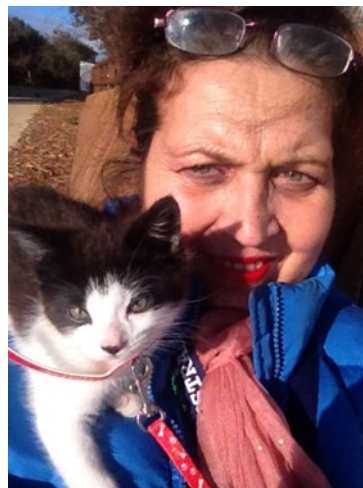


Lara in the arms of one of the Brisbane Baxter pharmacy staff during the Awareness Week 2016 visit

TERESA

WORDS BY GILLIAN

Recently, we had more sad news. Firstly, in February, Teresa passed away. I 'met' Teresa on the phone early last year when she wanted to join PNDU. She was an enthusiastic advocate for her hospital, her medical team, HPN and life in general. This enthusiasm came across in all her posts on PNDU's email chat forum and from her discussions at our annual PNDU social gathering in Melbourne last November. Despite having a serious form of cancer, she made the most of her remaining life by being a loving mother and grandmother, travelling, rescuing a kitten called Victory (who made her hospital ward his home at times) and continuing to teach Spanish at a local school. You can read Teresa's story in [issue 15 of Dripline](#).



EMMA

And then sadly, as a complete shock, we received the news of Emma's sudden passing away on 9th April. Emma will be remembered by us all for her 'never give up' attitude. As well as living her everyday life and coping with the side effects of her illness, and also continuing to work as a GP, she also put a lot of determination into planning and carrying out 3 major overseas trips, which took a lot of behind the scenes work. You might like to read her 'A Scandinavian Story' in [Dripline issue 11](#). Last May, on the celebration of her 35th Birthday, Emma shared with us: "Thanks for all the birthday wishes. I was just grateful to get to 35. A milestone for me that most thought was impossible. I took my family to high tea to thank them yesterday." Emma's zest for living was obvious. I met her at a Sydney gathering when she was up one weekend to go to the theatre! As well as the Sydney gathering, she also attended a couple of PNDU Hobart catch-ups, as well as our annual social gathering in Melbourne last November (even though she was in a wheelchair due to a broken ankle!), so many PNDU members knew her, not only from the email forum, but also in person at the various PNDU gatherings.



Emma, and Emma (with a broken ankle) and Teresa, at the annual social gathering, Melbourne 2016

CVADs (Central Venous Access Devices): Members' Thoughts

Editor's Comment: In view of PNDU exhibiting and presenting at the Australian Vascular Access Society's 2nd Scientific Meeting in Perth in May, members were asked to comment on the positive and negative aspects of their central line (catheter), or CVAD

I had a Hickman Line for four years and then a port for the past year. I love the freedom that the port offers, particularly greater safety with swimming. The downside is of course accessing with a needle, so it is obviously a choice adults can make (can't see a port working for children) and the pros and cons should always be discussed with patients. When I first started on HPN I was very ill and did not have the energy to needle myself, so circumstances are another factor. I just accept that a dressing may be visible (particularly in summer) and don't really care!!

- Renee

We have always been told Jordan and Logan (young HPNers) only have 4 access sites in their chest. Maintaining 2 unused sites (50%) was a requirement for access to the transplant program (should we ever consider taking this path).

Jordan has already used 3 sites and his 3rd site had the central line migrating out of his chest. We were lucky enough to have a radiologist who was able to remove the migrating line and replace a new line in the same site.

Logan has also had this procedure carried out, once after his central line blocked with fibrin sheaths and again after a central line repair caused the line to block. Logan has used 2 sites (50%)

- Chris (carer)

For me, I love my port! Having had a nasty fungal central line infection in hospital before going home on HPN, a port means I don't have anything hanging out of my chest to potentially collect bugs (or clamps sticking into me) when not infusing. It means I can safely go swimming, have long hot showers, and not worry about dressings lifting when not infusing. The downside of that freedom and peace of mind when not infusing is that I need to do a full medical procedure each night, preparing the skin, inserting the needle, dressing it, and connecting up which takes concentration, energy and about 25-30 minutes each night. Also, the port itself only lasts a few years of needling every night before it wears out and needs replacing. That said, it's what I've always done since starting HPN and am most comfortable with. It's working for me!

- Karen

I don't mind having my Dingle dangle (Hickman line) being seen, people can take it or leave. No one asks me what it is, if they do notice. The only downfall is not being able to swim, I do miss being able to swim. I do hate where it is, it was clearly a man that put it there, as it sits right under my bra strap which is uncomfortable, and it is very close to my armpit. As it was tunnelled so far to the right, this means it's very short and I cannot access it for connection, myself. This means either my husband or daughter have to do that for me, which is often difficult to organise with busy social lives. If my daughter does move out, then I will have to train a son to do that. Otherwise I love my dingle dangle and it is my lifesaver.

- Sal

I have lived with both a port and a Hickman line (as well as a PICC line between these) over the nearly 11 years that I've been on HPN. I coped with the port, the original line put in (although it was meant to be a Hickman - oops!) but found aspects of it quite annoying. For the first couple of years I travelled once a week to the hospital to get a new Gripper needle for access, until I was finally trained to do it myself. I didn't like needling my chest in such a tiny area, plus, it had to be a totally sterile set up complete with gloves, so it took much longer to do. I also didn't like the way it bulged under clothes. Finally I got a granuloma, so I changed to a Hickman line. Since I was always needled with my port, I was used to having something dangling down my front (as is the case with a Hickman Line) as well as a dressing (IV3000) possibly visible when wearing certain necklines.

Whilst waiting for this, I had a PICC line put in temporarily. A PICC is annoying because it leaves you dependent on someone to attach the PN infusion pump tubing to the end because it is too short to hold yourself...although I have recently learnt that there is an extension piece now available to lengthen it, which would solve this problem.

I have had 2 Hickman lines now – the first one had to be replaced after a fungal central line infection. I am quite happy with this type of line as it is much quicker to set up (about 10 minutes now that I have experience and confidence) and it sits flat on my chest. My hospital team allows me to swim with it, which I only do when I'm on holiday, and I've never had a central line infection as a result of swimming. I had my port and my first Hickman for 3-4 years each. I had central line infections about once a year with both of these, slightly more with the port; I've had no infections with my second Hickman which I've had for over 3 years.

- Gillian

Some PNDU members have an AV fistula formed for HPN use, learning how to cannulate it themselves for their PN infusion. An AV fistula for HPN has the benefit of no catheter to cause thrombosis, attract biofilm and create an infection risk. ***Editor's note: For further information about AV Fistulas, read the article by a member at the time who had a fistula and was also a nurse, in [issue #4 of Dripline](#), titled HPN AND ARTERIOVENOUS FISTULA (AVF).***

The End of the Line...or not

Over the years I have had lots of central line infections resulting having about 4 Hickman Lines and about 10 ports replaced, resulting in my Superior Vena Cava and all other major veins in my chest becoming blocked. I have had central lines in both Jugular Veins then I was told there were no more veins left. However, a vascular surgeon managed to insert one below my right breast. I was told this was the last vein I had left. But when I got another infection, they managed to insert the port in my right femoral vein and up into my heart. This one lasted for 2 years and then they inserted one in my left femoral vein, which lasted 3 years. It became blocked and had to be replaced in the right femoral vein. After another year this became infected, so it was back to the left femoral vein where it remains today, 18 months later. In the mean time I was lucky to have a stent put in my Superior Vena Cava by an Interventionist Radiologist, so if and when the femoral vein gets an infection I have the SVC to access.

- Rosie

Fun in the Water

Editor's note: Please consult your medical team for advice about swimming with a central line.

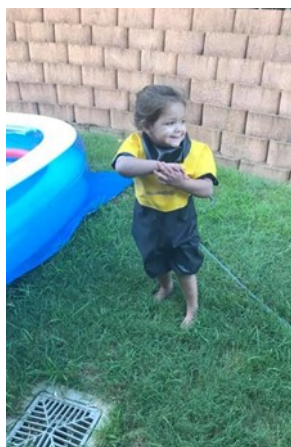
I just thought I would share Zander's first time swimming with you all! His dry suit arrived yesterday 😊 After the swim, his back was a little sweaty, but the dressing and his nappy were perfectly dry. It was custom made in the UK (**Editor:** google 'dry suits for children' to find places which sell these). They are quite pricy but I am so glad we bit the bullet and ordered one! He was scared to begin with, which I expected since he had not been exposed to it before (I am a swim instructor as well) but by the end he was jumping off the ledge by himself. He starts swimming lessons next week, I am so excited! Ha! Ha!



MayMay has finally had her first real swim - her swim suit ('dry suit') arrived today.

She loved every moment!

There was no problem getting it on as long as there are two people to do it. We had the best time! Just seeing MayMay's reaction was priceless. A very happy little girl and extra happy Nana.



Camping (glamping) Patonga Style with HPN

WORDS BY JUSTINE

Editor's note: Please consult your medical team for advice about swimming with a central line.

As anyone who has known me for longer than a year will tell you, my annual camping trip to Patonga is my sacred pilgrimage, an event that cannot be interfered with, my return to my place of balance. I totally cherish my 2 weeks under the big flame trees watching the river flow and the playful relaxation of family-based camping. My dear friend Julie and I have been going to Patonga on the Hawksbury River (North of Sydney) for many years. We started as two mums taking 8 kids, 5 tents, 7 pushbikes, and enough swimming gear and towels to clothe a small town. Many things have changed over the years, the kids have grown and no longer come for the two weeks (but do come for short visits as work permits); we now only have 2 tents (a 6-man each) and the kitchen gazebo to erect; and our days are planned according to how many swims/ cups of tea/ or scrabble games we want to have.

So how was this all going to happen in 2017, our 15th summer, now that I was on HPN?? With consummate planning and sheer determination, of course! – this was my time and nothing was going to take it away!

Like so many of us do, I pack ziplock bags for each aspect of my HPN day – connection, disconnect, morning and evening medications, needle change, air-in-line, etc etc and store them in plastic tubs. So going to Patonga was going to be no different – I packed 1 week's worth of 'baggies' and 2 extras into their respective tubs, and 2 boxes of Plasmalyte (I have daily IV hydration as well as HPN) – thank goodness for that 6-man tent, haha. My plan was to return home on the following Sunday to replenish my stocks; it was my grandmother's 95th birthday and I had to be home for a visit anyway. I had already bought a new (second-hand) bar fridge for my HPN bags to keep them separate from our food and beverages – hence the "glamping", because we have power and amenity facilities - and loaded the HPN bags I had at home into an esky with the cooler blocks (thanks Baxter) for the 45 minute drive and 2-3 hour setup time; and we were off.

Patonga bookings run from Saturday to Saturday and my HPN delivery day is Wednesday. I hadn't arranged alternate delivery options, but thankfully my daughter-in-law had agreed to accept my delivery at home and bring the boxes down to Patonga for those 2 weeks. I'm sure I could have organised delivery to the camping area, but it was a potential hassle and I didn't want to complicate my 'zen', and it was her excuse for a Patonga visit (though she didn't need an excuse). Two years previously I had had my post-op stoma nurse visit in the tent at Patonga – I had my proctocolectomy by laparotomy on Dec 10, discharged on Dec 24 and encamped at Patonga Jan 03; as I said, NOTHING prevents my Patonga sojourn.

An integral element of any Patonga holiday is the swimming, kayaking and fishing in the creek or beach front - as I mentioned earlier, the success of the holiday is measured in the number of swims taken and books read (and if you are the scrabble champion that's a bonus). I had had my port for 2+ years (but until April 2016 had only had hydration 3 days/week – I did do hydration at Patonga the previous year) and was usually accessed 24/7 for HPN, but this January I also had a PICC line thanks to a hospital visit in Dec and another one planned for the new year; so how was I going to swim, kayak & fish in the creek? I de-accessed & removed the port needle every second day; on the days when my needle was in, I put extra IV 3000 over needle & extension and made sure I floated with my upper chest above the water line (Julie had given me a floaty ring with coloured LCD lights! for Christmas); I had also purchased a latex sleeve for my PICC (from Theraquatics in Qld) and it worked brilliantly – no water issues at all. Kayaking in the creek while accessed and infusing was without issue, but one day when coming across the sandbar after a beach kayak I was overturned by a wave – I think I did the fastest crocodile roll in history & came up with the pump dry & ok (shhh! don't tell Baxter that one).

When it was time to do any sterile tasks, I cleared and cleaned our 'kitchen table', washed my hands at the site tap and did any further hand washes with alcohol-based hand gel. I did use sterile gloves for access and de-access, but only hand washing for medication administration. While infusing my hydration bags I mostly used my Infinity paediatric enteral backpack, and when I connected the HPN bag I had a camping IV pole – commonly known as a Coleman Lantern pole (it was very light to manoeuvre and held the bag well). As we had a powered site, recharging the Bodyguard pump was not an issue.

So my holiday was amazing as usual, nil incidents (except the kayak roll and that was all good), I swam, read books, enjoyed many conversations with the people we know



IV Medications Patonga style



Julie the 'flathead queen'

only from our recurring annual holiday, and I was the scrabble queen (yay!). Will I do it again next January? – you bet, have already confirmed my booking; is camping possible on HPN – YES with extra planning and thinking (especially about how you are going to do your sterile set up with probably less access to running water than usual).

So be brave, plan or book to do that thing from your 'past life', it is all possible - just remember "Failing to plan is planning to fail". My next adventure is a 10 night cruise with my daughters in April. I'll let you know how that one goes 😊



Penelope visiting Nanna at Patonga

Molecular chameleons can help track formation of bacterial biofilms

Published on November 23, 2016 at 11:39 AM

Source: Linköping University

Molecules that change colour can be used to follow in real-time how bacteria form a protective biofilm around themselves. This new method, which has been developed in collaboration between researchers at Linköping University and Karolinska Institutet in Sweden, may in the future become significant both in medical care and the food industry, where bacterial biofilms are a problem.

Biofilms are formed when bacteria growing on a surface form three-dimensional colonies in which they survive better than when living alone.

"What characterises biofilms in particular is that the bacteria produce a special slime that binds the bacteria to each other. The biofilm helps the bacteria to withstand external stresses, such as antibiotics, the flow of fluid in a catheter and detergents in the form of dishwashing liquid and other cleaning agents," says Professor Agneta Richter-Dahlfors at Karolinska Institutet, who has led the study together with Professor Peter Nilsson at Linköping University.

The protective biofilm is a problem in, for example, medical care and the food industry. Until now, no specific method to detect biofilms has been available.

"This is the first method that specifically labels the biofilm components. This means that researchers who want to study the mechanisms behind how bacteria form biofilms now have access to a new tool in understanding the process," says Agneta Richter-Dahlfors.

In the present study, published in *Nature Journal Biofilms and Microbiomes*, the investigators have developed molecules that emit a sort of optical fingerprint that depends on what they bind to. One part of the molecule has the ability to emit light, while another part can bind specifically to a target molecule. In this case, this is a molecule present in the biofilm. When the tracer molecule has bound to the target molecule, the colour of the light emitted changes.

"The molecules that we have developed are unique in that they can emit different colours, depending on their conformation. We call them 'molecular chameleons', since they change colour according to the surroundings," says Peter Nilsson at Linköping University, whose research group has developed these tracer molecules.

The researchers have demonstrated in the project how the method can be used to study *Salmonella* bacteria, both in cell cultures and in infected tissue. The researchers hope that it will be possible eventually to use the method within medical care and the food industry, where biofilms are a problem. There are, however, also contexts in which the ability of bacteria to form biofilms is positive, for example when bacteria are used to produce biogas to be used as fuel.

"It is possible with the new method to follow in real-time how the bacteria form a biofilm. Now that we have a tool that we can use to see how biofilms are formed, we can also use it to evaluate methods that influence the process," says Peter Nilsson.

The research has been financed with support from the Swedish Research Council, the Swedish Foundation for Strategic Research, the Erling-Persson Family Foundation and Carl Bennet AB. Some of the researchers who work in the study are part-owners in a company that may commercialise the molecules for use within medical care and industry.

A Great Day Out

WORDS BY KAREN

Over many dark days/years of out-of-control Crohn's disease, my Mum was my carer. Not for the first time, today my carer became my caree ☺. Today is my Mum's Birthday, and at 77 she is on the waiting list for a hip replacement. But she's had her heart set on Taronga Zoo! so we did it ... with a wheelchair!! ☺ If anyone knows Taronga Zoo, it ain't flat! Mum didn't have a gentle sedate cruise around the zoo - so much easier (and fun!) to just go with the momentum and jog down the hills and skid around corners ☺. A few small uphill took the wind out of my sails though and I'm seriously going to sleep well tonight. Thank goodness for the Skylift to get back up to the top again. A fun and absolutely beautiful day with my dear Mum!



PNDU invited to Parliament House Canberra

WORDS BY CHRIS

Background:

PNDU exists for all Aussie and Kiwi adults and children living with Home Parenteral Nutrition (HPN) for Intestinal Failure (IF). Our numbers are small. Intestinal Failure is considered a rare condition. In this part of the world there are only around 250 adults and children on HPN across both countries. New Zealand now has a National Intestinal Failure Service for the benefit of all Kiwi HPNers, which PNDU supports.

Without a national service for HPN and IF in Australia however, we know from member experiences that there is disparity and inequity of services for HPNers between states and territories and between hospitals. PNDU is therefore involved in various advocacy projects to highlight the challenges for Aussie HPNers and to help bring about changes. Fair for Rare is one such project. I have been representing PNDU as a member of the Rare Voices Australia (RVA) "Fair for Rare" campaign working group.

The Fair for Rare Campaign

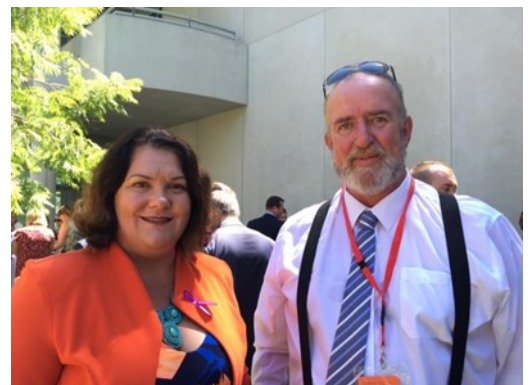
The Fair For Rare campaign advocates for a 'fair go' for Australians living with rare disease. The campaign showcases the critical need for a National policy framework for Rare Diseases in Australia – an action plan from early diagnosis, as gatekeeper to best clinical care and intervention, to timely access to treatments and coordinated care. Effective policy development in key areas would transform patients' lives.

In the lead up to Rare Disease Day, the Parliamentary Friends of Rare Diseases, co-chaired by Hon Trent Zimmermann MP and Hon Steve Georganas MP, together with Rare Voices Australia and Metabolic Dietary Disorders Association (MDDA), successfully launched the 'Fair for Rare' campaign at Parliament House on 16th February.

RVA Executive Officer, Nicole Millis spoke about the need for rare disease to be made a national health priority. Our health system needs to



Chris with his local member, The Honorable Meryl Swanson MP



Catherine King MP, shadow Minister for Health, with Chris

be Fair For Rare. She issued a Call to Action to our Government and proposed a pathway forward. Effective rare disease policy is crucial, and transforms patients' lives.

Louise Healy, Vice President of MDDA and Director at RVA, spoke about the impact of effective rare disease policy and highlighted potential for further development, through a focus on newborn screening.

As an HPN carer and PNDU representative, I was able to engage my local member, The Honorable Meryl Swanson MP, who was kind enough to introduce me to Greg Hunt MP, minister for health, Catherine King MP, shadow minister for health, along with Tasmanian Senator Catryna Bilyk and respected paediatrician Dr Michael Freeland MP, just to name a few of the MP's and Senators I had the chance to engage with. In keeping with the "Fair for Rare" campaign theme, I had the opportunity to speak with the MP's and senators, about what it is like living with, and caring for, the rare condition of Intestinal Failure requiring Home Parenteral Nutrition. All the ministers were very interested in how different our lives are without a national plan for IF and HPN, and the inequitable levels of care that exist.

Overall the day was a very successful event. PNDU is very thankful for the opportunity to be involved in such a successful project.

Be Fair For Rare. www.fairforrare.com.au



Chris, Catherine King and Nicole Millis, RVA Executive Officer

Birthday Corner

Editor's Note: I recently decided to open Birthday Corner to adult HPNers, too, since an extra year is a celebration for us all.

Emily (HPNer in the middle of the picture to the right) turned 8 and was home to celebrate with her brother and sister, pictured and the rest of the family. They had a great time together.



Logan (HPner) had a SUPER birthday and was very excited to receive a birthday card from his friends at PNDU on Friday, thanks to PNDU's 'birthday fairy'.

Turning 5 was huge a milestone for Logan and our family of carers and a very special day was arranged for Saturday.

Logan enjoyed a birthday party with friends from preschool and a very special guest appearance from SUPER HUBERT the magician. Super Hubert kept all the children entertained with his special magic show.



Super Hubert and assistant Logan put on a great show for all his friends.



Auntie Katie's cakes made an appearance for Logan's preschool party and Logan's family on Wednesday – Logan loves PAW Patrol!

Jodie (HPNer) wrote:

I had brekky out with Ryan (husband) and Daniel (son) and a dear friend who was down from Kalgoorlie for the weekend. I met her BF for the first time. Ate eggs hollandaise and just about died and went to heaven. In the arvo, I went to the Dolphin Discovery Centre with the boys, which was lovely. Daniel was very excited to take me as I'd not been before. Great aquarium set ups there. We spent ages looking at fish, octopi, eels and crayfish. Even a small shark. No dolphins spotted in the bay though. As I'm not a huge fan of cake, the boys had bought me a slice of GF lasagne for dinner from one of my fave cafes and put a candle in it to sing happy birthday to. Oh man, the lasagne was delicious!

My scooter was a gift from my in-laws. I got thoroughly spoilt this year with that and a huge new TV from my mum. Plus I ended up with six book presents from friends. I only turned 34yo - can't believe how spoilt I was!



Out Yonder (Again)

WORDS BY SAL

Here is our latest tale of our trip out yonder, so pull out your map of Australia and follow our journey! We left behind our eldest to house sit, and our good mate Ian from church came with us.

We left early on Boxing Day from our place in Western Sydney, it was rather a hot day for travelling in the bus, (no aircon unless the generator is going or we are plugged into power). So it was wet washers to keep us cool. We made it to St George in Queensland by dusk and stopped by the Balonne River for the night. Matt discovered that one of the front tyres had a bulge in the side wall and had to change it, better to change it then in the cool of night. We nicknamed the tyre Bulgy Mc-bulgy and you will hear more about him later. We ran the generator (Gennie) with what little fuel was in its tank (we forgot Gennie's best friend Jerry) to try and cool the inside of the bus with the aircon. The thing is, the aircon is at the opposite end of the bus to our bed and our bed is over the top of the hot engine, so the songs 'hot in the city' or 'beds are burning' came to mind. Only bonus to our beds location is looking up through the hatch and seeing the stars glisten. The Gennie ran for a couple of hours before running out of fuel. The thing about the Gennie, is that it's as loud as the Detroit engine of the bus! It was a loooong night.



The next day we continued on and our mate Ian had a turn to drive the bus. We headed through Bollon where we had helped a farmer in 2010 and through Cunnamulla and Eulo (where the mega fauna fossils have been found). We then went to Toonpine, a town that consists of just a pub. We stopped here and went into the cool of the pub to tell the owner of how much help his caretaker had been, when we broke down there back in 2014 in 42 degree heat. The irony is that after we left there and travelled about 5kms down the road, the engine temperature went through the roof and we had to stop and make repairs. Matt discovered a bracket of the radiator had broken and this pushed the fan a bit and the fan then cut through a hose and temperature sensor. So Matt had to create a bypass. An hour or so later we were back on the road and carefully driving so as to not overheat the engine. We went

through Quilpie and then out 25km short of Eromanga (the furthest town from the sea in all directions). We were helping a family we had helped in 2013 and again in 2014. Our outback family's dog recognised the bus immediately and went nuts. He loves us and all the extra attention and pats we give him. It was great to see this family with their two sons again.

We got stuck into the work the next day, levelling the uneven concrete floor before laying down vinyl floor planks in the kitchen and living area. The house was over 100 years old and had been jacked up and added rooms were put underneath in the '60's and it was all a bit imperfect and rustic shall we say! Our outback family was also running the New Year's Eve party in Eromanga and so we helped set that up and prepare food. It was meant to be a fundraiser for the upcoming Rodeo, with a live band and all, but sadly it was such a hot night that they didn't get the turnout they were hoping for.

Meanwhile we were doing all this, our boys Callum aged 15 and Bradden almost 14, were fixing a paddock basher Mini that we had got running and then broken on our last visits. Callum was also trying to get an Old Holden FC Ute going, but alas there were too many parts missing, that didn't stop him trying though. Juliet is on her 'L's and has been hesitant to learn to drive. She even got behind the wheel of one of their cars and had her first driving lessons up and down the runway. Because we all have a runway in our backyards!



By the end of the trip she had 10 hours of driving and even drove to Quilpie under supervision, to get my Intravenous nutrition from the hospital. The boys got the Mini going and had a blast driving that around and Callum gave up on the Holden and got a very old Land Rover going instead, that hadn't been started in over 25 years. He had fun driving that around too. The only casualty was my youngest; he had managed to crush a finger whilst doing the work on the Mini. So it was off to Quilpie (80km Away) for an x-ray. Luckily nothing was broken.

We had the bus aircon running 24/7 and it would only really cool things down by 5 degrees or so, it really struggled on the 40 plus days (which was most days). The homestead only had evaporative coolers, which only cooled things down a bit too, so lots of water to drink and wet washers was needed to survive. The evenings were sometimes really hot too, even after sun down. The sunsets were amazing and the stars and moon just twinkled so brightly, in fact the moon was so bright some nights, you didn't need a torch to walk out in the dark.



Matt and Ian managed to complete the floor, tile the kitchen splash back, install missing kitchen cabinets, doors and panelling, tile a shower floor and level and paint a bathroom floor, amongst other odd jobs. This family had started a renovation in the kitchen and living area over 2 years ago but couldn't get a builder back out to finish it and so it had been incomplete for that long. So to get all that work done meant so much to this family.

But it wasn't all hard work. We spent one day at Kyabra Creek, which is really like a river in size. I sat there and fished while the others swam. I caught 5 little yellow belly fish that all had to be sent back. My son had more success with getting yabbies. I managed to get sunburnt where I had missed with the sun cream, and I am still red, 10 days later. We also went out to Durham Downs, a former Kidman property that now belongs to Gina Rinehart. It had 2 million acres! We saw some Aboriginal sites on this property and the kids swam in the Cooper creek.

Another day we went to the new dinosaur museum at Eromanga, as they have uncovered the largest dinosaur fossils in Australia and possibly the world there.

We had so much fun experiencing life in the outback. It's not every day you look out the window and see a rooster staring back at you. Rex the rooster is free range, you could say.

The boys also enjoyed sharing the shower with the frogs. In fact, around 9pm every night, the frogs would all start to croak. There was a plague of crickets and they would come out in the evening. There were so many that it almost sounded like light rain outside, and you had to sweep up the casualties every morning, as the house floor was covered in dead crickets. Their dogs thought we were the best, as they got lot of extra attention and rubs. One of the dogs was only young and looked like our Jack Russell and she was very cute and fun. Their two boys also loved having us there and having someone different to play with.



Back row: Callum, Ian, Sarah, Fiona with Luke and Adam with Sam, Matt; **Front row:** Juliet, Link the dog and Bradden

We decided to head home in the cool of the evening, as it was going to be 47 plus the next day, and heat and the bus engine were not friends. So we tried to make our way to Cunnamulla to get fuel before it shut at 11pm as advertised on the Internet. Poor Juliet developed heat stroke and was very ill all the way, as we bounced along. We managed to hit 4 Roos and rearrange the front of the bus. When we reached Cunnamulla at 10.20pm, the fuel stop was closed. They had changed their hours but just not the details on the internet to match. So we were forced to stay the night there instead of driving in the cool. We filled up with water from the caravan dump point. The cold water was so hot you could make a cup of tea with it and you had a hot shower with just running the cold tap. It was a long night with the Gennie running for a couple of hours for the aircon and not making much difference.



The next morning Juliet felt better and we headed off. It was Friday the 13th and all went well amazingly with the bus, despite the heat. A guy in our bus club dug up some history on our bus. Our bus was the most notorious of its kind for Pioneer and not in a good way. It was the first to blow the original engine and many other parts in its time of service, and if one was to break down in the fleet, chances were it was our bus, bus 445. So this guy in the bus club nicknamed our bus the devil bus, the undead, as it despite all this, it just doesn't seem to die, someone, being us now, keeps resuscitating it!! Of the 49 of its kind made in Australia by



Reg Ansett, ours is one of about 2-3 we know that is still registered and driving. We even have a Tassie devil mascot in the bus! So for it to behave on Friday 13, not that we are superstitious at all, was pretty good. It just lulled us into a false sense of security and got us back the next day!!! We ended up at Moree and spent the afternoon in the pool there. Bliss! Even I couldn't resist and went in as far as was safe for me medically to keep my Central venous Line dry. We parked by the Gwydir river that night. Again it was a hot night and the Gennie ran a few hours for the aircon to try and cool the bus down.



We left early the next day, as it was cooler at last, being 35 degrees! All was going well until on a bend in the road, just out of Boggabri, there was a horrific bang.

The front right tyre had literally exploded and Matt somehow managed to steer the bus on one front wheel and we came to a stop. Lucky it was cooler and a bit overcast, as Matt and Ian set to work to try and jack the bus up enough to get the rim off. 3 nice people stopped and offered help; we must have looked a bit tragic with the shredded tyre and the damaged front from the Roos. So Matt had to pull out Bulgy Mc-bulgy and put it on. We then had to travel the next 50kms to Gunnedah slowly, so that Bulgy Mc-bulgy didn't do the same thing. But Bulgy Mc-bulgy saved the day. We made it in

time before the tyre shop closed for the weekend and they had tyres that fit more importantly. So after all that excitement, we then made it home safely. Overall, despite the heat, we were able to bless this family and have fun. Even though the bus needs repairs, we are so glad we went. Our mate Ian had a wonderful first time in the outback as well. So all good all round. If you are interested in doing something like this, or sponsoring someone to do this, we did this through the Outback Links program as part of the Frontier Services (the services provided by the Uniting Church for the outback).

Check out their website www.outbacklinks.com.au or email them at outbacklinks@frontiereservices.org

You don't have to be superman to go out there, companionship is just as important. It will be an adventure you will never forget. The weather is far more pleasant other times of the year too, only crazies like us go out in Summer.

Surveys, studies and data – all about HPN down under

WORDS BY KAREN

2017 started with a quick member survey of experiences with Central Venous Access Devices (CVADs) and infections. Gillian and I have been invited to share the results of this member study at the 2nd annual Australian Vascular Access Society's Scientific Meeting in Perth in May. We'll also be exhibiting for PNDU for the 3 days of conference.

Then in late March we launched 2 studies of member experiences – PNDU's long-awaited swimming survey looking at what members have been advised regarding swimming with a central line and what they do. We're also really pleased to be once again working with Royal Prince Alfred Hospital in Sydney, this time on a quality of life study for adult HPNers in Australia and New Zealand.

All of these surveys and studies provide really valuable data on our very small HPN patient number in this part of the world and we really appreciate our member involvement.



Editor's note: This feature has been reproduced with consent of PINNT, www.pinnt.com – Online magazine, Issue 2, 2016, 18-19.

Muscle cramps and HPN

Dr Barry Jones, Lead, Virtual Nutrition Team (VNT), PINNT.

VNT members: <http://pinnt.com/About-Us/Virtual-Nutrition-Team-VNT.aspx>

A PINNT member has asked for advice on the causation and prevention of muscle cramps during HPN.

Muscle cramps are an extremely distressing problem which prevents sleep even more than normal on HPN, and definitely affects quality of life (QoL) adversely. Cramps usually start in the lower legs or feet but can involve arms and hands. These patients do NOT describe similar painful spasms when OFF line.

There is remarkably little in the literature on this subject but a recent British multicentre survey recorded 12/45(27%) as having cramps. A comparison of HPN patients with a control group of IBD patients not on HPN showed an increased incidence of cramps on HPN (51% v24%). Pharmacological measures (quinine sulphate by mouth) were

required in 9/12 and in 2 patients, the rate of infusion was slowed with some benefit. As a result of their study, they stated that this problem is the commonest complication of HPN! Perusal of various textbooks on HPN does not reveal any helpful information but a Google search revealed some centres around the world including the subject of cramps in their advice to patients on HPN.

The crucial facts relating to cramps are:

1. It always occurs during feeding and never off line unless a severe underlying and identifiable metabolic deficiency state is present.
2. **It usually occurs earlier during the infusion.**
3. Glucose does not need to be in the infusion for cramps to occur.
4. Increasing sodium content of feeds may be appropriate if urinary sodium levels are low indicating sodium deficiency. However, this rarely seems to improve cramps. If sodium deficiency is suggested as a cause, why would symptoms be worsened during infusion when the sodium is being infused? Those who have had cramps due to sodium deficiency (e.g. during exercise) know that repletion of sodium stocks removes the cramps.
5. Similarly, magnesium or calcium deficiency are unlikely causes if proper monitoring is performed but it can be extremely difficult to control magnesium deficiency due to excessive losses and limits on Mg content of IV feeds. Again, why would cramps occur during infusion of these ions? Experience with cramps or tetany due to deficiencies of these ions is that pains improve during infusion of these ions.
6. **The same criticisms can be extended to the possibility of phosphate deficiency.**
7. Something is happening to the metabolic status of patients during HPN infusion which has nothing to do with deficiency of single or multiple nutrients/electrolytes.
8. Sudden metabolic changes across muscle or nerve cell membranes could trigger spontaneous painful contraction of muscle fibres. So what could the change be? Infusion of glucose with electrolytes has long been recognised as a way of shifting electrolytes from outside a cell into that cell (e.g. potassium). However, we have one vital piece of information from an HPN patient who suffers from cramps despite having NO glucose in her feeds. This theory is therefore unlikely to be the explanation.
9. For many years, the normal response of HPN teams to such problems has been to exclude electrolyte deficiencies or treat them. This does not seem to have had much impact on cramps. The next step is an empirical one: to slow the infusion rate. I believe that infusion of high sodium containing HPN fluids may explain this problem. HPN fluids containing sodium chloride as the sole source of sodium have a tendency to cause acidosis. This means that the infusion of NaCl drops the pH of plasma and extracellular fluids towards acid from the normal of 7.4. It has long been known that changes in extracellular pH occur faster than those inside cells which can resist acidosis longer. Any changes to extracellular pH would be temporary during feeding but could affect muscle membrane function through the effect on calcium ionisation. The body's ability to control pH within tight boundaries is extraordinarily powerful but could be overwhelmed during non-physiological infusions which bypass the gut and liver. The homeostatic control mechanisms which keep the pH of the body fluids so constant under normal circumstances are severely impaired in many HPN patients (short bowel syndrome, PPIs, fistula losses, vomiting) despite normal renal and respiratory function. Any deterioration in the major organs (kidneys and lungs) controlling acid levels exacerbates pH shifts.
10. In my unit, we observed a number of patients with long term problems affecting acid-base balance on HPN. As a result, we started to use sodium acetate instead of sodium chloride to reduce the stress on the control mechanisms. I have no data to indicate whether this approach works as far as cramps are concerned but as a working hypothesis, I think it demands further examination and study. Interestingly, one VNT member stated that cramps were not a significant problem in her centre where sodium acetate is used regularly. Reducing flow rates would accord with this hypothesis as it would lower the acid stress on homeostatic control mechanisms. Another VNT member comments that they use sodium acetate to reduce acid-base stress but they still see cramps.
11. At least one major unit advises an INCREASE in sodium intake for cramps, going as far as advising licking salt off the back of the hand. The specialist nurse from that unit does not recall anyone benefiting from this approach! Another nurse reports some improvement with a salt lick but maybe from the slowing of the infusion and the addition of quinine sulphate by mouth too. This is a time honoured treatment for muscle cramps particularly at night in people who suffer night cramps for no obvious reason. There is thus little objective evidence of what really works or does not.
12. As children are smaller than adults, one might expect cramps to be a common problem in children but one VNT member with great experience has not heard of this in children.
13. A patient from the USA, writing on the Oley foundation blog, records that she had bloods checked before and during HPN to see if there was an explanation for her cramps. Although some nutrient deficiencies were noted prior to infusion, and excesses during infusion, no details are given as to which electrolytes were involved. Nor is there any mention of blood pH or acidity before or during infusions. She does detail her symptoms which sound most unpleasant and clearly intruded on her sleep pattern and QoL. Interestingly, she noted that changing her pump to a slower infusion rate at the beginning of the infusion did help.
14. An alternative theory could be that infusion of a 3litre bag over night could temporarily LOWER levels of critical extracellular electrolytes such as sodium, calcium or magnesium. If the concentration of sodium is 200mmol in 3 litres or 66.6mmol/litre, dilution of the plasma sodium would be inevitable and this would be transferred to the

rest of the extracellular fluids. If the total extracellular fluids amount to 15 litres, an extra 3 litres would dilute electrolyte contents by 20% and with lower sodium content in the HPN, the effect on sodium would be even greater. I calculate that after 3 litres of HPN containing 200mmol sodium have been infused, this would result in a theoretical drop in sodium concentration from around 140mmol/l to 127.7mmol/litre. This could be enough to cause transmembrane potential changes sufficient to cause cramps. If this is so, increasing sodium content in the feeds or by mouth is not the answer. Only slowing the rate would work thus giving opportunity for redistribution of fluids and electrolytes and offsetting the potentially adverse effect of dropping sodium levels. Similar effects can be calculated for sudden drops in calcium and magnesium levels.

15. Could acidosis also contribute to this scenario? Perhaps - but studies are needed to look into this in detail.

In conclusion, Cramps are a common and very distressing complaint experienced by our HPN patients, often over long periods of time. No single cause appears to explain this problem and the prevailing theory that a deficiency state is the most likely is illogical and not evidence based. It seems that it is time for HPN centres to get together and consider how best to study this challenging question – what causes on line HPN related cramps and what can be done to alleviate them? In the meantime, slowing the infusion rate or addition of quinine sulphate by mouth are the only 2 options which seem to work. Slowing the infusion might improve cramps but will itself intrude on QoL by prolonging time online.

Dr Barry Jones, Lead, Virtual Nutrition Team (VNT), PINNT.

VNT members: <http://pinnt.com/About-Us/Virtual-Nutrition-Team-VNT.aspx>

References:

1. "Muscle cramps are the commonest side effect of home parenteral nutrition" Clinical Nutrition, 2009, 28; 351-4. Elphick DA, Baker M, Baxter JP, Nightingale JMD, Page KB and MacAlindon ME.
2. Acid – base disturbances in home parenteral nutrition. Jones BJM, Chopra P, Deel – Smith P. e-SPEN, the European Journal of Clinical Nutrition and Metabolism 6(2011) pp.e31-e35

A Day in the Life of an HPNer – weight a minute!

WORDS BY GILLIAN

Before the Intestinal Failure that caused my going onto HPN (Home Parenteral Nutrition), my weight was fairly consistent. I weighed about 64kg, but aimed for 62kg as a healthier option for my height. Weight change was very slow and over a prolonged period of time and I had to be careful that I didn't eat fattening food too often.

How life has changed! After spending a few years of trying to vary my diet to lesson my ileostomy output, eating lots of this, but none of that, with no affect on output or weight, I now eat whatever I feel like. I still mostly eat healthily, but if there is a morning tea with lots of cakes and cheeses, then I don't need to restrict myself – it doesn't affect my weight.

My 64 kg had dropped to about 45kg in the hospital after the operation which found that all my large intestines and most of my small intestines were necrotic, apparently due to an auto-immune reaction to an unidentified virus. It was at this point, after various other options had been trialled, that it was decided to put me onto HPN. I was told that my intestines could adapt and begin to absorb food again, although there were no guarantees. After several weeks at home, my weight increased almost back to normal, so when I ran into my intensivist at the hospital and I told him proudly that my weight was that good, he totally squashed my hopes by saying 'it's the PN'.

My almost 11 years on HPN has been a roller coaster ride with my weight, which does a gradual climb up and up and up until I plateau and begin the slow down, down, down trip. There is no obvious reason for this, as not all people on HPN have this problem – some remain at a stable weight for long periods of time. The mid-fifties are my new norm, although I sometimes drop as low as 50kg and have reached as high as 63kg. Unfortunately, stabilising my weight isn't as easy as tweaking my PN by adding or subtracting calories, although this is certainly part of it. It's a far more complex decision made by my intensivist consulting with my dietician, including the need for monthly blood tests to keep track of various aspects of my health. Changing the calories can affect my kidneys and liver, so this needs to be considered when changes are made.

And changing weight wouldn't be a problem if we didn't have to wear clothes. But since we do wear clothes, they become tighter and tighter, or looser and looser. Buying new clothes because my weight has increased/decreased is an unwanted expense, because I know that in a few months it will be back to 'normal'. But pulling up jeans which now hang



At the peak of my weight



Enjoying life

on me, trying to hold them in place whilst doing up a belt tightly to hold them up, is a nuisance. And wearing tight jeans with a high output ileostomy bag can be dangerous – many trips to the toilet needed so accidents don't happen. Before my operation, I wore size 14 pants – I now wear size 8! And one of those is a bit loose at times! Surprisingly, although I definitely am skinnier around my collar bone, arms, etc, my top size is still 12.

AND when I lose weight, so do my fingers, so my wedding and engagement rings become very loose and threaten to slip off, especially when washing my hands with slippery soap!

For an HPNer, weight change is just one of the by-products of our life-giving nutrition. When put into perspective, it's a bit of a nuisance, but a small price to pay in the scheme of things.



A skinnier me

PNDU participates in a QLD Home Therapy Ideas Forum.

WORDS BY CHRIS

On 14 February, the Australian Centre for Health Services Innovation (AusHSI) hosted an Ideas forum at the Queensland University of Technology (QUT) bringing together almost 100 leading clinicians, academics, policy makers, managers and carers to discuss the opportunities and barriers to adoption of home therapies – from 'hospitals in the home' to Home dialysis and **Home Parenteral Nutrition. (HPN)**

To inform debate at the forum, AusHSI produced an issues paper "Taking Healthcare Home", which pulled together existing research and case studies comparing hospital treatment with acute and chronic treatment services in the home. The paper found that, in many cases, it was better for the patient and more cost effective to treat patients at home rather than in hospital. But cultural change in the health profession was needed to overcome uncertainty about quality and safety, and funding mechanisms had to ensure that home care providers were appropriately compensated while avoiding cost shifting between state and national funding systems.

Dr. Norman Swan was the facilitator for the panel discussion and world café sessions (workshops of about 10, discussing various topics, each group led by 2 facilitators)

The forum brought together leading speakers including Nick Gray, Director of Renal Medicine Sunshine Coast Hospital and Health Service, Melissa McCusker, Nurse Unit Manager, Acute Care @ Home, QEII Hospital, Kate McCarthy, Clinical Director of Hospital In The Home and Outpatient Parenteral Antibiotic Therapy, Metro North Hospital and Health Service, Jane Partridge, Director, Health Economics and Purchasing Unit, Queensland Health, Amanda Dines, Executive Director, Royal Brisbane Women's Hospital and Martin Chamber, member of Health Consumers Queensland.

PNDU was invited to participate in the AusHSI Ideas Forum. As **PNDU Management Committee representative**, I was given a great opportunity to contribute to both the issues paper, (via a video interview) and, by attending the Ideas Forum, I was able to provide an insight into the life of a QLD HPNer, from the invaluable information received from QLD PNDU members (HPN consumers and carers.)

Following the event, AusHSI will prepare a Recommendations Paper, to be released in June of this year. **PNDU** looks forward to the release of the Recommendations Paper and would like to thank AusHSI and Baxter Healthcare for the opportunity to participate in the Ideas Forum.

The Great (HPN) Family Holiday Road Trip

WORDS BY CHRIS

Our family has always undertaken, and very much enjoyed, an annual road trip and camping holiday. Eight years ago, unfortunately, these trips came to a sudden halt. Our second grandson Jordan was born with the rare condition of Intestinal Failure requiring Home Parenteral Nutrition. The unstable nature of Jordan's underlying XCIPO condition, along with the complex cares and associated risks involved with the administration of parenteral nutrition, have kept us at home and close to our treating hospital. The birth of our third grandson, Logan, with the same XCIPO condition, also resulting in Intestinal Failure requiring Home Parenteral Nutrition, all but guaranteed anything other than a day trip was out of the question for our family.

After almost two years without any major complications with Jordan's and Logan's health, our family made the decision to plan a road trip from Port Stephens NSW to Beachmere in QLD.

Planning for our road trip was a logistical nightmare; taking six adults, three children (two with special needs) and

three vehicles on a two day 1000km journey, was no small undertaking. Each step of the journey had to be carefully planned and reverse engineered in case of an emergency. The first step was informing our treating hospital team of our intention to undertake such a journey. The distance between dedicated PN children's hospitals was almost as great as the distance we would have to travel. Such a trip and length of time we intended to stay at our chosen destination dictated the necessity to have a treating hospital that was able to cater for Jordan and Logan's care while we were away. Our team made contact with the nearest children's hospital to our destination. Exchanges of medical records and required care needs, along with contact information and appointment dates, were all confirmed three to six months in advance.

Baxter Healthcare was contacted and arrangements made for PN deliveries during the Christmas Holidays. The bulk deliveries of fourteen bags of PN also meant arranging a dedicated PN fridge at our destination.

Packing all the necessary PN ancillaries and medical supplies for a two week holiday made it apparent there was the need to individually pack the supplies for Jordan and Logan, just in case we encountered a problem along the way. All medical supplies were packed into plastic tubs and divided between two vehicles. Everything non-medical was carefully packed and covered with tarps in Pop's (my) trailer.

We planned for a 4am departure in the anticipation the boys would sleep for the better part of the first leg of the journey. As we (Nana & Pop) pulled into the driveway at 4am, we were met with great shrieks of joy from Dylan, Jordan and Logan. The expressions on their faces told the story, the boys were bursting with excitement and eager to get underway. Our chosen route was along the east coast, with carefully planned rest stops that would allow for sheltered play areas in case of wet weather. Packing the last of the supplies and the esky containing the PN into the vehicles, we were finally on the road- Poppy Chris (me) and Nana Tanya, accompanied by Jordan, led the way, towing the trailer and setting the pace for the journey. Mum Brooke and Dad Michael, along with Dylan and Logan, followed as we made our way north to Kempsey. Aunty Katie and Brendan would meet us in Grafton the next morning. The early start ensured very light traffic and no stops at the numerous roadwork sites along the first leg. We arrived at the South Kempsey service centre without any drama. Stop, revive, survive were very welcome words and a pleasant break from almost three hours of continuous chatter from Jordan. (Poppy, Poppy, Poppy, Nana, nana, nana) it was time for coffee, coffee, coffee! The outdoor play area, although far too wet for Jordan and Logan, was closed and the boys were far from impressed with the inside covered play area- 'this is for babies!' they exclaimed, three disappointed little boys at our first stop, not a good start to the day.

After coffee and breakfast we were on the road again, we headed for Coffs Harbour and a wonderful park near Emerald beach. Strike two Pop! A major development had moved in and our beloved little park no longer existed! A quick decision and we altered plans for Woolgoolga rest area, plenty of room for the boys to run around and stretch, although the amenities left a bit to be desired. (and there's no park Pop)

Rested and stretched we began our final leg from Woolgoolga to Grafton. Surely nothing could go wrong now! Oh dear, Pop's got a tummy bug, so we quickly changed drivers and headed to Glenwood caravan park, Grafton. Instead of putting the tent up for the night, pop and nana booked a motel room. Brooke, Mick and the boys unpacked and settled into their family cabin, plenty of space and very clean. We gave Glenwood caravan park the thumbs up. The three boys were quite agitated after almost nine hours on the road and the only stops we made didn't have a park to play in. It was decided to leave me confined to my motel room and Mick to prepare a space in the cabin for the PN setup, while Nana, Mum and the boys set out in search of a suitable park to play in. A little sightseeing around Grafton with the Jacaranda trees still in bloom, and Nana and Mum found a park, much to the joy and excitement of the boys, and Nana.



Returning to Glenwood Caravan Park, the boys were bathed, quickly changed and set up on their PN, while Nana cooked a BBQ for dinner. No sign of poor ol' Pop until next morning.

The morning of day two allowed enough time for breakfast and the boys to be taken down from their PN, as we eagerly awaited the arrival of Katie and Brendan. With the family finally together, our convoy headed to the nearest service station for a quick check of all vehicles and to refuel. As we headed north from Grafton, the traffic started to increase and our journey slowed to a crawl near Broadwater as we snaked our way along achieving only 40km's in the next hour, until we reached the Ballina bypass and traffic started to flow along the new section of Highway. 60km's north of Ballina we pulled into the Sleepy Hollow rest area and let the boys play in the well designed and fenced park.



We had a bit of a dilemma for Jordan and a good lesson for our family of carers- always ensure Jordan's drainage tubes and bags are protected while playing in the park. Catching a bile bag clamp on the slide resulted in the pulling of an intestinal tube, not exactly the type of roadside maintenance anyone wants to be performing. A situation our family of carers had encountered in the past and were able to manage without too much fuss. I can't say the same for the crowd of onlookers that a distraught child can attract; some of the would be sightseers were very traumatised by what they saw. With the required maintenance and dressing changes complete, everyone was calm again and it was time to hit the road. We made good time along the new stretches of highway and soon crossed the border into QLD, continuing north to Coomera service centre for lunch at McDonalds. Much to the delight of everyone, the McPlay area was given the thumbs up by the boys and even the coffee was more than acceptable for weary travellers. The wonderful people from Baxter Healthcare had been in contact with us, confirming the delivery of fourteen bags of PN had arrived safely at our destination, so we pushed on for the last two hours of our journey to Beachmere.

Arriving in Beachmere was a joyous occasion. We would be staying with Tanya's parents (the boys' great grandparents) for the next two weeks.

Unpacking the trailer, Jordan and Logan were suddenly aware a tent was being erected in the backyard. Jordan and Logan have never experienced camping before and the excitement level hit an all new high as they were eager to know who would be first to sleep in the tent.

The tent would accommodate Katie, Brendan and Dylan for the majority of the time, with Jordan and Logan both having a chance to experience camping out. "The best Christmas ever" they exclaimed.



The next two weeks were a wonderful time catching up with Tanya's extended family, picnics on Bribie Island, cricket in the backyard, day trips to places such as the Glasshouse Mountains and a family BBQ almost every night, kept us all entertained for many hours. Maintaining the PN routine seemed to come naturally and all our daily events were planned around the boys' routine. Our scheduled appointment at hospital was the most amazing experience; we can't speak highly enough about the way the boys were treated; the wonderful staff welcomed us and made us feel right at home. There was a calming effect on Jordan and Logan, and neither boy seemed troubled by the new surroundings or treatment from new faces, so everything went like clockwork.



By far the highlight and main reason for the trip was Christmas day with the family, the first time Tanya had been able to enjoy Christmas with her family since the passing of her brother Maurice (also a HPNer) in 2010. Every family member, four generations of descendants of Tanya's parents, gathered to celebrate Christmas and what a gathering it turned out to be, excited children filled the house eagerly waiting great grandfather to distribute the presents. (more toys than toyworld) Seafood on the BBQ, roasts in the oven, ham and chicken salads on every flat surface and plenty of Christmas cheer. Memories of this day will last a lifetime.



The time passed far too quickly and the time came to say goodbye and head home. The weather forecast for the first day of the return trip was appalling and after the exchange of family presents and Santa Claus our load for the return trip had considerably increased in size, a dash to BCF on the afternoon prior to departure was required, more plastic containers and tarps were required. Camping on the way home was cancelled in favour of returning to the Glenwood Holiday

Park. A phone call to the park managers and our accommodation was arranged, a superb cabin and motel room, a discount for the repeat business was a bonus. Tears flowed as we said our goodbyes and started our trip south. The weatherman didn't let us down and the heavens opened up a deluge, visibility was terrible and speed was down below 60km/hour taking almost four hours to reach the border (2 hours is normal). We pulled into Chinderah service centre for a welcome break, where the carpark was more like a lake as we covered the boys and swam for the shelter of the indoor area, along with every tourist on the east coast. After a bite to eat and some maintenance on the boys, with no letting up in the weather we were again on the road and bound for Grafton, a slow trip taking any chance we had with breaks in the rainfall to stop. Unable to get Jordan and Logan out of the vehicles in the wet, it was becoming an uncomfortable trip for everyone. Finally the rain stopped as we pulled into Grafton and checked into our accommodation- no parks or BBQ's today- take away, PN and off to bed.

We set off on the last day of our adventure with more intermittent rain showers, heading for Coffs Harbour. No east coast road trip would be complete without a stop at the Big Banana and the world famous choc coated banana.



Leaving Coffs Harbour and the Big Banana behind us and with the weather now improving, we comfortably cruised south to Kempsey for our last planned stop and scheduled roadside maintenance on the boys. I had been instructed to find better places to stop in bad weather, the Kempsey play area just wasn't good enough. The final leg of our road trip home was uneventful, the turn off to Raymond Terrace was a welcome sight. Our road trip was a truly wonderful experience for our family, with careful planning in advance and attention to detail, PN road trips are possible. We will all have lifelong memories of this road trip adventure.

PNDU in Perth – May 2017

WORDS BY KAREN

PNDU is really excited to be part of the **Australian Vascular Access Society's 2nd Scientific Meeting in Perth 10-12 May**. Gillian and I have been invited to present the findings of our survey on member experiences with Central Venous Access Devices (CVADs) and infections, and exhibit for PNDU over the 3 days of conference.

Before that however, we will be meeting up with our WA members for a **PNDU social gathering way out west** – 3 years since the first one in 2014 (see [Dripline #8](#))! If you know any HPNers and carers, please let them know the details and ask them to contact us as soon as possible to find out more. We'd love for all WA HPNers and carers to have the opportunity to meet and chat with others 'living with a drip' and to find out more about PNDU.



In Perth with Gil, Steve, Sharyn and Janine in 2014

PNDU regional social gathering – Perth

Open to all HPNers (adults and children) and their families

Date: Saturday 6th May 2017, 12-3pm

Venue: South Guildford, Perth

Register: to PNDU at contactpndu@gmail.com or 0413715187 for more details

Bring: all you need (including food and drink)



Brisbane events for HPNers and carers – May 2017

WORDS BY KAREN

While so many Queenslanders face rebuilding in the wake of the recent devastating natural disasters, Queensland HPNers and carers have something to celebrate and enjoy. Only 18 months since the last time, PNDU's annual social gathering AND AuSPEN's HPN consumer workshop will once again be held in Brisbane.

These are not-to-be-missed annual consumer opportunities and our 2017 travel sponsorship winners – Jacqueline and Daniel – have planned their travel. The social gathering provides valuable opportunity to meet with others who totally 'get' living with HPN, and learn more about PNDU; and the AuSPEN HPN consumer workshop is a unique opportunity to learn more about our HPN from experts working in the field. This time those experts include HPN clinicians from St Marks Hospital, London!

We are very grateful to AuSPEN for once again holding this workshop specifically for HPNers and carers. We aren't aware of any other clinical society for parenteral & enteral nutrition worldwide that provides this opportunity to consumers. Way to go AuSPEN!!

And all of this for free! If you haven't yet registered, do it today and don't miss out! We hope as many HPNers and carers as possible grab these opportunities.

PNDU annual social gathering

Open to all HPNers (adults and children) and their families

Date: Friday 12th May 2017, 12-3pm

Venue: Roma Street Parklands, Brisbane City

Register: to PNDU at contactpndu@gmail.com or 0413715187 by Sunday 7th May

AuSPEN HPN consumer workshop

Open to all adult carers of children/adults on HPN, and adult HPNers only

Date: Saturday 13th May 2017, 12.30-4.30pm

Venue: Mantra on Edward, Brisbane City

Register: to AuSPEN at sue.larsen@waitematadhb.govt.nz by Monday 1st May



PNDU annual social gathering – Brisbane 2015



AuSPEN HPN consumer workshop – Brisbane 2015

Please don't tell me I'm looking well

Editor's Note: When people interact with the chronically ill, they often tell us how well we are looking – which can be quite annoying if we are feeling awful at the time!

*I got two comments at two different Christmas events over the weekend about how 'well' I look.

I couldn't bother explaining YET AGAIN that it's the PN. Looking well doesn't mean I'm feeling any better than usual. I was struggling with many gut symptoms and exhaustion as I was told this. Both times. People seem to equate fatter Jodie with more well Jodie. Even family - who ought to know better. Sigh. I was also asked twice if I was tired from all the Christmassing. 'Yes', I said. 'Exhausted. I feel like a zombie.' In which came the reply, 'Oh we feel exhausted too' and laughing. Yeah - thanks a million. Bah! - Jodie

*Yes! Definitely. I was the same on Christmas Day... One good day after several weeks of feeling terrible, and everyone behaved like I was magically cured. Another time I was explaining to my aunt how I got a birthday card from PNDU, and how we like to celebrate them because each year is an achievement for us. And she said, "well that's the same for all of us really isn't it? None of us know how long we have." I tried to convey that although that's technically true, it feels much closer for some of us generally, but she didn't get. I don't like to catastrophise things but literally one slip when we're connecting could end in an infection and a stay in the ICU. Pretty sure that's not the same when she's getting her own food. - Lara

*It seems that for some, understanding is the most difficult to come by amongst some of our nearest and dearest-family. That's really tough. We need more of our family members to better understand us. I get comments all the time

such as.... you look so well. I know it's meant to be a compliment, but it doesn't always feel like it. If you want empathy don't wear make up....particularly mascara! (Not sure if that would work for men.

- *Jacqueline*



*Isn't it amazing how people seem to equate a good looking body with good health! I have given up trying to explain that our bodies may look good but they do not represent how we feel! They don't understand that looks are deceiving! I am lucky that my parents and siblings fully understand my condition! I realise that this is not the case with many people like us!

I always found that when I was working, my workmates were the least understanding / forgiving of all! I understand all too well how frustrating "you look so well" can be. I, too, feel exhausted. Due to HPN I have put on 11 kg starting at 40 kg (when I was really sick) so everyone, and I mean everyone, told me I looked fantastic over Christmas. If only they really knew how I felt! - *Helen*

*It's amazing how well we can look with sufficient calories, but as we all know, artificial nutrition doesn't cure the underlying illness, has its own problems and just isn't the same as the real thing.

I reckon we need an easy line we can all use that helps people think without condemning. I often say 'it's amazing what sufficient calories can do' - *Karen*

*I have mixed comments. Usually people tell me I am looking well, and since I am very lucky that I never feel sick, this doesn't bother me. BUT sometimes they continue with telling me that the last time they saw me, I was looking too thin, or unwell etc – despite them telling me the last time that I looked well! But the opposite also has happened, when friends look at me (when I'm feeling fine) and ask me if I'm tired as I look unwell. Very disheartening!

- *Gillian*

Lunch with Bev

WORDS BY GILLIAN

Aussie HPNers of more than a couple of years who receive their ancillaries from Baxter Healthcare, would have spoken to the lovely, interested Bev on the phone at Baxter when ordering new ancillary supplies. For many years she was Aussie HPNers' main contact for ancillaries and always showed a genuine interest in our well-being. When Baxter allowed a Sydney pharmacy tour for interested HPNers several years ago, those who were able to attend met her and could finally put a face to the voice and name – as she could for us! She went on to win PNDU's inaugural Outstanding Achievement Award in 2014 for her work, care and dedication.

Since her well deserved retirement, she has kept in contact with PNDU's President and earlier this year, suggested that she host lunch at her house in Sydney for any HPNers who may be available to attend, to catch up with what is happening in their lives.

Four of our Sydney members were available that day in January – Karen, Jane, Chris and me. We had a lovely, relaxing time, enjoying each other's company and the delicious meal that Bev had prepared. We heard a little about Bev's travels, both past and upcoming, and were able to admire some of the artwork she had around her house.

Thank you Bev for a delightful day!



Jane (HPNer), Gillian (HPNer), Bev, Karen (HPNer) and Chris (carer)



Chris, Bev and Jane

PNDU's new website launch

Thank you for your patience.

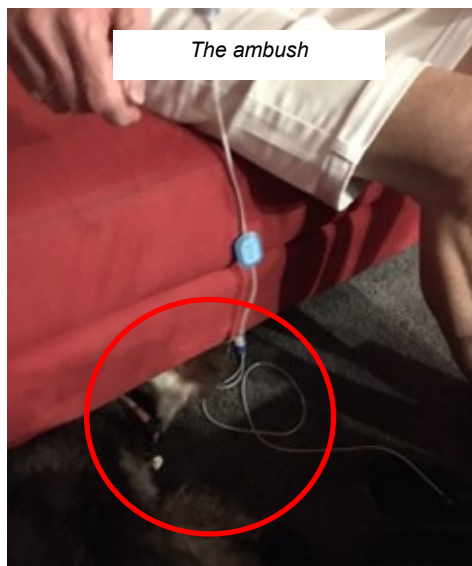
It's almost ready! Watch this space!



HPN Line - A New Toy

WORDS BY GILLIAN

We stayed a couple of nights with friends who were dog sitting for their brother. It's a bit hard to see, but Riley took a liking to my line and kept coming back to play with it...finally had to put my backpack on the lounge with me!



Planning Overseas Travel with HPN?

WORDS BY KAREN

PNDU can put you in contact with sister organisations in various countries overseas which may be able to assist with any HPN travel questions in those countries. PNDU has long-standing friendships with sister organisations in the **UK and USA**, and through our ongoing involvement with **PACIFHAN** (International Alliance of Patient Organisations for Chronic Intestinal Failure & Home Artificial Nutrition), we also have friendships with patient support groups in **Czech Republic, Denmark, Italy, France, Poland and Sweden**. All of these groups support people living with HPN, and some also support those living with Home Enteral Nutrition (HEN).

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

If you are considering travel overseas and you'd like us to put you in contact with any of these patient organisations, please just let us know at contactpndu@gmail.com.



Upcoming Events

6th May	PNDU Perth Social Gathering
10-12th May	Australian Vascular Access Society conference – Perth
12th May	PNDU Annual Social Gathering – Brisbane
13th May	AuSPEN HPN Consumer Workshop
15-21st October	HPN Awareness Week

Thank You

We wish to thank the following for their generous donations which totalled \$6,160:

- Baxter Healthcare Pty Ltd
- Fresenius Kabi Australia Pty Ltd
- S Balsdon WA
- E St Clair VIC
- A Lesser USA

PNDU Membership for Aussie and Kiwi HPNers and carers:

We welcome all Aussie and Kiwi HPNers and carers to become PNDU members. If you are interested in joining PNDU, please email us at contactpndu@gmail.com, telling us about yourself.

Benefits: Through membership you are invited to join one or both of our private forums: our Google Groups email forum is where conversation relevant to living 'down under' with HPN happens; and our closed Facebook group is more of a noticeboard where members can easily keep up-to-date with PNDU activities. You also have access to all pages of our website, and are on our mailing list to receive Dripline and notifications of other important occasions.

No computer? For those who prefer communication the 'good old-fashioned way' – by letter or card – PNDU offers correspondence with one of our members. If you are an Aussie or Kiwi HPNer or carer and are interested (or as a clinician, you have an HPN patient whom you think would benefit from letter/card correspondence), please contact us at contactpndu@gmail.com or PNDU, 128 Rainbow Street, Randwick NSW 2031, Australia to find out more.



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

We also welcome others to join PNDU as Associate Members, giving you access to all pages of our website as well as receiving Dripline and notifications of other important occasions. To join, please sign up on our website www.pndu.org

Donations

If you would like to support the work of PNDU, we would welcome your donation, no matter how big or small. Now that incorporation has been achieved(!), PNDU has its own account!

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

AUSTRALIA:

Direct deposit (Australian dollars only) to PNDU Inc.'s bank account:

Bank: Westpac
Account name: PNDU Inc.
BSB: 032056
A/c No: 482738

NEW ZEALAND:

For our Kiwi members, our sister charity IPANEMA (Charities Commission Registration CC21178) kindly continues to receive donations on our behalf:

Online donations: PayPal via our website www.pndu.org

Or **direct deposit** (New Zealand dollars only):

Bank: ANZ
Account name: IPANEMA
A/c No: 0602730308799-00
Payment Ref: IPANEMA "PNDU"

Management Committee members

President – Karen
Vice-President/Editor – Gillian
Secretary/Public Officer – Miranda
Treasurer – Chris
Assistant Treasurer – Gil

Contact us

Parenteral Nutrition Down Under Inc. ABN 49742201085

If you have an experience with Parenteral Nutrition that you would like to share, or if you have questions please email these to contactpndu@gmail.com

PNDU Inc.'s privacy policy is available on our website www.pndu.org

DISCLAIMER: PNDU has made every reasonable effort to ensure that the content of this newsletter is accurate, but accepts no responsibility for any errors or omissions. The views expressed are not necessarily those of PNDU and no reference to any product or service is intended as a recommendation or endorsement. You should always seek advice from your own team of healthcare professionals in relation to your specific needs/treatment.

Designer: Sal

In Memoriam



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.

Hebe – 3 January 2008, aged 2½ years

Pauline – 29 April 2011, aged 38 years

Aria – 20 June 2011, aged 5 years

Tynesha Rose – 29 October 2012, aged 5 years

Jessica – 24 January 2014, aged 20 years

Carol – 2 September 2016, aged 67 years

Sam – 13 September 2016, aged 14 years

Natalie – 18 September 2016, aged 27 years

Lara – 16 February 2017, aged 7 years

Emma – 9 April 2017, aged 35 years

Teresa – 15 February 2017 aged 58 years

May the cherished memories of these dear ones never fade.

