


DRIPLINE

PNDU

Parenteral Nutrition Down Under

We have our usual mix of patient stories and comments, medical research information and PNDU activities. Read the very detailed article written by Konrad's mum about her exhausting days; see pictures of 2 of our young members on their first day of school; read about Emily's choice of central line location; a radiologist wrote an article on mammography with a central venous access device, especially for Dripline; Read about Karen's activities at the IVNNZ (Intravenous Nursing New Zealand) conference in Rotorua last month, including her speaking to the conference about the point of view of the patient on the receiving end; read how a family with 2 HPN dependent children traveled to the UK for Christmas; read a review of the book about the first patient on Home Parenteral Nutrition and how she and her doctor paved the way for all of us; and much more, including a recipe for a GF nut free chocolate cake! How good is all that?

Gillian – Editor

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CONTENT

Heart-felt thanks to our wonderful Dripline designer - Sal!

Words by Karen

For the past 3½ years, Sal has been formatting and designing our newsletter. That's 13 editions! Alongside PNDU's website, Dripline is PNDU's primary resource, reaching an audience of 250+. Sal's design work has significantly contributed to a newsletter we are very proud of.

Formatting and designing has involved an incredible amount of work and many, many hours of her own time to do her magic and turn lots of content into an enjoyable, bright, easy-to-read newsletter. PNDU is incredibly grateful to Sal for donating her time, skill, expertise and efforts to PNDU over so many editions! And we hope it hasn't been too crazy working with your mum as Dripline editor!

Thank you Sal and we wish you all the very best as you hand over the Dripline design reins.

A Day in the Life of an HPNer: A Life in the Shoes of Konrad's Mother

Words by Shannyn

Editor's comment: This is an extremely long and detailed article, but it's very worth reading carefully in order to get an idea of how demanding and draining it is, being the carer of a baby on HPN.

As a mother to Konrad, to say that each day is a challenge would be the understatement of the century! Each morning begins with challenges and even after a year into this role, not a day goes by that another challenge doesn't arise. Physically, mentally, but most of all, emotionally, this role has a limit.

Konrad was born with gastroschisis at 33 weeks then had a spontaneous perforation which required the surgeons to resect a significant portion of his small intestine, leaving 27cm with no Ileo-Caecal valve. For this reason, he has two issues - shortened gut (inadequate absorption) and poor motility (from the gastroschisis).

To manage his condition, he has formula (enteral feeds) put through his PEG via a pump for 12 hours in total over 24hrs, accompanied by 12hrs of Parenteral Nutrition (PN) through his Hickman's® central line.

6:00AM

Each Morning begins at 6AM sharp, when I have to make up formula to begin Konrad's 6 hrs of PEG feeds. This will take about 15mins and then he will be awake as I'm connecting him, so we now both begin our day.

At this point of the morning Konrad is now attached to both his central line and his PEG and this is quite a struggle alone. You have a baby who is completely mobile and wants to crawl around and get into things like most healthy children, but with both of these tubes attached to him, it's not something that any of my ideas can manage. You may think of some known trick such as taping the tubes, or putting them all in a back pack, but it's just not logical with a 14month old who would happily pull any tube out of his chest if he had a split second to do so, or more recently 'eat it'. So, we resort to swapping between a walker, swing, high chair and porta cot. You could honestly say the lounge room looks like a circus of seats, it so jam-packed, but Konrad will get bored with one seat and all you can do is rotate him to something else and hope that satisfies him while I run around sorting everything.

My part of each morning entails not just rotating Konrad, but also his toys, trying to ensure he is stimulated, rather than just sitting him in front of the TV (Not that I'm saying I'm perfect and some days this is what happens). But in reality, in this small gap of the morning, I have to clean bottles, syringe, medicine cups, feed lines & extensions (all for his enteral/PEG feeds) and then sterilise them all. So at this point, I will be in the kitchen eating my soggy Weetbix one bite at a time as I walk from the lounge to the kitchen 50 odd times to both watch Konrad and get these errands done in this small gap.

The next stage is attending to Konrad's bedroom which no doubt is an absolute mess by mornings - but not from Konrad, from me - with medical waste packets, 4 wet nappies from overnight changes, and of course 4 bottles that you realise should have been sterilised with the ones you did 15 minutes ago! So, I remove the rubbish and head back to the kitchen to refill the sink and sterilise more bottles. Then, it's back to Konrad's room to change his sheets and open the blind and window and allow the room to air out, as Konrad's bowel actions have a one-of-a-kind smell with his gut in the condition that it is.

8:45AM

So now its 8:45am and I know this because this is my 2nd alarm on my phone for the day after the 6am alarm. It's time for me to head to Konrad's medical room and prepare everything for disconnection of his HPN, followed by preparing 4 types of medications to administer into in PEG at the same time.

9am has now clocked over and it's time to disconnect his PN. At this point of the morning, Konrad is now getting tired. He is about due for a nap, which certainly makes this all the more challenging. But to give you an idea on just how hard it is to wrangle a 14 month-old and keep him still long enough to complete a sterile procedure, this is how it goes... I have to lay him on the floor with my tray of supplies beside me and put one of my legs over Konrad's top half to restrain his arms and my other leg over his legs to hold them down also. Now it sounds kind of cruel but ultimately letting him kick and grab things while I'm trying to hold a needle and syringe isn't ideal either.

So now he is crying and screaming as I have him restrained and on so many occasions I slip or knock something where I shouldn't and its hard, but this does mean start again. And by start again, it literally means I have to walk him back to the high chair in the lounge to make sure he doesn't crawl away from his IV pole as his PEG is still connected, and then I have to go back to the medical room and re-draw up the syringe and prepare fresh gauze and chlorhexidine. I think on my worst day, I have had to re-do it 5 times! It's not easy keeping him still and fighting him off while trying to concentrate and keep a steady hand. But once the central line is done, I pause Konrad's PEG feeds, clean his PEG site, administer his medication, re-dress the PEG and cream it, then recommence the enteral/PEG feeds.

Once the medical stuff is done at this point, I put Konrad in the porta cot to crawl around and I head back to the medical room to clean up the rubbish and clean and sterilise everything I just used to ensure its all ready for me again next time.

Christmas Morning

Recent Photos

Our Medical Room

But half an hour has passed and it's time for Konrad to crawl around in the porta cot while I clean the medical fridge and wait for the medical delivery of his PN. (Although this isn't every day, it is frequent. We get supplies from 7 different suppliers; the only scheduled deliveries are PN twice a week, however, given how many deliveries a month we get, it is often 3 – 4 deliveries a week of all sorts of supplies.)

9:30AM

Often it will arrive around 9:30am but there are occasions when it won't arrive until after lunch, so I can be waiting almost all day sometimes.

Assuming the delivery arrives around 9.30am, it's then time to get Konrad to bed for his nap. And I wish I could say this was simple, because like everything else it really isn't when it comes to a baby who is attached to a tube. The sleep routine begins with making up an oral hydration flavoured drink for Konrad in his sippy cup. Then putting him to bed by laying him down positioning his PEG tube so that he can't kick it and tucking the blankets in to ensure it doesn't get caught in the side of the cot. Then I jog around the house tidying up with the baby monitor in one hand because Konrad will sit up and start crawling around in his cot and get his PEG tube all tangled up, or even more recently, stand up in his cot with his PEG tube under his foot pulling it, so I have to go back in, lay him down, give him his sippy cup and tuck him in again. And honestly, I will have to do this on average 7 times before he finally gets the hint and goes down for a nap.

In addition to Konrad being a fulltime job, I work part time from home for my partner's business, doing the books, so when Konrad naps, I'm strictly in the study dedicating this couple of hours a day to work - otherwise I would have to be up until midnight trying to get it all done.

11:30AM

Konrad will often wake up at 11:30am from his nap and this means its go time again. By this point, I realise that we are both still in our pyjamas and I haven't showered in 2 days, because if Konrad sleeps in until 12 rather than 11:30, I miss my chance for the whole day.

So, I have half an hour to lay Konrad on a towel and wash him down as he can't have a bath because we can't allow the central line on his chest to get wet. This means getting 2x towels, 2x face washers, bowl of water with soap and wrangling up a baby still connected to his enteral/PEG feeding tube and trying to get him to lay still long enough to give him a decent wash down. After Konrad's all washed I have about 10mins to get him in the high chair in the bathroom so that I can shower myself, but I won't even begin to mention how hard it is to juggle a baby, IV pole and a high chair. But once we are all settled into the bathroom, I jump in the shower for a quick wash until my 12pm alarm goes off on my phone telling me it now time to turn Konrad's enteral/PEG feeds off.

12:00PM

Off to the medical room we go and turn off his enteral/PEG feeds, draw up a flush to flush his PEG and then administer the flush and that's it.

I then sit Konrad on the ground and watch him crawl off as a free little man with no tubes attached and a huge weight lifts off my shoulders. The feeling of not breaking a central line or ripping out a PEG for one more day is such a relief!!

For the next several hours, Konrad crawls around and plays while once a week I check stocks of my medical supplies. I have to order regularly from 4 different places for certain bits of stock, so after several phone calls, several calendar notes on which days I have to be home to receive the deliveries, I'm done with my only opportunity for the day to possibly do my hair and duck to the supermarket or possibly do some more work in the study.

2:00PM

At 2pm my alarm goes off and it's time to get some medications ready for Konrad. So off to the medical room to draw them up, then find where Konrad has crawled off to, clean up whatever mess he has made and

take him back to get his medications. This means trying to restrain him long enough to slowly administer these medications enterally.

About this point of the day is the time that the Enhanced Maternal Health Nurse comes for her weekly visit to weigh Konrad to check for a weight gain or loss. This means undressing Konrad for the weight and redressing him again. After the visit, I then have to write up and email the results to a few people to ensure everyone has been updated: one email to our 2 gastroenterologists, then one to both of our dietitians (one in Melbourne and one local), one to our local GP and one to our local paediatrician. Then I have all the follow-up replies to answer.

3:00PM

3pm comes around and it's time to try and fight Konrad back down for another nap so that I can get some more office work done. This can take about 30minutes of back and forth to actually get to a point where he can sleep.

4:00PM

At 4pm alarm goes off on my phone and it's time to get him another medication to administer enterally and try and give it to him into his PEG without him waking up. Once he has had these medications, it's time for me to go and make formula for his enteral/PEG feeds to go back up at 6pm.

4:30PM

Around 4:30pm, Konrad wakes up from his nap and its play time for him again, so this time I play with him for a while to tire him out. We basically do a physio session, as his milestones are quite delayed after being in hospital, basically bed ridden, for the best part of his first year of life.

5:00PM

Once a week at 5PM, my family arrives to assist with Konrad's weekly dressing change of his central line. This procedure requires 5 family members. The system we have is that my father restrains Konrad's legs, mother restrains Konrad's arms, my sister distracts Konrad and covers his mouth when he gets upset to avoid him spitting over his clean site, my partner services anything I require on my trolley in the case that I drop something or require more of something and I get sterile and glove up to actually conduct the procedure.

This procedure is hard on my son, my family and myself as it causes a lot of distress on my son to peel off a dressing and clean him with an alcohol fluid that stings on his skin, however I have to mentally turn off the fact that my son is distressed and focus on what I am doing otherwise one slip up can lead to an infection that can make us lose the line to an infection or if I slip I could even pull the stitch holding it in place.

6:00PM

My 6pm alarm goes off and it's time for Konrad to go back on his enteral/PEG feeds. Often at this point, I will hang it up on the IV pole and my partner will continue to let Konrad crawl around and play but simply following him with the pole.

This is then my time to prepare dinner and tidy up from the long exhausting day we have had.

7:00PM

I remove the PN bag from the fridge and get Konrad changed into his pjs and into bed for the night. This is followed by getting a chance to eat my dinner in between attending his cot to lay him back down for the usual sleep time routine.

8:00PM

At 8pm, I get Konrad's medications ready and pause his enteral/PEG feeds and disconnect them to administer medications into his PEG while he is sleeping and reconnect his feeds and start them again.

8:30PM
Now I prepare everything for Konrad's PN to be connected at 9PM. This will almost always take 30 minutes to clean everything first then prepare the equipment.

9:00PM
At 9pm I connect PN to his central line, then return everything to the medical room to dispose of rubbish and needles correctly, then re-clean the room to ensure it's clean for the morning. At this time, I also have to prepare 30mls of sterile water to flush through Konrad's PEG feed line when I disconnect at midnight so I also put this in his room.

Then its relax time for me, with bed calling my name!!

12:00AM
At midnight I get up to turn Konrad's enteral/PEG feeds off and disconnect him. I then run water through the line to ensure it's clean of milk for recommencing of the feeds at 6am. I also do a temperature check, respiratory rate check, untangle him from his lines and do a nappy change. Since Konrad gets more than a litre of fluid overnight, his nappies need changing every 3 hours, otherwise they get so full that they leak out onto his sheets.

3:00AM
I get up again to once again to check Konrad isn't all tangled in his PN lines, check the readings on the pump, check Konrad's temperature and change his nappy.

6:00AM
Start from the beginning again...

Now with all of this no doubt there are days I feel like it's too much to bear and I either break down in the middle of the supermarket or on the floor of my shower... but then I also wake up some mornings and thank God my son is alive. I lost him so many times and after spending 11months in hospital it still to this day feels great sleeping in my own bed rather than in a hospital!

Mammography and People with Implanted Devices

Dr. Trudy Ross BMedSci MBBS FRANZCR

Mammography is the proven best screening test for breast cancer. Its success lies in its ability to achieve compression and contrast within the breast tissue as well as the assessment by qualified radiologists. A mammogram consists routinely of two views of each breast, in simple terms, from above and from the side. From there, more views and extra compression is used where necessary for better visualisation. Mammography is performed on both men and women.

The chest wall is our most commonly used site to place implanted devices due to the close access to large veins and relatively 'out of the way' but still easily accessible location. These vary widely from pacemakers to portacaths. Many of these devices are temporary but many are there for life.

It stands to reason that if there is a device implanted in the chest wall it will impact in some way in performing and assessing mammograms. Every person's implanted device will be in slightly different position and depth depending on anatomy, body size and technicalities of where it was placed at the time. Therefore, this is not a 'one size fits all' problem.

In some people the device may project (cast an xray shadow) over parts of the breast when a mammogram is performed, more common on the side view than on the top view. Tissue under this will not be visualised

on the images. There is a small, and unlucky, chance that breast abnormalities could be hidden in this small area. There is a small chance that devices can be disrupted/broken by the compression; however, this has been recorded as occurring only rarely in medical literature. The presence of a device can also prevent certain extra manoeuvres that radiographers and radiologists utilise to better assess the breast tissue, in particular spot compression where a small area of the breast is compressed more strongly rather than the whole breast.

A study of women with implanted devices showed reduced xray contrast in both top and side views, less projected breast tissue and reduced projection of the pectoral muscle (the muscle behind the breast). Patients experienced more pain and anxiety during mammography in the breast compared to those without implanted devices. Also, radiographers taking the pictures were more cautious, more anxious and used less compression during mammography of breasts with devices.

In short, mammography with an implanted device is almost always possible with some mild reductions in its capabilities. Radiographers are also probably more cautious so as to reduce pain and potential damage to the device. In some more challenging cases, radiographers with the most experience in positioning and compression might be called upon.

This advice is general in nature and does not replace advice given to you by your own practitioner

Central Lines: Location, Location, Location!

Words by Emily, USA

Editor's note: Emily spent a couple of months as a uni student in Sydney in 2015. During this time, she attended a PNDU Sydney social gathering and met some of our members, as well as enjoying the Hawkesbury River Postman's cruise with Karen, Gillian and Ray. When she offered to write an article for Dripline, I was excited – not only a volunteer, but a young adult, to tell about HPN related topics from her perspective!

As a person dependent on PN, I've had many, many IVs placed throughout my life. Different veins, different exit points, different lines. More than I can count on one hand. And it may sound silly, but I form deeply emotional attachments to these IVs. Love, hate, frustration. There was never such a sense of betrayal than when my Broviac® of six years was pulled due to something as minor as a localized skin infection that wouldn't heal.

Et tu bruti?

But it isn't really all that weird if you think about it: I use it everyday, it's always there, it's helpful. Think of it like a car, and I know some real weirdoes that name their cars and give them personality. At least I'm not like that.

So when I was told that the only way to clear the bug living in my IV was to pull it and replace it with a new one, I was ecstatic. Never mind that I went through three rounds of heavy duty antibiotics, missed a total of month of work, and missed out on two vacations. I was thrilled to get rid of this little sucker. Why? Location, location, location.

For me to fully explain what I mean, let me go back to 2014. I was an intern at a neuro-tech company in San Francisco simultaneously fighting a nasty localized infection (they'll get ya, those localized skin infections) at the exertion site for the past few months. Every three days I would do a dressing change only for this little mass of undoubtedly puss to get worse and worse and more and more tender. I went to the children's hospital in Boston before school let out and in my hometown of Missouri only to be told that the infection would go away. San Francisco's children's hospital said the same thing until I showed up in the ER.

Turns out, I had a case of acid-fast bacilli lurking around my IV and the fear was that it would travel up the

tunnel that my IV takes to get to my heart. Oh, and acid fast bacilli is really hard to cure with antibiotics. And since new hearts are hard to come by, the line and these pockets of infected skin gotta go.

But my problem was that this was my all-time favourite line. All my other IVs were in what I consider to be the worst place ever, centre chest. Do you have any idea how hard it is to wear low cut tops with an IV centre chest? I mean, I have to hang around my friends wearing shirts with great cleavage and I can't even join in! I have strategically bought shirts that dip a bit, but not too much, or wear a cami under my shirt like I'm 14. It's just so easy for all the other girls to put on whatever and not even worry!

It was in 2011 that I got my most favourite line ever and what makes it the best IV is that I got to choose the exit site. My paediatric surgeon of 10 years was pretty sceptical when I said I wanted it two inches down from my right armpit but I swear by this IV placement. It's out of the way, I don't see it glaring in my peripheral vision, and most importantly I can wear whatever tops I want without worrying that that it might slide down too low to expose the IV. Cute boys in the product section of the grocery do not like IVs in centre chest. They prefer them under the arm, I asked. So when it was pulled in San Francisco two years later I was intent on getting it replaced in the same spot...except that I couldn't because the entire site needed to heal after they removed parts of infected skin. So back to the horrid centre chest location it went. I left my heart in San Francisco, and my favourite IV.

Flash forward back to 2017, I'm being told my IV needs to be pulled because the bug inside it won't clear. Normally, I'd groan and think of how I have yet another scar that one can only hope will heal back to skin tone without it concaving. Instead I say "ok", but what I really mean is "ok, let's do it, let's do it now, I'll pull it myself, why aren't we moving to OR?" But I will say I was a little nervous. I called in the surgeon, a man I have never met before, and very seriously told him exactly where I wanted the IV to come out. I even marked the spot with a pen because I didn't want any screw-ups. The IV I wake up with is the one I have for the next two, three, maybe four years.

What I was expecting was the surgeon to be puzzled and then sceptical and then insist on another location, like so many nurses, attendants, and residents before him. Instead he shrugged "ok". When I returned to work from a two-week departure, with blood-soaked bandages on my neck, my co-workers were extremely concerned and sympathetic for my situation.

My only concern? Summer was another two months away.

'Forgotten' antibiotic offers hope against worst superbugs

Editor's note: The following interesting article recently appeared in Medical Search.

An antibiotic overlooked since its discovery 40 years ago could help develop new drugs against life-threatening infections caused by some of the world's most dangerous superbugs.

University of Queensland Institute for Molecular Bioscience (IMB) researchers synthesised the antibiotic and increased its effectiveness against extensively drug-resistant bacteria, then collaborated with Monash University to evaluate the drug using animal models of infection.

Professor Matt Cooper, Director of IMB's Centre for Superbug Solutions, said the study was prompted by the urgent need for new drugs to counter widespread resistance to last-resort treatments.

"Octapeptins were discovered in the late 1970's but were not selected for development at the time, as there was an abundance of new antibiotics with thousands of people working in antibiotic research and development," Professor Cooper said.

"Given the very few researchers left in this field now, and the sparse pipeline for new antibiotics, we've used modern drug discovery procedures to re-evaluate its effectiveness against superbugs."

Professor Cooper said there were no new classes of antibiotics available for Gram-negative bacteria, with increasing incidence of extensive drug resistance around the world.

"Gram-negative bacteria are harder to kill as disease organisms, because they have an extra membrane to penetrate that is often hidden by a capsule or slime layer which acts to camouflage them from drugs and our immune system," he said.

"The emergence of resistance to meropenem, and now colistin, the antibiotic of last resort, means multi-drug and extensively drug-resistant bacteria are now a reality confronting clinicians.

"Octapeptin showed superior antimicrobial activity to colistin against extensively resistant Gram-negative bacteria in early pre-clinical testing.

"In addition, octapeptin was shown to be potentially less toxic to the kidneys than colistin."

Professor Cooper said the study laid the foundation for the development of a new generation of antibiotics to treat life-threatening infections.

Researchers from Wayne State University in Detroit, the University of Melbourne, Germany's EMBL, and Victoria University in New Zealand collaborated on the project.

IMB research was supported by the National Health and Medical Research Council, and the US National Institute of Allergy and Infection Disease, part of the US National Institutes of Health.

The patient on the receiving end - IVNNZ conference 16-17 March 2018

Words by Karen

The way it came about is a story in itself, but in March this year I crossed the ditch from Sydney to Rotorua as an invited speaker at **IVNNZ** (Intravenous Nursing New Zealand) conference 2018 to talk to an auditorium of intravenous nurses and researchers. I was asked to speak about what it's like for a patient 'on the receiving end' and suggest how things can be improved! Quite a daunting brief for an HPNer talking to clinicians! But what an incredible privilege too!

The 1½ day conference itself was a great success, and as an HPNer (not a clinician), there was so much to be encouraged by – passionate nurses and researchers seeking to do their best for best outcomes for patients. Alongside that, an efficient and very welcoming IVNNZ team! Some of us from further afield were privileged to be part of a Maori welcoming ceremony to start the event – a very special experience. Then local Rotorua mayor and former midwife, Steve Chadwick, opened the conference with her own heart-rending medical story.

Introducing the traditional Maori Welcoming Ceremony

Keynote speaker, Dr Vineet Chopra travelled from Michigan USA where he is Associate Professor of Medicine and Research Scientist at the University of Michigan Health System. With his opening presentation, Dr Chopra began a conference filled with all things vascular: latest data and findings, new technology, research methods, progress reports and loads of

encouragement to change some not-so-great results.

What I liked about this conference was not just the obvious efficiency, and comradery amongst organisers and delegates (this is IVNNZ's 16th conference!), but that there was both big picture topics, including Dr Chopra's **MAGIC** (Michigan Appropriateness Guide for Intravenous Catheters) ensuring PICCs are used more appropriately, as well as grass-roots ideas, successes and research. There were numerous nurses who presented on how they had seen in their own setting a problem or need for improvement and brought about change in their hospital and/or area health board. To add to all that, there was fascinating research being undertaken by various team members of the Brisbane-based **AVATAR** Group (Alliance for Vascular Access Teaching and Research). Encouraging and inspiring all round!

With invited speaker, Briar McLeod, HPN nurse specialist at Auckland City Hospital

In this setting, Auckland City Hospital HPN nurse specialist, Briar McLeod spoke about New Zealand's **National Intestinal Failure Service** – a first worldwide. And a little later I presented "On the receiving end – Vascular Access from the Perspective of a Consumer living with a long term CVAD" (central venous access device). Using my own story, as well as what happens for other PNDU HPNers and carers, it was a privilege to represent all PNDU members and highlight to the delegates what life is like for us as HPNers and carers. We are a rare bunch in that we live with a long term (as in life-long for many of us) central line or CVAD, and as we well know, that brings challenges in our daily lives and in the hospital setting.

With keynote speaker, Dr. Vineet Chopra of University Michigan Health System

The outline of my presentation went as follows:

1. How I ended up on HPN, and a little about PNDU
2. Challenges of HPN and vascular access for the consumer:
    a) Rare; complex; life-threatening risks; and yet I look normal
    b) At the start (learning to care for a CVAD)
    c) Going to the Emergency Department
    d) Staying in Hospital
    e) And more ...

3. How can we together improve things:
    a) Confidence building and encouragement
    b) Positive and open two-way communication
    c) Education, training and re-training for consumers, carers and staff at all levels
    d) The value of research
    e) The holy grail – consensus of protocols

I am no confident speaker, but the encouraging response and feedback was a wonderful reflection of the heart and passionate care for patients that these delegates and organisers have. Even a heart-warming round of applause for my 11 years of CVAD care for PN without a CLABSI (central line associated bloodstream infection)! Thank you delegates and IVNNZ!

And thank you IVNNZ for such a well-organised and well-run conference, an inspiring variety of speakers and topics, and for the privilege and honour of being able to remind a great bunch of hard-working and inspiring nurses and researchers of what it's like for HPNers and carers 'on the receiving end'.

Thank you IVNNZ also for your generous payment of my flights and conference accommodation!

Above left: with PNDU's friends - the PICC Chicks from Gold Coast University Hospital
Above right: some of the Australian contingent who crossed the ditch for IVNNZ conference 2018

The Frustrations of living with HPN

Editor's comment: I asked permission of our member to print this private email group post in Dripline, because it gives a good idea of the frustrations that can be felt by our HPNer members.

Hi everyone

I rarely post on the forum but I am feeling a little down and would like to share something with you, the only people who might understand.

I am feeling a little down as on this day 26 years ago my life was changed forever. It was the day I had an operation to resect a tumour in my small bowel resulting in the blood supply to my bowel being cut off causing me to lose all of my small bowel and most of my large one, causing short bowel syndrome and relying on HPN for the rest of my life.

I have always accepted that in order to live I need HPN but after 26 years of relying on a machine to feed me over 16 hours a day and all the inconveniences being on HPN causes, I would like just one or two days

to be normal.

- To be able to get out of bed and go straight into the shower without first having to disconnect from my machine and tape over my port.
- To be able to stand under the hot shower and wash my hair without worrying if my port is getting wet.
- Then go and have breakfast at a trendy cafe with family or a friend.
- Not having to run to the toilet to either vomit, or have diarrhoea, or both after that outing.
- Deciding at the last minute to go away for the day and night and just throw in a few items of clothing and driving to where ever you want to.
- Not having to pack all your medical stuff and worrying you might have forgotten something. Making sure your HPN is stored cold enough.
- Not having to make sure you connect up early so that the next day you aren't disconnecting too late and miss an appointment.
- Go to a movie or concert at night without having to carry a back pack.
- Go to a restaurant with family and friends and eat a 3 course meal, also without a backpack.
- Get a good night's sleep without waking every two or three hours to go to the toilet.

I know a lot of you are in a worse position than I am but sometimes it gets all too much. I probably have no right whinging, but I cannot help the way I'm feeling.

I am so grateful to still be alive, which would not be possible without HPN. I thought I'd never see my three children grow up and all have successful careers. (Still waiting for one of them to get married and have my grandchild - that would be the icing on the cake!)

Thank you for taking the time to read my post and as I was writing this, I realised my life isn't too bad after all and I should stop feeling sorry for myself. I'm just an old whinger!
development," Professor Cooper said.

Travelling to the UK...With 2 HPN Dependent Children!

Words by Clare and Mike, parents of Elsie and Bertie

Editor's Note: In this excellent travel story, Clare and Mike refer to the 'PNDU travel checklist'. This is found in PNDU's Information Booklet 'Travelling with Parenteral Nutrition' available on the Travel page of PNDU's website https://pndu.org/ (log in to the Members-only section is required - why not join today to access!). PNDU also provides hard copies of the booklet to Australian and New Zealand PNDU HPN families and HPN clinicians. Contact us today for a free hard copy.

For many, travelling from Australia [or New Zealand] to England is daunting; travelling that far with an 18 month and 3 year-old is crazy, and if you added chronic illness with Home Parenteral Nutrition, ostomy bags and PEG feeds... well that's just plain bonkers. But travelling 14,000km with two HPN dependent children we did this Christmas, and it was magical.

Having all of Clare's family in Oxfordshire, the idea of travelling with two chronically ill children so they could visit their Grandparents, Great-Grandparents, Aunts and Uncles seemed like an unachievable mission. How could anyone on HPN travel when hooked up to machines and dependent on them to live?!

Last year Clare was invited to meet other HPN families at the PNDU get-together in Melbourne... and there a seed of inspiration was planted from those who had overcome huge obstacles to make their dreams come true. If they could travel the world, could we?

After speaking to our gastroenterology team at Perth Children's Hospital (PCH) the reaction was of surprise, but supportive. After nearly 12 months of organising and liaising between Baxter Australia and UK and

the paediatric hospital in Oxford, we were confident and very nervous on our first flight and holiday with the kids.

After months of preparation and planning, ticking every box on the PNDU travel checklist(!), the day finally arrived. The security and passport control did take time, but we expected and allowed for that and the staff were friendly in Perth, Singapore and London. Having the letters on hand, controlled items easily available for scanning and a lot of deep breaths, we boarded the plane and successfully achieved four uneventful flights and two transits through Singapore airport (albeit the normal toddler craziness that comes with flying and no sleep).

Our holiday in England for Christmas could not be any more cliché. We had snow 4 days after arriving, went ice skating, visited Santa and their Aunty organised her horse to become a Unicorn. One quick visit to Emergency as we couldn't find the filter needles- the nurse got some for us straight away and we left – although they turned up the next day as we'd placed them in the Baxter Lines box!

Our medical team in Perth and Baxter (Australian and UK) were amazing. We did have to send a few reminder emails to our Doctors to keep the ball rolling at times, but mainly it was easy enough. Delivery in the UK is different to what we are used to in Australia; the delivery window was longer, however, Baxter UK are far more safety cautious too [ensuring maintenance of the cold chain]. Their drivers are responsible for unpacking the PN and placing into the 'criteria met' fridge and testing the temperature. They also provided us with portable IV poles and an alarm system to alert us if the fridge went below 5c, which we thought was brilliant.

The best things we did were organise insurance in plenty of advance time; our first insurer called a few days later and decided to cancel the policy after reviewing our circumstances. Paying extra for Bertie to have a seat allowed us all to have 30kg luggage allowance each, and halving our carry-on supplies on the way home as we totally over packed on the first flight... although we were ready for every eventuality, paid off.

Overall, it was magical and worth all the planning, stress and trepidation. I'm not sure we are quite ready for another long-haul flight soon, but it certainly hasn't put us off going back again in 2 years and has given us lots of confidence to travel interstate. PNDU members were our inspiration and we hope this will inspire you to go on an adventure too. You're never too young or too old!

Clare and Mike, parents of Elsie and Bertie.

Mike, Elsie (HPNer), Bertie (HPNer) and Clare- with their luggage and in the snow

Rise Up Kiwis! Let's increase New Zealand representation in PNDU!

Words by Karen

That's PNDU's call and the challenge we face – very sadly, our Kiwi representation within PNDU is waning. As our name states, we are Parenteral Nutrition Down Under, and New Zealand as well as Australian representation and voice within PNDU is an integral part of who we are. So how do we bring more New Zealand HPNers and carers out of hiding and encourage them to join PNDU? HPN clinicians!!

The primary way information about PNDU is passed on to HPNers and carers is by HPN clinicians. We are very grateful for the many HPN clinicians who do just that – pass on information about PNDU, our resources etc to new and existing HPNers and carers. PNDU has worked very hard over many years to build up the trust of HPN clinicians – for them to know that PNDU is a safe place and a great place for their HPN patients and carers to receive support. With Australian member numbers steadily increasing however, the same can't be said of New Zealand.

So it was time to meet with some NZ HPN clinicians, introduce PNDU to those who hadn't yet heard of us, and together brainstorm ways to increase the NZ voice in PNDU. We are incredibly grateful for the time given by members of the Nutrition Support Teams at Auckland City Hospital, Starship Children's Hospital and North Shore Hospital in March 2018. It was a privilege to meet with these hard-working teams in their busy weeks.

We've all come away with more knowledge and understanding, as well as ideas and plans to work together for the benefit of New Zealand HPNers and carers. And PNDU really looks forward to working with these teams, and in time, greater NZ representation and voice in PNDU!

While in New Zealand, it was also really encouraging to touch base with Prof Gil Hardy (PNDU lifetime member, founding member, and recipient of a special Lifetime Achievement Award in 2017), Jodee (PNDU lifetime member and founding member), and Biomed's Jessica Gordon plus new to the Biomed team, Liz Walker (at IVNNZ conference – see article above).

With Jodee

With Prof Gil Hardy




Top left: with members of Starship Children's Hospital's nutrition support team (NST): Cate Fraser-Irwin, Kim Herbison and Amy Andrews
Top right: with Auckland City Hospital's NST: Julian Hayes, Kerry McIlroy, Candice Gemmell, Lisa Guest, Briar McLeod and Prof Ian Bissett
Bottom left: with members of North Shore Hospital's NST: Jasmine, John Pulford, Simon Hill and Becs Coggins
Bottom right: with Biomed's Jessica Gordon and Liz Walker

Milestone: First day at School for 2 of PNDU's Young Members

Editor's Comment: The first day of school is special for all parents and children, but is an especially anxious time, as well as exciting, for parent carers of a child on HPN.

Our little Thomas started his first day at kindy yesterday. He was very excited to go along with his three big brothers. He looked so tiny, but was determined to carry both backpacks on his own! He had a happy day with lots of smiles, no tears. - **Susie**

Our little Logan started school today. He looked so tiny with his school bag on his back.
No tears, just lots of smiles and excitement. Logan had a wonderful day, he came home just as excited as he was in the morning and can't wait to return.
Chris



I Am That Parent

Words by Amy R. L. Rule, MD, MPH

Editor's Note: In the February 6th, 2018 issue of JAMA, an international peer-reviewed general medical journal, there was an article that many of PNDU's carer parents (as well as some of our adult HPNers) could relate to. It was about the frustrations of doctors' responses to the author's family as they try to get proper treatment and answers for a child with a chronic, rare disease. Although not about HPN, many will relate with the author gradually becoming 'that parent', the one who won't be fobbed off. The very interesting thing is that the author, Dr Amy Rule, is a paediatrician who has discovered what it is like on the other side of the desk, and now has a different perspective on some of the patients she had treated who had 'that parent'. Unfortunately, although I tried to obtain permission to print a copy of the article, I wasn't able to get it, but clicking on the link below is well worth the effort!

https://jamanetwork.com/journals/jama/fullarticle/2671471?utm_source=facebook&utm_campaign=content-shareicons&utm_content=article_engagement&utm_medium=social&utm_term=020718#.WntbkOK7mIx.facebook

Birthday Corner

Happy 2nd Birthday, Bertie!

Hi all! Thank you for Emily's birthday wishes and the lovely card last week. Emily had a great time at the movies with her friends, and then a big family party at night. We had lots of relatives come and stay.

Original image, birthday banner and party popper

Effect of pre-filled flush or manually prepared syringes on central venous catheter occlusion and CLABSI

Editor's note: The following interesting abstract appeared in IVTEAM newsletter 21 March 2018

Reference:
Gerçeker, G.Ö., Sevgili, S.A. and Yardımcı, F. (2018) Impact of flushing with aseptic non-touch technique using pre-filled flush or manually prepared syringes on central venous catheter occlusion and bloodstream infections in pediatric hemato-oncology patients: A randomized controlled study. European Journal of Oncology Nursing. 33, p.78-84. doi: 10.1016/j.ejon.2018.02.002

Abstract

PURPOSE: To compare standardized flushing methods with aseptic non-touch technique; (1) Manually prepared syringes (2) Single-use prefilled flush syringes.

METHOD: Forty-eight PHO patients with Hickman or Port catheters were recruited to participate in a prospective, randomized study. Standardized flushing methods with aseptic non-touch technique (ANTT) using single-use pre-filled flush syringes (intervention group) or manually prepared syringes (control group) also included the pulsatile technique, use of 10-mL syringe size with 0.9% NaCl for flushing, flushing once a day, flushing training of the nurses. The effects of standardized flushing methods on occlusion and CLABSI evaluated.

RESULTS: Of the patients in the intervention group, 8.7% (n: 2) had catheter occlusion, while this rate was 20.0% (n: 5) in the control group. Of the patients in the intervention group, 8.7% (n: 2) had CLABSI, while this rate was 36.0% (n: 9) in the control group. While there was no difference in occlusion, there was a difference between the groups in terms of CLABSI development. In the intervention group, CLABSI rate was 1.9/1000 per catheter-days, in the control group CLABSI rate was 10.1/1000 per catheter-days. In the intervention group, occlusion rate was 1.9/1000 per catheter-days, in the control group, occlusion rate was 5.6/1000 per catheter-days.

CONCLUSION: Standardized flushing and single-use prefilled flush syringes are effective in reducing CLABSI rates in PHO patients.

How old is your line?

Words by Gillian

I posed this question on our private email group out of interest. Some of our members have limited central venous access after years of PN and the damage caused by DVTs, central line insertion and removal because of infections, damaged central lines etc. Whether limited access or the full 'kit and caboodle', the preservation of a central line is of major concern to those of us on HPN, since it's the only way that Parenteral Nutrition (PN) can be administered. Sadly, there are still some clinicians whose first instinct is to remove a central line at the first suspicion of a central line infection. I have had this reaction from the Infectious Diseases Team on a few occasions over my 12 years of HPN, and my HPN team has needed to negotiate with them and convince them that treatment is the preferred option, to save the central line wherever possible. Of course, this is dependent on the type of infection and other medical concerns eg I had to have a central line removed after a fungal infection as both teams felt that they couldn't successfully eradicate it. I have had my current Hickman's® catheter for over 4 years now, with one repair a year ago, so I was curious to see what has been the longest central line duration in our group.

I had many replies to this question, beginning at around 2 years, then improving to around 4 years, then a couple at 6 years. But our longest known duration belongs to a member who has had a Hickman's® for about 10 years.

This member wrote: ... In that time, it has been repaired once due to a crack in the hard, plastic end and has been treated for 2 staph infections without being removed. After spending about 2 weeks in hospital each time, I returned home with another 8 weeks' worth of antibiotics to put through my Hickman's® each day. Interestingly, my hospital now realises that I have limited access to put in future lines, so they will do anything to save it; before that, they were very quick to just pull them out without trying to save them.

As PN and the administration of PN continue to improve, providing longer life opportunities for those of us with Intestinal Failure, the importance of preserving our central vein access increases. We are a small patient group with the highly unusual need for long term (as in life-long for many of us) central venous access in order to live. We look forward to more stories from members of central line preservation and more hospital teams whose protocol is to first try and save a central line whenever possible, with replacement only happening when necessary.

Lifeliner – the Judy Taylor Story by Shirleen Jeejeebhoy

Words by Gillian

Editor's comment: At the start of 2011, PNDU ran a competition to describe in a lay person's terms Intestinal Failure or HPN in 50 words. I hadn't before heard about PNDU, but I entered and won! The prize was a copy of "Lifeliner, the Judy Taylor story" personally signed by the author and Dr Kush Jeejeebhoy – a fascinating read. I was asked to review it for PNDU's website, so I did. I've decided it is time to publish this review in Dripline, to make people aware of this fascinating insight into the first HPNer. It is our history! If you wish to purchase this book, PNDU receives a 5% donation for any book purchased through The Book Depository icon on its website www.pndu.org homepage. A great gift idea too!

'Lifeliner' is our story, the story of why all of us on HPN (Home Parenteral Nutrition) are able to live without food, or without absorbing nutrition from the food that we eat. It's a story of a remarkable woman determined to live, and her dedicated doctor, equally determined to keep her alive. Judy Taylor was the first person to be put on long term HPN, the name given to this method of feeding by its pioneer, Dr Khursheed Jeejeebhoy. This is the story of how, over the next twenty-one years of her life, Judy was a willing 'guinea pig', as she, led by 'Jeej', blazed the trail for the rest of us to follow.

In September 1970, after three years of pain with no specific diagnosis, Judy ended up in Toronto General Hospital where surgeons found that all her large and small intestines and gall bladder were necrotic, caused by a blood clot. In 1970, this meant that she would starve to death. Although short term intravenous nutrition was available, long term was only a dream. She was passed on to Dr Jeejeebhoy (Jeej), a newcomer to the hospital, as a hopeless case, yet she was desperate to live. Jeej was determined to do all that he could to save her, and spent much time reading all the available research from around the world, including veterinarian animal studies, in order to decide what and how to feed her.

Jeej had to decide what nutrition was needed in order to live, and in what amounts; in what medium to deliver them – fat or no fat?; and how to deliver them into her body. At that time catheters had to be changed every couple of days, so one had to be developed especially for her circumstances. Also, no pump existed to deliver the PN at a rate fast enough that she could unhook and have her days free to walk around. The team had to develop a way of keeping the line open when she was unhooked, and whereas nowadays doctors can obtain much information from blood tests, Judy had to go to hospital for biopsies.

Throughout her remaining life, Judy suffered pain daily from a drain which took bile from her stomach, but luckily she always had a good sense of humour, and could usually joke even when in pain. Over the years she suffered from infections, skin breakdown and hair loss, sometimes due to a lack of something in her PN, which Jeej would have to discover. During her worst times she would alternate between anger, fear and acceptance, but always bounced back.

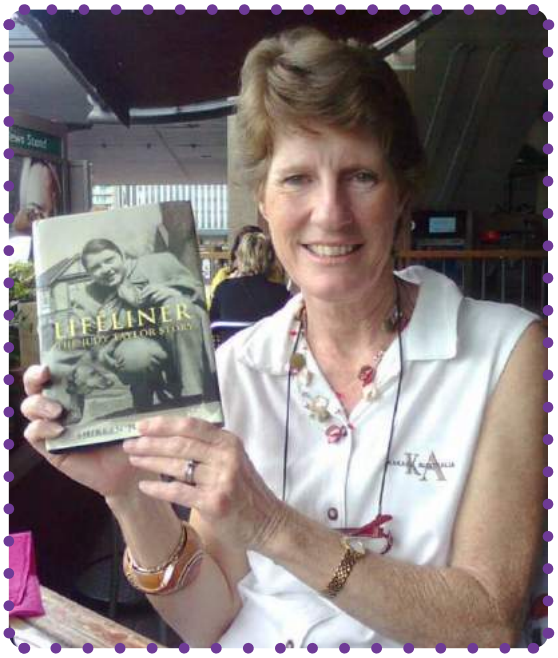
'Lifeliner' has other 'heroes' apart from the two main participants. Judy could not keep going without the love, support and assistance of her husband as carer and the others in her family. Also, she had a large support group of friends, including the new friends that she made as she mentored new PN patients, as well as the nurses who became close to her. Jeej relied on the work from many researchers and doctors whose ideas he tried, adapted and sometimes rejected. The work of these doctors supplied Jeej with answers or possible directions to many problems that occurred over the years, and ultimately kept Judy alive. In turn, his work led to papers and talks which other doctors around the world could use in their work, and the further development of HPN, ultimately keeping us alive.

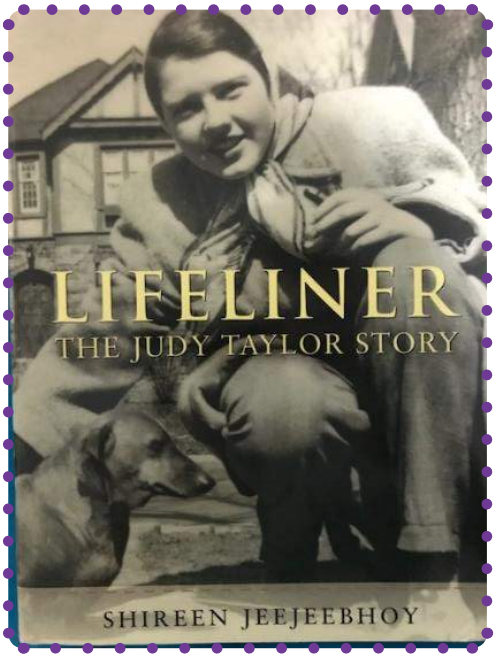
Throughout all this, Judy had a strong faith in God, and thanked Him for every day she lived. She had a great attitude to life, filling her time with much volunteer work over the years. She once told a friend, "Stop and take time to look around....don't take anything for granted.... take time to work in your garden and take the beauty out of the flowers...most people are in the fast lane and go, go, go and they miss 90% of their lives."

I loved reading this book, because until then I'd used HPN much as I would antibiotics, as a cure for a medical problem, without any thought to the human side of its development. I enjoyed learning about the difficulties faced and overcome by Dr Jeejeebhoy and his staff in developing HPN and the related equipment. But the largest impact was from gaining a bit of insight into the struggles and joys of Judy Taylor as she made the most of the twenty-one extra years that HPN gave her. Her determination to live meant that many medical break-throughs were possible, as different things were tried and either succeeded or were rejected. She could easily have given up, not able to face more tests, hospital spells, pain, but she kept going, trusting in Jeej and his team. This enabled them to see the long-term results of HPN on the body and to make adjustments as new information was discovered. Her strength, determination and sheer joy of life was an inspiration to the many people who came to know her, and continues to be an example for us today.

Many thanks should also be given to the author, Shireen Jeejeebhoy, Jeej's daughter. She decided to write this story after Judy's memorial service and began research immediately, but due to problems in her life, including a closed head injury, it took her sixteen years to complete. Thankfully, she didn't give up, giving us a chance to learn of our HPN roots.

To whom would I recommend this book? Anyone on HPN who has returned home from hospital and begun to get on with life could enjoy reading it, as well as hospital staff working with HPN patients. It's an easy book to read, with short chapters; but have a box of tissues handy for the occasional weep.





Jodie's (GF, Nut-free) Chocolate Cake

I just made a yummy, moist, GF, nut free cake for Daniel's lunchbox this week. Thought those of you who can manage a bit of food might be interested. The recipe said 180g sugar but I only used 100g and found it was enough.

Ingredients:

429g tin kidney beans, drained
1tbsp water or coffee
1tbsp vanilla extract
70g cocoa powder
1 ½ tsp bicarb soda
¼ tsp salt
125g butter or marg
5 eggs
100g sugar (up to 180g to taste)

Method

- Puree the beans, water or coffee, 1 egg and vanilla until smooth.
- Beat the butter and sugar until creamed,
- Add the remaining eggs and beat.
- Add the bean mixture.
- Add cocoa, baking powder, bicarb soda salt and blend.
- Pour the batter into a greased ring tin pan and bake in a moderate oven for 30 minutes or until cooked – test with a metal skewer.
- If you use a round tin, this will take a little longer.
- It's yummy, moist and nut, gluten free and high in protein!

Well-meaning Advice to 'Heal' Us

Editor's Note: One of our members posted a piece of 'advice' from a friend to improve her health. It can be very frustrating that after telling people about IF (Intestinal Failure) and our reasons for being on HPN (Home Parenteral Nutrition), that they come up with incredibly simplistic 'cures' for us to try!

- A well-meaning, caring friend gave me some advice about things I should try to 'get better': I should eat more garlic to restore my gut bacteria! Made me laugh.

- On a similar vein, I was explaining to a fellow I was sitting next to at the hospital last week. He was interested and enthusiastic about good diet, so I tried to give a basic explanation of PN and what it contained. On thinking about what's in food, he suggested the PN should also contain bacteria for the gut. I think I was called away then, but I pondered his suggestion - bacteria in a sterile solution administered into a central vein straight to the heart!!?? Not quite!

- The one that stays with me: The word "Disease" comes from "dis" and "ease". If I learnt to come to terms with the things in life causing me such "unease = disease", I would immediately be cured. This apparently especially relates to gut type diseases! Who knew??!!! Go relax and be cured, my friends!

- Over the years I've had a few people tell me how to get better...different vitamins, yoghurts, etc. Sometimes I wish they would go away, but they are trying to care I guess, in their own way...

- Ha! Garlic seems to be able to cure everything. I was told by a nurse at my local hospital I should be eating more green, leafy vegetables. I can't eat anything, let alone vegetables!

- You wonder where they get these ideas from!

UPCOMING EVENTS

21 August	PNDU's AGM & Annoucement of PNDU Annual Award Winners
15 October	World HAN Day
14-20 October	HPN Awareness Week

Planning Overseas Travel with HPN?

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**.

THANK YOU

We wish to thank the following for their generous donation:

Fresenius Kabi Australia Pty Ltd **$3,000**

PNDU 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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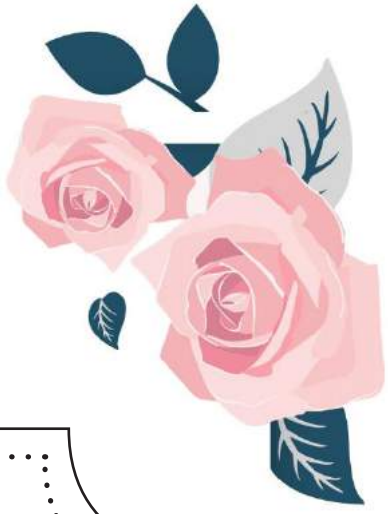

PNDU remembers past HPNers

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.

Celena – 27th November, 2017, aged 43
Emma – 9 April 2017, aged 35 years
Lara – 16 February 2017, aged 7 years
Teresa – 15 February 2017 aged 58 years
Natalie – 18 September 2016, aged 27 years
Sam – 13 September 2016, aged 14 years
Carol – 2 September 2016, aged 67 years
Jessica – 24 January 2014, aged 20 years
Tynesha Rose – 29 October 2012, aged 5 years
Aria – 20 June 2011, aged 5 years
Pauline – 29 April 2011, aged 38 years
Hebe – 3 January 2008, aged 2½ years

May the cherished memories of these dear ones never fade.

Original images by FreePik, bear and flowers