

DRIPLINE

PNDU
Parenteral Nutrition Down Under

ISSUE 22
Nov 2017
to
Jan 2018

Happy New Year to everyone! The past 3 months have been very busy for PNDU Management Committee members with involvement in several events, as well as in up-coming events, which you can read about. There are a few member articles, including a fun-to-try hospital bingo game, devised by one of our members. PNDU's Facebook group members contribute ideas related to central line issues with babies crawling, and there is a poignant article written by an Oley Foundation member about the reality of the impact of having a new born needing HPN – feelings which our carer members will certainly relate to. On a sad note, one of our PNDU members passed away in November, so read the lovely tribute another member, her friend, has written. I hope you find this latest issue informative and, therefore, enjoyable.

Gillian - Editor

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Happy Birthday PNDU!

WORDS BY *KAREN*

PNDU turned 9 on 6th January 2018!

We are incredibly grateful to PNDU's founder, Brenda, and the small band of founding members, for their foresight, efforts and initiative to bring PNDU into being in 2009. From those humble beginnings, with increasing support from, and working with clinicians and industry, PNDU has been able to make great strides in reaching and supporting HPNers and carers across Australia and New Zealand, as well as raising awareness where it's most needed – in our own communities and in the health system. Thank you to all our members, supporters and friends, and thank you to those members and helpers who give their time and efforts to help PNDU achieve all this!

We look forward to the year ahead.

Tribute to Celena

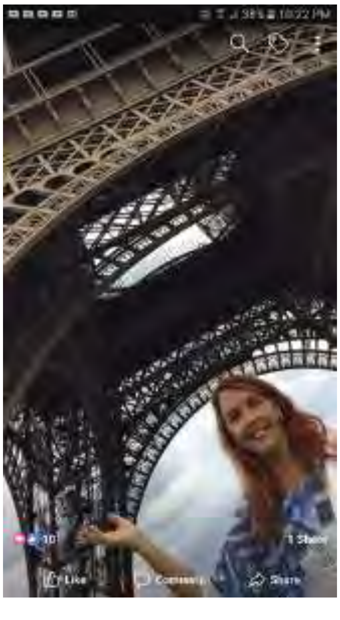
WORDS BY *SONJIA*

It is with great sadness that we say farewell to Celena McGovern as she stepped into eternity and went home. Celena had faced incredible tragedies and battles but did so with courage, honesty and a strong family support system. Later in life she met and fell in love with David. David and Celena shared the same passion for all things books. Celena loved her books!! Books were her escape and a constant throughout her 43yrs.

Celena married David in the hospital grounds where she had spent so much time growing up. Soon after little Amber was welcomed into the world and, despite escaping the Hollow Organ Visceral Myopathy diagnosis, passed away after open heart surgery. Amber was just 3 months old. Celena and David's world collapsed. Brodie was born some years later and gave Celena and David such immense joy and helped heal their hearts. Brodie did have Hollow Organ Visceral Myopathy like his mum but he also had her zest for life and fierce determination. Brodie loved The Wiggles, especially the Big Red Car, and Spot, the dog. Tragedy struck again when Brodie passed away at just 5 yrs old. Once more Celena immersed herself with books and became a librarian at the very library she and Brodie visited so often.

Celena and David managed to find ways to pick themselves up and move forward together. Whist their lives have been peppered with unimaginable grief they also went after their dreams. Just before her death Celena and David undertook a mammoth trip of a lifetime to America and Europe. Those who knew Celena know she hated pink, but loved shopping and Paris. David took Celena to Paris and shared a kiss at the top of the Eiffel Tower.

Celena will be greatly missed by all who were privileged to know her. Our hearts go out to Celena's husband David and her parents and family who now must try to grieve and move forward.



Thank you, thank you, and thank you to Orange Line!

WORDS BY *KAREN*

PNDU's wonderful new website was launched in August 2017, but it was just recently that Miranda and I had the opportunity to formally say thank you! To Orange Line's generous directors, David and David, and the wonderful creative and technical team, Carina, MJ and Donna, we presented a Certificate of Appreciation, at their offices in early January.

Our new website is something PNDU is very proud of and grateful for. It contributes significantly to PNDU's credibility and provides a welcome and easy place for people to find resources and information, learn about who PNDU is and what we do, and become a member! Our hope is that members and supporters will make use of all the information and resources on the site, not just once, but time and time again.

We really appreciated the opportunity to say thank you in this simple, but important way for the generosity, time, skills and efforts of the whole team at Orange Line.

Karen presenting Director, David Einstein with the Certificate of Appreciation

Donna, Carina, Karen, MJ, Miranda

HPN Awareness Week 2017 – an Overview and THANK YOU!

WORDS BY *KAREN*

Here it is – our HPN Awareness Week 2017 wrap-up!

HPN Awareness Week was held in October last year to coincide with the first World Home Artificial Nutrition (HAN) Day on 15th October, which kicked off the week. As usual, we provided lots of resources to our HPNers, carers, hospitals and industry friends so that everyone could celebrate and make the most of this dedicated week to raise awareness and understanding of our amazing life support therapy – Home Parenteral Nutrition.

We want to thank everyone –all our HPNers and families, the many hospitals, and our industry friends for getting involved. It was our most successful HPN Awareness Week yet! And thank you to the many generous folk who donated so that PNDU can continue to do what we do. Donors' names are included in 'Thank you'

Resources

Comics, pro-forma newspaper article, posters, stickers, quiz, social media profile, Twibbon… All were used during Awareness Week. Here's some feedback:

- "your quiz was fantastic! Loved the humour, but also how it was from a patient's perspective! The comics were a great idea, we actually managed to print them."
- "The resources you provided were really helpful. The quiz was a great 'ice-breaker' that the nurses really enjoyed."

For HPN Awareness Week this year we will be creating and providing a Hospital Pack to help hospitals get involved and celebrate.

Photo collage: Our HPNers, families and friends get into the action

Hospitals

A record number of hospitals got involved in 2017 – 14 in total. We look forward to even more this year!

Gold Coast University Hospital

Tanya Clark: A display in our main hospital foyer, an afternoon tea in our Gastro ward where our HPNers often are admitted to, a spotlight on our hospital intranet and a little sweetening up to our Gastro Registrars and Residents who kindly help us out.

Photo: Melanie Nelms and Tanya Clark 'PICC Chicks', Infusion Therapy, HPN nursing support.

Westmead Kids

Susan Klemesrud: During the week I have conducted 4 education sessions with different groups throughout the hospital. (photos above)

Royal Brisbane & Women's Hospital

Emma Osland: We've had a lot of comments about the badges this week and looking forward to next year, when our service has found its footing bit more strongly to be able to more extravagantly promote HPN awareness week.

Photo: Part of the RBWH Specialist Nutrition Support team here - Ismail (pharmacist), Jaz (Admin support), Lauren (nurse), Emma (dietitian).

John Hunter Hospital

Photo: PN team: Justin Singleton (dietitian), Peter Cocking (CNC), Jane Gillard (pharmacist), Dr Ken Havill (Director, intensivist), Dr Ed Martinez (intensivist).

Fiona Stanley Hospital

Terry Tremain: Our morning tea was well attended and quite successful… It was lovely to have Jodie present. She managed to chat to a few ward nurses and it was great for them to see a home PN patient looking well and functioning in everyday life. Something that when you work on a ward is hard to remember: that people are well at home.

The Royal Melbourne Hospital

Beth Hede: … overall the staff on the gastroenterology ward really benefited from a patient's perspective of HPN as I presented one of our patient stories. Thank you for the push (HPN awareness Week) to present this, as it was well received.

Townsville Hospital

Jo Cromley: we had a lovely morning tea.

Princess Alexandria Hospital, Brisbane

Courtesy of QLD Metro South News: This week, Jeanette and her team set up a stand in the Main Foyer raise awareness of HPN and provide PAH staff, patients and visitors an insight into what goes on behind the scenes for people needing HPN.

Sydney Kids

Samantha Kelly, gastro CNC

Lady Cilento

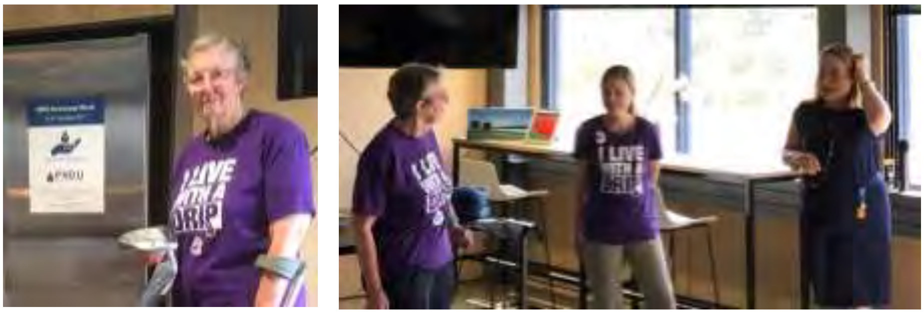
Katie Howard: We had a morning tea to celebrate HPN week, with a purple food theme to match the PNDU colour! I wanted to use it as a chance to also say ‘thanks’ to the nursing team in 10A.

I had your posters in all the staff lifts. We did your quiz (even the cleaning team had a go!) and lots of stickers were shared to raise awareness.

Industry friends

Fresenius Kabi

Everyone really enjoyed Jane's talk and her great sense of humour - it has led to lots of discussions re PN in our office so a great outcome!



Shire

We had a company morning tea and a presentation about the awareness week and the work that PNDU does to support people with Intestinal Failure. Our team had posters up all over the office [and] a desk drop with your information flyer and the quiz.

Pharmacy Tours

Once again, these were a great success, and we thank Baxter Healthcare, all the pharmacy managers and staff, and in particular, Mary for making these tours happen. These tours are wonderful opportunities for HPNers and carers, and clinicians, to see the facilities and expertise involved in making our PN, meet some of those who work diligently to prepare it, as well as opportunity to tell their story to staff, who in return gain a greater understanding of the lives of those 'on the receiving end'.

Tours took place around Australia and New Zealand and below are some photos and snippets of feedback from these tours. For more detail on the pharmacy tour experience, be sure to see the following article by members, Noel and Jill.

Perth

Jacqueline: Never expected to see such a laboratory in the building. So many people involved to make our PN. When I looked at all the people in white, even their faces covered, it reminded me of being in SPACE. (Ha-ha). I am glad I took the tour...never knew there was so much involved making the bags of PN. And all the vitamins and minerals that they all put in separate, for each individual. And everything so, so sterile. I am so grateful that these bags keep me alive!

Clare: We had a great day. Elsie and Bertie were very much on form and loving the attention ☺.

Melbourne

Elise: Had my first Baxter tour today. Loved it! The staff are so amazing and wow what an opportunity to see the patience, skill and care that goes into keeping us alive! Had an opportunity to share my story and give feedback on my experiences. But seriously consider going if you haven't been before. Everyone wearing the stickers too which was great to see.

Baxter manager: …the presentation by Eli here in our Melbourne pharmacy was extremely informative and really very moving.

Sydney

Wendy: Our Baxter pharmacy tour in Sydney really was an eye-opener as we were shown through the various sections involved in the production of PN. We greatly appreciated the friendliness of staff and their willingness to take time to answer our questions while we were shown around and also over a coffee at the end.


Adelaide

Annie: The tour was amazing, such a gorgeous day. Thank you for the opportunity. It was beautiful to be able to say thank you to all the people that make the thing that keeps us alive every day. It was lovely to meet 2 other HPN patients as well. I even met another patient who has been on HPN for 40 years! … It was so funny because everyone knew me. It was nice for them to put a face to all the names.

Cathy: We enjoyed the Baxter Adelaide visit. We found the people there very happy to show us their work place, and it was great to see how the PN bags are made, including the number of people involved and the processes and double checking that they do to ensure quality. They found it useful to also meet us, to put faces to names and to hear our stories, and likewise, we were able to thank them for their assistance. It was certainly worthwhile going.



Brisbane

Amanda (clinician): I found the pharmacy tour very informative - it was great to see what goes on behind the scenes at Baxter as well as hear from patients receiving HPN.

Alida: My husband and I found the tour to be very informative and were amazed at the level of sterile procedures that they follow every day. This went far beyond what we imagined. We were very impressed. We could not believe that they spend 2 hours on every individual order to get it ready from start to finish. These people go through an amazing amount of effort in order for us to have a reasonably normal life and nothing is too much trouble. When I told them that PN had taken me from 34 kilos back up to 60 kilos within a 12 month period they were thrilled because they never get to see what their jobs actually do and the difference they make for people like me. Baxter and their staff are amazing and we thank them for this opportunity and I would recommend all patients do this tour at some stage.



HPN Awareness Week 2017 Baxter Brisbane Tour

WORDS BY *NOEL* AND *JILL*

We arrived at the Baxter Coorparoo, Queensland facility on Friday 20 October 2017 at about 10.30 am. Meeting us in the carpark was Marina, from the Baxter staff. She directed us to reserved car spaces [right out front and on-site, which was fabulous!] and then she started the introductions in the foyer.

Another home HPN patient [Alida] and her carer [David] arrived at the same time. We four are all from the Gold

Coast area and supported by the Gold Coast University Hospital. Three hospital staff from 'The Royal' also arrived to participate in the tour of the compounding facility.

We met a number of other Baxter staff in a meeting room; all of the people were very friendly knowledgeable and open. Nobody wore name tags and that made it hard to remember names. So, if we could suggest that name tags are included in future tours, this may stop one of us confusing a Royal staffer for a Baxter staffer [which we did]!

After observing the Baxter process, I could not help being impressed with the meticulous care that is taken with every step of the process. Everything is checked, and then checked again by another independent person. As patients, we rely on the product being exactly as prescribed every time.

I have a background in engineering and production and I was very impressed. I think that I can speak for everyone that was on the tour when I say that our mixes are in good, safe hands at Baxter's pharmacies.

Our pharmacy tour wouldn't be complete without mentioning the Baxter staff. Everyone was open, friendly and extremely capable. The staff made us welcome and answered any questions without hesitation. The quality staff, coupled with a great facility and an excellent QA system, provides great comfort to those of us whose lives depend on the product and services of Baxter.

At the end of the tour Noel provided a short story of how a patient comes to need and depend on the PN service. He spent some time explaining how his cancer was detected in 1992. This was followed by many operations and radiation therapy to stop the cancer. After this, came the period of adjusting to life with the after-effects of cancer and radiation treatment. Then, over the years, slowly deteriorating health finally led to a system collapse that was checked by HPN: firstly in hospital then with HPN. Noel stressed that every home HPN patient has a story leading up to the home IV.

Noel emphasised how important the Baxter work was to surviving and told the staff that their work was life-giving and life-changing. They should be proud of the work they do and the difference they make to HPN patients.

Alida also provided valuable input as she has been on HPN for more than 3 years, whereas Noel is a relative newcomer who commenced PN in January this year – with HPN in February. We are both on PICC lines currently but that may change. This seems to be relatively new to long-term HPN.

Noel finished up with questions from the approximately 150 Baxter staff present. It was great having two patients and two carers to answer with a broader experience base. The staff listened attentively and a number come up to speak with us afterwards, thanking us for the talk and wishing us all well.

We finished the tour at about 1.15 pm and said our farewells in the foyer. It was a very worthwhile activity and we thank PNDU for organising such a wonderful outing. We should mention that many HPN stickers were on display and some people commented that they had been asked by a number of friends what it meant – so that was positive feed-back. It would be great if more people were able to attend next year's tour. The staff were as interested in us as we were in all they did and how they did it.

Thanks to everyone involved!

* * *

Jodie's Hospital Talk – This is my Life

WORDS BY *JODIE*

Hi, my name is Jodie and I've been on home parental nutrition for 20yrs now. I'm a member of a group called PNDU (which stands for Parental Nutrition Down Under), I'm an outpatient at [this] Hospital and I've been asked to share with you today why I'm on long-term parental nutrition and how it's impacted my life.

Here's a picture of me as a happy, healthy 6yo. I was well up until the age of 8. Then a major sickness hit me out of nowhere. At 8yo, for no known reason, I became severely ill and lost so much weight, it was scary. At 9yo I was diagnosed with Chronic Intestinal Pseudo Obstruction. The most devastating symptom of this illness, in my case, is malabsorption.

You can see that I was like a mal-nourished kid; skin and bones with a huge, angry belly (and here, I wasn't even at my worst). My growth was severely stunted. By age 13, my bone density was that of a 10yo.

During the six hard years from age 8 to 14, I struggled without parental nutrition and depended on daily nasogastric feeds, which later became jujenostomy feeds. Having extra food pumped into my sluggish gut was a living hell and for all the pain it caused, did not add much weight to my bony frame.

This [right] is me playing a prank on my family, saying that I'd gained heaps of weight by stuffing my clothes with rags. Gaining weight became the biggest focus of my childhood; it was our number one goal. If I could get fatter, I would be healthier.

After struggling to get by for six long years (my body essentially starving that whole time due to malabsorption), other organs starting to fail in addition to my small intestine. After countless hospital admissions, home parental nutrition became the only viable treatment left to try.

This [above] is me with my mum and sister as a 'fat' kid at age 14yo when I first started parental nutrition. I was bloated with fluid. You can see my right arm is bandaged where I have a picc line.

The bloating eventually settled down and I gained muscle mass. I grew taller. Each year we all hoped that that this was the year I would finally get my period. At age 18, I began menstruating, thanks to the good work parental nutrition had been doing for the 4yrs leading up to this point. It was a communal celebration. Maybe, just maybe, one day I could have a baby.

Although I had a new lease on life, there were many things I couldn't do as a teenager, but at the age of 17, I was able to get my driver's licence and at the age of 19, I was able to attend university part time to further my education. I later went on to study theology and also gained a diploma in beauty therapy. I was ambitious and parental nutrition gave me the go.

Here's a photo [right] of me in my early twenties, enjoying a weekend away free of PN. By this stage I've exhausted the use of picc lines and have had a few infusaports.

At 20yo I became close friends with an amazing guy. 8 months later, we were dating and by the time I turned 22, we were married.

It was an absolute dream come true to find someone who loved me despite my illness and who was prepared to hold my hand through every difficulty I'd ever have to face. This guy here is Ryan. He's one in a million and we're still together today after 12yrs of marriage.

I worked on a casual basis throughout my late teens and twenties and whilst I loved the work while it lasted, every job ended in tears (and sometimes hospitalisation) because I just physically and mentally couldn't cope with employment.

Today, we live in Busselton and my 'work' is being a mum, housewife and writing (mostly fiction). Last year I got a story print published for the first time. It was so exciting. Without parental nutrition, I wouldn't have been able to achieve even this small milestone.

Here's me meeting one of my favourite young adult authors: Isobelle Carmody. I read a lot of her books during my many hospital stays, so it was a pretty exciting and very surreal experience.

Ryan and I have travelled to a few Asian countries and had several domestic holidays. Back then, it was much harder to travel with parental nutrition due to the short shelf life of the bags and the bulky equipment – so our holidays were short and sweet because we couldn't take any PN with us and I could only last at maximum of a couple of weeks without it. We had to cater our holidays for my decrease in energy and increase in symptoms due to not having parental nutrition while we were away from home.

I came home thoroughly depleted and had always lost a few kilos. The next few months were always spent recovering and building up my strength again.

At 27yrs old, after a lot of talk with medical professionals, Ryan and I decided to try for a baby. It was a big decision and took us a long time to make. We had the full backing of my medical team and were given assurances that even though pregnancy with chronic intestinal pseudo obstruction and parental nutrition wasn't common, it could surely be done.

After a lot of preparation and 11months trying to conceive, I finally fell pregnant. Everything ran smoothly. I was having a little more parental nutrition as my needs and those of our baby, increased. Regular scans showed that our baby was developing on target and I was even feeling healthier than before I became pregnant. We found out we were having a boy and decided on Daniel for his name.

We hit a snag in our smooth sailing, just on week 32 of gestation. My bowels had seized up, I was getting a lot of back pain and then started bleeding. Off to the hospital we went, where we discovered I was already 5cm dilated and Daniel would be arriving early. I was rushed up to [a large maternity hospital] via Royal Flying Drs and ambulance.

There were complications during birth. My labour wasn't progressing, Daniel became stressed and wedged himself in an awkward position. He was delivered with the aid of forceps which marked his sweet little face pretty badly.

We only got to see our son for a minute before he was taken by the paediatricians and made comfortable in ICU. I stayed close to Daniel for 6 weeks while he was in hospital before we were allowed to take him home.

This is me holding Daniel a week or so after birth. I would hang out for my brief cuddle session every single day. It was a rough ride having a premature baby and we faced a few difficulties with Daniel's development. But we got through it and Daniel is now a happy, healthy boy keeping us on our toes with his constant chatter and 5yo demands.

The reasons for Daniel's premature birth are just theories – we don't really know why he came early. It could have been due to the chronic intestinal pseudo obstruction or it could have been for more 'normal' reasons. There is also speculation that parental nutrition can be associated with premature births. But the fact is, I wouldn't have been able to support the growth of a baby without parental nutrition. Daniel is such a miracle for us.

At 32yo, I went on a solo trip to Bali. It was the first time I was able to travel with PN and all necessary equipment. It was also my first international trip alone and my first visit to Indonesia. With the help of the PNDU community, parental nutrition bags with a longer expiry and the compact Bodyguard pump and backpack, the trip was a success and I was able to enjoy a whole week of bliss in Seminyak. I should also mention that we've successfully managed several family camping trips (in a tent) with parental nutrition over the last 6yrs.

So, I've shown you some of the big things I've been able to do in life because of parental nutrition. It's probably important for me to mention that not everyone on parental nutrition has the same quality of life as I do. We all have different medical reasons for needing parental nutrition and as such, are restricted by the symptoms of different illnesses.

Some of our common life-threatening concerns are liver damage, line infections and loss of central venous access. I've had so many picc lines and infusa-ports in the 20yrs I've been on parental nutrition (I've actually lost count) so I do worry about venous access in the future.

Parental nutrition helps – a lot – but it isn't a cure. Like real food, the effect of PN runs out and the tank has to be topped up regularly. As a HPNer, I often look a lot healthier than I feel. Don't get me wrong, parenteral nutrition gives me quality of life (in fact, it saved my life at 14yo), but I think it's important for people to understand that it does have a certain way of disguising the severity of intestinal failure. Parental Nutrition doesn't heal illness so much as it treats some of the major symptoms. So I guess what I'm trying to say is that long-term parental nutrition fosters good health, it's my fuel and I can't live without it, but it isn't a cure.

This is my little family [below] late last year, holidaying in Perth. Again, my port is deneedled. I tried to find some photos of me connected to PN or even showing my needled port but I don't have any. I guess it's always been something I've kept pretty private.

I guess the last thing I want to say, you probably already know and that is: some people on parental nutrition are sicker than I am. Others are healthier. So my story is just one among many but I hope my story has given you some insight into the power of long term parental nutrition and shown you just how life changing it can be.

Please feel free to contact me. If you want to follow my writing journey, you can find me on social media.

PNDU will be presenting at IVNNZ Conference 2018 in Rotorua

WORDS BY KAREN

PNDU is thrilled to be heading to Rotorua this year! I have been invited by Intravenous Nursing New Zealand (IVNNZ) to present at their upcoming conference.

The conference will be in Rotorua on 16th and 17th March and this will be a wonderful opportunity to provide insight to New Zealand vascular access clinicians about living life with a long term central venous access device, from the consumer perspective.

We also hope to reach more Kiwi HPN clinicians (and their HPN patients and carers), to let them know about PNDU and how we can work with them to provide even more support for their HPN families. (See also PNDU social gathering in Auckland below).

Save the date

PNDU Social Gathering in Auckland – 11 March 2018

WORDS BY KAREN

When: Sunday 11th March 2018, 12.30-3.30pm

Venue: Community hall in central Auckland

Bring: Anything and everything you need for a picnic.

The venue has wheelchair access, accessible toilets, off-street parking, and kitchen facilities (although the focus will not be on food).

RSVP: contactpndu@gmail.com by 4th March 2018 for address details

I will be in Auckland in March and would love to join with familiar and new HPN families for a relaxed time of meeting and chatting about life on HPN in a non-medical environment. This is just for HPNers (past and present, adults and kids) and their families, so there will be no giving/receiving of medical advice, but simply opportunity to meet and share experiences with others who totally 'get it'.

If you are an HPN clinician, please pass on this information to your HPN patients and carers.

Line Issues with Crawling Babies

***Editor's Note:* One of PNDU's closed Facebook group members brought up the subject of coping with CVADS (central venous access devices) with a crawling baby. These are some responses.**

Please remember to discuss with your own HPN team regarding any questions or concerns you may have in relation to your/your child's CVAD use and care.

QUESTION:

For the mums with little ones, I have a question. My 1yo is crawling around like crazy and I need some ideas on how you stop them pulling the cords and how to secure them safely. He is on HPN until 9am and usually wakes at 6, so when I get him up it's the hardest 3 hours to manage him. I've been putting him in the high chair and non- mobile seated object, but he just wants to crawl now. He is also on PEG feeds from 6am to 12pm and 6pm to 12am. I need suggestions for stopping him from breaking his line.

COMMENTS

- When my 2 boys were little, we had to build a barrier so that they could only crawl around in the space where their IV poles were and had to watch where their free draining bile bags were so they weren't getting tangled. It's hard at first but they got used to it.
- When my nephews came to my house I put them in a port-a-cot with toys and put it near a window or door. They loved this.
- [My child] has been on HPN since 4 months old, so if anyone gets it, I do! I used to use A LOT of Hyperfix tape. I would put a singlet or shirt on him and leave a little bit of cord for some give so it's not pulling on his tummy or chest etc and tape it to the back of his shirt. That way he isn't going to crawl on it and accidentally rip it out. The hard part is the pole or bag having to move that constantly.
- I use the tape in the nappy to make sure a loop is in place so he can't pull the lines but taping it to the back is genius! The pole is a problem, because he is trying to stand up on it and ends up pushing it away. But if I put him in the play pen as suggested and tape it, I certainly think we might have a safe option.
- When [my child] was little (actually, she still is!) we always had a singlet onesie on her and would use the 3 clips in the crotch area to loop her line around to give another safety point. That is, it would pull those clips before pulling on her line in her chest.
  We have also been known to tie a ribbon that was just short of her line to her tummy and the other end to her IV pole so that she couldn't pull the line tight if she suddenly took off.
- Also try to avoid the same point in the line where it comes out from the tape, because having the movement all at the one spot on the line will cause it to weaken and can snap.
- This [below left] is how I do [my child's] dressing, so when connected it goes to the back then I loop and tape the line to her singlet and had a playpen for when she was still connected. I use an extension as well to give more length. It worked well and by the time she outgrew the playpen she was used to the fact she just goes where she knows her line won't pull. She is now 3.5 years old and sleeps in her own bed in her own room and has never moved out of her bed until I go into the room. They do get used to it.

- [My child's] line points down (see picture above right), so where the blue filter is on the line, I tape that part to the front of his nappy and then use snap stud onesies so the filter part of the line can't come out. It's very secure, and touch wood, we haven't had a problem so far. A play pen is perfect because earlier on I just put him in his high chair, but looking back, it really delayed his physical development so had to think outside the box. The play pen was awesome and worked as soon as we used it. He also has an older sister, so was quite happy he had his own toys without her taking them from him.

- I find the 150cm extension cords are awesome for more metres to move. One of the other mums we were with in hospital with for those 5 long months when he was a baby told me to use these so that you don't go insane.

Quality of Life and Patient Preferences Research

Summary

The Royal Prince Alfred Hospital Intestinal Failure Team (Ms Lynn Hyde-Jones, Dr Sharon Carey and Associate Professor Cherry Koh) would like to thank all those people that participated in a recent Quality of Life and Patient Preferences phone survey for adults on Home Parenteral Nutrition (HPN). As many PNDU members are aware there are very limited treatment options for people on HPN and this survey was aimed at determining (i) what factors negatively impact people so that these can be the focus of future treatments (ii) assess which current and potential future treatment options people on HPN feel would be beneficial to them.

People who participated in the survey undertook an open ended discussion and also some questions in which they were asked to rank how different scenarios impacted their quality of life. The last part of the survey used a very different methodology known as "time trade off methodology" in which each participant was asked hypothetically how many years of a potential 20 year life span they would trade to have access to a different treatment option, knowing all the potential complications and benefits of that option.

We had 19 people participate in the survey. There was a good mix of rural, regional and metropolitan participants, and the majority were female. When assessing aspects of care that impacted on quality of life (where 10 had the greatest negative impact on your quality of life), these are the issues that you felt impact your quality of life:

Concern/Issue	**Score out of 10 (where 10 has the greatest impact on Quality of Life)**
Nights on HPN	8
Diarrhoea and/or high stoma output	8
Line infection	7
Limitations in being able to travel or go on holidays	7
Pain	7
Dietary Restrictions	7
Sleep Deprivation	6
Distance to travel to receive specialist care	5
Number of medications required	5

With regards to the "Time Trade Off" part of the survey assessing different treatment options, most people opted to trade years for (i) optimisation of diet and medications and (ii) a medication that may enhance bowel adaption. While these results are useful for health professionals to be able to target services, it is important to remember that not all people are suitable or eligible for all treatment options.

Treatment Option	**Years willing to trade (out of**
An option to be able to optimize current treatment with strict diet,	10
A medication that could allow enhanced bowel adaption	10
A preparation to aid reduction in line infections	5.4
Small bowel transplant	0

While all participants overall expressed happiness with their HPN health professionals, many of you expressed the following:

1. You would like better communication with your HPN health professional team
2. Often rotating health professionals within the treating team meant you had to retell your medical history multiple times and this was frustrating.
3. The HPN health professionals often had a lack of understanding and empathy.
4. There is a lack of support when issues arose during out of hour's times.

In summary this research identifies key issues and concerns for people on HPN, and gives health professionals key areas to focus on improving services. Once again, Ms Lynn Hyde-Jones, Dr Sharon Carey and Associate Professor Cherry Koh would like to thank PNDU for their support of this research, and also all the participants who volunteered their valuable time.

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Hospital Bingo

BY *LARA*

Editor's note: One of our members, Lara, has developed this game to amuse her/relieve her frustrations when she is in hospital or 'ClubMed' as we like to call it. The aim is to see how long it takes to tick off a complete line through the centre star.

Something in your room is brown	Room-mate is unpleasantly chatty	Nurse forgets pre-meal meds	Have no fluids charted	Booked for procedure-no-one knows when
Visitor cancels	See a bare bum	Wait more than an hour for the doctor	Interrupted during the only TV show you like	Nurse tries to give me Clexane-not supposed to have it!
Elderly patient wanders into room by mistake	Room-mate has an unreasonable amount or visitors	★	IV line dies	Doctor talks over you
Wait more than 10 minutes for nurse	Interrupted within 5 mins of putting on head phones	No cup of tea when you want it	Middle of the night BSL (blood sugar level) check	WIFI is dead
Served food you're not allowed to eat	There's a screamer on the ward	Random person uses your bathroom	Nurse uses poor aseptic technique on line	Hear details of someone else's bowels

Editor's note: As the above game focuses on negative aspects of hospital life, I thought I would develop a positive game. Patients can play both together and see which one is completed first!

Enjoy most of your meal	At least 1 lovely nurse per shift	Your hospital teams co-operate	Correct drugs arrive from pharmacy	Ward provides hospital PJ pants
Ward has a definite quiet time-main lights out	Bathroom kept clean	Room-mates considerate	Medicine charted correctly	Magazine lady visits with up-to-date issues
TV changed promptly if bed moved	Phone works	★	Electric bed	Nurses cheerfully provide PN set up stuff
Room-mates friendly	Enough blankets to keep warm	Your PN team keeps in contact with you	Your discharge day is not put off	Room-mates quiet
You're well enough to walk to coffee shop	Air conditioner works	You get the meal you ordered	Doctors introduce themselves on rounds/visits	Nurses wear identity tags with name

How did we Survive Christmas?

Editor's note: One our members posted the following question in PNDU's private email group:

So, how did everyone survive all the celebrations? I hope there weren't too many difficult moments, that you found at least most people accommodating of your needs and that your bodies allowed you to enjoy some festivities.

Tell us how your Christmas/Hanukkah and New Year went. What was the best bit, and did you experience any major problems with lack of understanding?

Karen:

As I was in charge of food for our Christmas celebrations this time, I made sure there was plenty I could eat, as well as accommodating everyone else ☺. There was also opportunity to explain … again … to a couple of family friends what Intestinal Failure/ HPN is. One of the nicest bits for me, however, was meeting my 7mth great niece, Poppy (who just loves books).

Renee:

I hope you had a wonderful Christmas and New Year. We don't celebrate Christmas but this is still a festive time with lots of visitors. Fortunately, I'm in charge of food, so it's always fine and my loved ones, family and friends, know what I can and can't manage.

On New Year's Eve, I went to a wonderful meditation group sending out wishes for peace and justice in the world. A great way to start the year. May it be a good one for you all.

Daniel:

I had a very chilled out time. Caught up with some mates and a game of big bash.

Fay:

Christmas was not so good for me as I was too sick to leave the house, but I started to improve on the Wednesday after Christmas, and New Year was great. We joined our good friends on their boat (very luxurious) and went around to Wangi (on Lake Macquarie), about a half hour trip in the boat. We ate, drank and just enjoyed each other's company until 9pm, when they put on the best fireworks on a barge in Wangi bay. Being out there on the water with the fireworks is something else. It's not the first time we have done that, but you just never get tired of the experience.

Hope everyone had as good a time as I did. Love to all for a wonderful 2018.

Gillian:

We celebrated our first Christmas with our almost 3 month old granddaughter, son, daughter-in-law, daughter and my 90 year old father. It was a lovely day.

Jane:

I was nil by mouth on Christmas day, so I didn't even get the card that the hospital puts on the brekky tray!

Chris:

We managed to survive the Christmas, New Year celebrations after a very bad week leading into Christmas.

A wild thunderstorm blew a colorbond gate into our car, causing quite a bit of damage that will require a respray sometime in the near future, next day we were stranded in the driveway with a dead car battery for five hours while NRMA tried to source a new battery for our European Renault. Then our refrigerator packed it in, full of food in 45 degree heat, had to happen while we were away overnight, saved everything in the freezer but the contents of the fridge had to be thrown out!

Christmas Day was wonderful, we spent the day at my daughter Brookes with Mick and the three boys. We were joined by Katie and Brendan. The heat dictated salad again this year (miss my Christmas roast ☹) a mix of ham, chicken pork and seafood. Dylan, Jordan and Logan delighted in making table decorations and were quite proud of their handiwork.

The three boys were seated at a table adjacent to the adults and seemed extremely happy to have their own table.

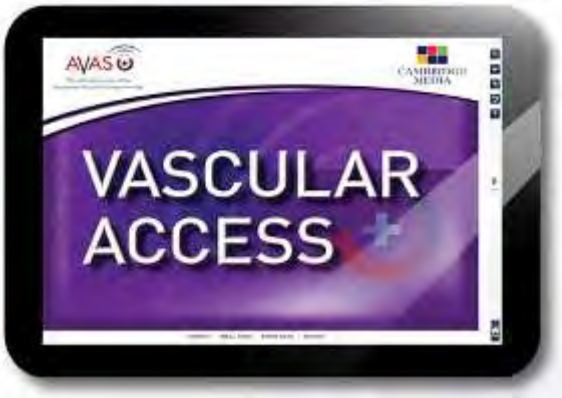
With Christmas out of the way it was time to settle back and watch the Boxing Day cricket test and start of the Sydney to Hobart yacht race, but the bad luck continued and the television blew up during the cricket.

We were joined by our niece and her family from Qld on Boxing Day to New Year's Eve. They have three children of similar age to Dylan, Jordan and Logan. Our families enjoyed picnic days by the lake and trips to the movies. It was great for the boys to enjoy time with their cousins from QLD. Jordan was so active and excited for the entire week, that by the end of the week he could hardly walk or move- he had been on the go every day from sun up to sun down; it was wonderful to see.

Tanya and I saw the New Year out on the banks of the Hunter River, watching a magnificent fireworks display over Newcastle.

PNDU's member study abstract is published!

WORDS BY *KAREN*



PNDU is very excited to have the abstract of one of our member surveys printed in a medical journal! The Australian Vascular Access Society (AVAS) included the abstract of our 2017 "Pilot Observational Study of CVAD Experiences by Australasian HPN Patients" in the October 2017 issue of its official journal, "Vascular Access" (2017, Vol 3, Issue 2).

PNDU presented the results of the study at AVAS' conference in Perth in May 2017, with an incredibly encouraging response. PNDU was congratulated as a consumer group for identifying an issue that affected us, doing our own research and presenting it to raise awareness amongst clinicians (despite not being able to draw any conclusions about CVAD type and infections from the results!!). A very encouraging clinical society! Thank you AVAS!

Quality initiative improves sepsis treatment for home parenteral nutrition children

Editor's note: The following interesting abstract appeared in IVTEAM newsletter 31 October 2017

Reference: Hudgins, J.D., Goldberg, V., Fell, G.L., Puder, M. and Eisenberg, M.A. (2017) Reducing Time to Antibiotics in Children With Intestinal Failure, Central Venous Line, and Fever. October 24th. doi: 10.1542/peds.2017-1201.

Abstract:

BACKGROUND: Children with intestinal failure (IF) on parenteral nutrition (PN) are at high risk for bacteremia, and delays in antibiotic administration have been associated with increased morbidity and mortality. We designed an emergency department (ED) quality improvement (QI) initiative to reduce time to administration of intravenous antibiotics in febrile children with IF on PN.

METHODS: Our aim was to decrease the mean time for febrile children with IF on PN to receive intravenous antibiotics by 50% to <60 minutes over a 12-month period. Secondary outcome measures were ED, hospital, and ICU length of stay (LOS). Our process measure was the rate of ordering recommended antibiotics, and our balancing measure was the rate of hypoglycemia. Interventions included increasing provider knowledge of IF, streamlining order entry, providing individualized feedback, and standardizing the triage process. Results were analyzed by using statistical process control methodology and time series analysis.

RESULTS: We identified 149 eligible ED patients, of which 62 (41.6%) had bacteremia. The mean time to antibiotics decreased after the onset of the QI initiative from 112 to 39 minutes, and the ED LOS decreased from 286 to 247 minutes, but the total length of hospital and ICU stays were unchanged. The rate of hypoglycemia was also unchanged.

CONCLUSIONS: Our QI intervention for febrile children with IF on PN shortened the time to receive antibiotics. Larger studies are needed to demonstrate the impact on overall LOS and mortality.

HPN Awareness: Getting real

BY *ANN WEAVER*

Editor's note: PNDU wishes to thank Oley Foundation and Ann Weaver for permission to reprint in Dripline the following article from the September/October 2017 edition of Oley Foundation's newsletter, 'LifelineLetter'.

Ann posted a version of the article below on social media for HPN Awareness Week in August. We thought it was poignant, and asked if we could share it. It has been slightly modified for the newsletter. At the end, Ann asks several thought-provoking questions to generate discussion. If you'd like to write to us with your answers, we would be happy to hear your thoughts and share them in a future issue of the newsletter. Or these could be great journal topics, if you find a moment to ponder them.

Any medical condition takes a physical toll, but we should never dismiss or deny the emotional toll of chronic disease and home parenteral nutrition (HPN). Some describe it as a roller-coaster ride. That doesn't quite work for me because roller-coaster rides typically end. You can get off and move on. For many on HPN, there is no end in sight.

The best analogy I can think of is riding waves. Sometimes things are very calm and almost peaceful. Unpredictably it can change and you can get hit by a large swell that bounces you up and down, disorientating you. If you get used to the rhythm it might be OK and you can keep your head above water, maybe even enjoy the ride.

Then there are times when the swell is engulfing. It overwhelms you; it pushes you under and takes your breath away. You might feel like you are drowning and you will never get your head above water. Back and forth, the ebb and flow of the waves doesn't end.

Looking back

I remember the start of our journey. Tears of sheer joy and elation at our second child's birth, after successive losses. The utter shock of the diagnosis, worry and fear with surgery at three days of age. Overwhelmed with words and terms we had never heard before, desperate to learn more. Devastated to be told there was no one else like this.

The heartache of going home for the first time without our newborn, the emptiness of sitting in his nursery without him. Waking up in the middle of the night desperately hoping this was all a nightmare, only to realize this was the beginning of a new journey.

The frustration and anger at the lack of information, the arrogance and divisiveness of the medical team. The devastation at being told at two weeks that our child's condition was incompatible with life. Becoming defiant and determined to keep him alive and prove "them" wrong.

The immense sadness of sharing this news, with my husband and parents as we cried together.

Worry at the impact on our older child, and immense sadness because this was not the life we had hoped for or expected. Thankful for family and friends who supported us, cared for our older son, and prayed. The slivers of happiness as I snuggled with my little one next to his NICU crib and visited as a family, then the heartache of having to leave him behind.

Up and down, bobbing, trying to keep our heads above water and not drown. This is just the first few weeks. One month in the first NICU, another two and one-half months in the next. More surgeries, anxiety, and fear as we sat in the waiting room. Mix of elation and fear with the talk of coming home.

The nausea and feeling of almost passing out watching the first dressing change. Remembering to breathe. Desperately praying, offering to do whatever it took to keep my son alive, only to be shocked by the reality of what I would need to do and the extreme fear that something I did wrong could cause harm or death.

Excitement of going home for the first time only to be overwhelmed with the reality of hospital home and the level of care we, primarily I, would be providing. Exhaustion beyond any I had ever felt before, both physical and emotional. Fear of ending up back in the hospital, anxiety of being back in the hospital, and frustration that despite our best efforts, we are in again and again. Ebb and flow.

Isolation...no one really understanding, alone on an island. Over time it was easier to just say everything is OK than to go into details that you barely understood yourself and couldn't wrap your head around.

Yet despite all this, we learned. We developed strength, resilience, and coping strategies that allowed us to walk or stumble through, while being tossed up and down, back and forth. Walking that tightrope between stability and not. Holding our breath, trying to remember to breathe.

Trauma is defined as a deeply disturbing or distressing experience. Individuals on HPN and their caregivers experience trauma, and often recurrent trauma related to re-hospitalizations, infections, surgeries and other medical procedures, and the disease itself.


Ann and Tim enjoying a peaceful, happy day.

Facing Realities

FDR said there is nothing to fear but fear itself....ha I say. I can think of a number of fears and anxieties that people in the HPN community face. Death, premature death, line infections, losing a line, losing central venous access, hospitalizations in July, emergency rooms, loss of a job due to health concerns, loss of health insurance, return of annual and lifetime caps....What fears do you deal with?

Isolation is not uncommon when you are dealing with HPN due to lack of understanding of the challenges of the therapy among family, friends, and the general public. The inability to eat can also lead to social isolation, since so many events and activities revolve around food. How do you deal with the feelings of being alone?

Grief is not uncommon, whether we recognize it or not. Grieving for the loss of your former life or loss of an expected life, loss of normalcy. How have you worked your way through grief, or deal with chronic grief?

Desperation is natural—wanting answers, solutions, normalcy, and cures. How have you turned desperation into action?

Anger and frustration come with lack of control, lack of support and resources, lack of understanding of chronic disease, which is long lasting, often without a cure. Have you been able to turn those emotions into positive action?

Depression, hopelessness, helplessness creep in. How have you kept your head above water?

We have learned to find joy and happiness along this journey. Being able to smile or laugh for the first time, celebrating life, celebrating each milestone. Savouring life and experiences more than we ever could have imagined. Giving thanks for each new day. What do you celebrate and rejoice in? How has humour helped in your journey?

Finding that new normal has helped us. But we continue, after almost twenty-three years, to bob in the waves, hoping and praying we don't get swallowed by the next swell.

PNDU at AuSPEN Conference November 2017 at the Gold Coast, Queensland

WORDS BY *KAREN*

It was great for PNDU to be there, be seen, reconnect with PNDU friends and supporters (clinicians and industry) and meet other HPN clinicians. Thank you AuSPEN for again allowing PNDU to exhibit for free at this important event.

Photo courtesy of AuSPEN and Corporate Communique

Novel tunnelled central catheter placement in a pediatric patient

Editor's note: The following interesting abstract appeared in IVTEAM newsletter 13 December 2017

Reference:

Goel, D., Yadav, B., Lewis, P., Sharma, K. and Vellody, R. (2017) Tunneled Catheter Placement in a Pediatric Patient: A Novel Approach. The Journal of the Association for Vascular Access. 22(4), p.205–209.

Abstract:

Establishing venous access can be an important and often complex aspect of care for pediatric patients. When stable central venous access is required for long-term intravenous infusions, several options are available including peripherally inserted central catheters (PICC), tunneled catheters and ports. Both PICC placement and tunneled catheter placement include an exposed external segment of catheter, either in an extremity or on the chest. We present a pediatric patient with complex behavioral history who required long-term intravenous therapy. After careful review, the best option for the patient was determined to be a tunneled catheter that exited the skin in the right upper back, making it difficult to grab and pull out. The catheter was successfully placed and the patient appropriately completed his intravenous antibiotic course. Upon completion, the catheter was removed without complications. This tunneling technique to the scapular region may be useful for patients with psychiatric or neurodegenerative disorders where purposeful dislodgement may be a problem.

Sydney Social Gathering 2017

WORDS BY *GILLIAN*

Sydney HPNers had the opportunity to meet and chat on Sunday October 29th, from 12:30 – 3:30pm. Again, Sal and Matt opened their Toongabbie home to us, providing a lovely outdoor covered space for us to mingle. We converged from all directions around Sydney.

It was lovely to see Renee (HPNer) and Merv again, as they now live a few hour's drive down the south coast, so it was very special to catch up in person, not just in the private email group. They also brought Renee's sister, Ann, who was visiting from the US, as well as their adult son, Justin, on his way out later in the day.

Fay (HPNer) and Lindsay made the drive from the opposite direction, the Central Coast, as did Chris and his wife, Tanya, one of his daughters, Katie, his other daughter Brooke, son-in-law Mick, as well as their boys, Dylan, along with Jordan and Logan, both HPNers.

Miranda and Dave were there from the Eastern suburbs, with their trio of daughters – Ariel (HPNer), Eadie and baby Florence. It was lovely to see one of the flow-on benefits of the SNUG camp (see Issue 21 of Dripline) which was the friendship that had developed between these children who had attended and shared this great experience. They played happily with the variety of toys on offer.

Karen (HPNer) drove from the north side of Sydney, bringing Jane (HPNer) with her. It was lovely to catch up with them both, especially since Jane has had many hospitalisations during the year.

Ray and I (HPNer) came from the southern suburbs of Sydney, so, since we met in the west, all points of the compass were represented!

Unfortunately, there were no new HPNer faces to meet and share experiences with this time, but maybe others might be encouraged to attend the next gathering in 2018, knowing that everyone is always welcome at these events. In all, we had 8 HPNers, 3 of them young children.

PNDU 'virtually' went to Amsterdam for an IF/SBS workshop!

WORDS BY *KAREN*

As PNDU's President, I recently had the opportunity to join other Intestinal Failure/Short Bowel Syndrome patient representatives from around the world for a 1½ day workshop in late November 2017, sponsored and organised by Shire. The aim of the workshop was to share ideas and achievements, find common challenges and brainstorm ways to overcome them. It was great to have the option of joining this workshop via Skype from home, even if the hours 'down under' were a shocker (7pm-3am!).

It was a productive time and we look forward to ongoing networking with existing and new HPN/IF/SBS patient group representatives around the world. Thank you Shire for organising and bringing us together.

Representatives from Canada, Czech Republic, Denmark, Estonia, France, Italy, Netherlands, Norway, Poland, Russia, United Kingdom, … and on Skype, Australia/New Zealand!!

Left: *The view out over beautiful Amsterdam* ***Right:*** *How technology worked in Amsterdam - slides with me live-streaming in the corner. At my end, I had 2 live streams - one of the room, and one of the slides*

A Day in the Life of an HPNer

Adjusting HPN routine for QOL reasons

WORDS BY *GILLIAN*

Editor's Note: Don't make any changes to your HPN protocols without discussing it with your hospital team first.

One of the main issues of being on HPN (Home Parenteral Nutrition) is adjusting to a new routine in your life – an essential routine. Unlike deciding when to wash the dishes, shop, dust, mop the floor, setting up our life saving HPN has to be done regularly at more or less the same time each day, over more or less the same period of time. There are benefits to this: because setting up becomes routine, when you adjust to this new way of life, you don't have to think about it, just get on and do it. But the problem comes when this routine prevents you from doing things you would enjoy doing. Surely the purpose of HPN keeping us alive is so that we have more years with loved ones to enjoy life and experiences with them?

Over the 11 plus years that I've been on HPN, I've worked out ways, with my hospital team's permission, to vary this routine at times so that I'm still able to attend functions, either while infusing, or put off setting up until after the event. Since we are all individuals, needing different volumes of PN to each other, infusing at different rates to each other, and could have different reactions to changing any of this, changing your routine needs to be discussed with your team, but you need to let them know that quality of life (QOL) is important to you and that sometimes you'd like to vary the routine somehow if they approve.

Note that my usual routine is that on 4 nights per week I set up at about 9:30pm for 9 hours; and for 3 nights per week I set up 1L of Hartmann's solution over 2 hours, commencing at about 7:30pm, then change over to my PN bag at about 9:30 for 9 hours. NB: These times might be too fast for many people. Here are a few examples of changes I've made to my routine in order to make life easier going out. The first 3 happened over this past

Christmas-New Year period.

- I sing in my church choir for the Carol Service in our church on Christmas Eve. Although the service begins at 8:00pm, we arrive for a last warm up and practice at 7:00pm. The service finishes at about 9:30, followed by socialising over mince tarts and punch, so it's after 10:00pm by the time I get home. **Adjustment:** Set up with Hartmann's at 6:30, infusing over 4 hours; change over to PN bag at 10:30 over 9 hours.
- On New Year's Eve, my husband Ray and I went with friends, to Brighton, to view the fireworks at 9:00pm, then returned to our friend's house for supper and to chat until midnight. We left home at 7:00pm and returned about 12:30. **Adjustment:** The same as for Christmas, but this time I had to swap bags at my friend's house, so had to go prepared.
- We went to a restaurant for dinner with my son and daughter-in-law and grandbaby (visiting from Perth over the Christmas/New Year period), daughter and friends of the family. We met at 6:30pm and returned home about 9pm. **Adjustment:** I usually alternate nights of PN only and Hartmann's plus PN, and this should have been a night with both; however, I swapped and had 2 nights in a row with PN only so I could simply put off setting up until we got home. This then also meant the next 2 nights in a row with both bags.
- There were two occasions over the years that I wanted to miss infusing my PN all together, which, in my case, means dropping 1kg in weight overnight. One occasion was wanting to walk one section of the Queen Charlotte Track which is beside Marlborough Sound on New Zealand's South Island. We were dropped by water taxi at one point, then walked for several hours to a lovely resort to spend the night, then back by water taxi the next morning. The other occasion was my son's wedding, when I didn't want to rush off early, nor set up early and lug my backpack around all afternoon and night. **Adjustment:** my team agreed for me to miss infusing on these two occasions, especially as my weight both times was at an acceptable level (sometimes it drops over a long period and ends up quite low)

These are just a few ways that socialising has been made easier for me by adjusting my routine occasionally. They might not work for everyone. A lot of life means being flexible and open to compromise, but with our health as our main concern, this isn't always possible. But until you ask and discuss your requests, you don't know what you are able to adjust and what has to remain constant. It's your quality of life that is sometimes at stake, so don't be afraid to bring this topic up with your hospital team.

Enjoying the night with my granddaughter at a restaurant

Upcoming Events

28 February	World Rare Disease Day
11 March	PNDU social gathering – Auckland
16-17 March	Intravenous Nursing New Zealand conference. PNDU will be presenting
August	PNDU's AGM & announcement of PNDU Annual Award winners
15 October	World HAN Day
14-20 October	HPN Awareness Week

Thank You

We wish to thank the following for their generous donations totalling $8,186.

M Bachmayer (in honour of Renee's birthday)
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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.

Donation

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.)

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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.

Celene – 27 November 2017, aged 43 years
Emma – 9 April 2017, aged 35 years
Lara – 16 February 2017, aged 7 years
Teresa – 15 February 2017 aged 58 years
Natalie – 18 September 2016, aged 27 years
Sam – 13 September 2016, aged 14 years
Carol – 2 September 2016, aged 67 years
Jessica – 24 January 2014, aged 20 years
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***