



DRIPLINE



PNDU

Parenteral Nutrition Down Under

Greetings, with another jam-packed issue of Dripline! You might like to start with the personal stories, of which there are several, including Part 2 of an article begun last issue; or discover who won the 2018 PNDU Awards; or find out the results of PNDU's search for a replacement medical play toy and why there was a need to do this – and see the recipients' excitement; or read an overview of a medical article about the complexity of choosing the right CVC for HPN; or read about PNDU's upcoming events – or simply read from the beginning to the end. There should be something for everyone!

I hope you enjoy it.

Gillian – Editor

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PNDU's Management Committee

Words by Karen

At PNDU's recent Annual General Meeting the following were elected unopposed:

President:	Karen
Vice President & Treasurer:	Chris
Secretary & Public Officer:	Miranda
MC Members:	Gillian (also Dripline editor) and Fay



Our Management Committee (MC) continues to meet mostly via Skype every 6-8 weeks as well as electronically in between. Thank you to our MC members for all their work to help this small volunteer organisation achieve all that it does. And thank, too, all who volunteer in various capacities within PNDU – Sal, Renee, Sharyn, Rachel, Ryan and Gil – you all help PNDU to function and achieve our purpose of supporting those living with HPN/IF 'down under'. We are proudly run by HPNers and carers.

HPN Awareness Week 14-20 October 2018

Words by Karen

By the time you read this, HPN Awareness Week 2018 will be finished for another year. This year we highlighted and celebrated that HPN is 'our food for strength'. Sometimes HPN can feel like a double-edged sword considering all the complexities and associated risks. As a result, we may not all be well or particularly robust, but HPN does provide the sustenance we need to live, and for that we are incredibly grateful.



To help celebrate, we once again made available loads of resources to help our HPN member families as well as HPN clinicians, hospitals (15 hospitals got involved!) and industry celebrate this special week on the calendar: stickers, posters, flyers, HPN bingo game, example newspaper article, social media profile and frame, and another great short video clip. In addition, this year PNDU launched PNDU's own Instagram account!



And again, Baxter Healthcare and Biomed (Auckland) opened their pharmacy doors across New Zealand and Australia for tours especially for HPNers, carers and PN clinicians, allowing us to see the amazing facilities and processes needed to make our PN, as well as opportunity to tell staff what it's like to life with HPN. This year, Baxter also invited politicians, and HPNers were enlisted to give a mock connecting up demonstration for the staff. Great education and awareness opportunities for everyone!

Thanks to the participating HPN hospitals and industry for all the support! And thanks to the Management Committee for the counting, enveloping and addressing of stickers! We hope everyone enjoyed this special week and had opportunity to help raise awareness and understanding of HPN amongst family, friends, work colleagues, hospital teams, and beyond. If you haven't already sent in photos, please don't delay! Send them to contactpndu@gmail.com.

Watch out for a photo collage of the Week to be emailed out soon, as well as a full write-up and photos of the celebrations in the next issue of Dripline.

And if you'd like to make a donation to PNDU's work as we continue to support those living with HPN in Australia and New Zealand, please visit the [Donate page](#) on our website today.

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: **MC Working Bee for Awareness Week** :
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Words by Gillian

Behind the scenes, in mid-September, PNDU's Management Committee – Karen, Chris, Miranda, Fay and Gillian – met to count and put Awareness Week stickers into envelopes ready for mailing to members to wear during Awareness Week. It was decided that since it was a large job, it would be made easier with many hands. Chris travelled from Newcastle NSW and picked up Fay along the way. They met up with Karen who drove them across Sydney to Miranda's house. Gillian travelled from the south and met everyone there.

It was nice to catch up with each other in person – usually we 'meet' once every 6-8 weeks talking on Skype to discuss PNDU matters, but this informal get together meant relaxed chat rather than business was the order of the day. Thanks Miranda for your hospitality!



Karen, Fay, Chris and Miranda
(Gillian taking photo)

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: **PNDU is turning 10 – please help us celebrate!** :
: **Two Sydney events for all HPNers and carers – December 2018 – register NOW!** :
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Words by Karen

We are combining our 2018 annual social gathering with PNDU 10th Birthday celebrations. This is going to be a very special event, with great giveaways, special cake-cutting, some reflections on PNDU's 10 years, PNDU merchandise for purchase, and opportunity to mix with other families and individuals who totally 'get' living with HPN.

The AuSPEN HPN consumer workshop is a unique opportunity to learn more about our HPN from expert clinicians working in the field.

These are both FREE events, specifically for HPNers, carers and their families (PNDU social gathering only)! Are you planning to come? And have you registered yet for both events? (Separate registrations are needed).



AuSPEN HPN consumer workshop

Open to all HPNers and carers only

Date: Saturday 1st December 2018,
12.30-4.00pm

Venue: Sheraton on the Park, Sydney

Register: admin@auspen.org.au by 16th
November 2018.

See the [Program](#).

PNDU annual social gathering

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

Date: Sunday 2nd December 2018, 12.30-
3.30pm

Venue: 5-10 minute walk from Central Station,
Sydney ([email](#) for details)

Register: To PNDU at contactpndu@gmail.com or
(+61)0413715187 by 16th November



Dominic's Story

Words by Lauren, his mum

Our son Dominic was born with Hirschsprung's Disease and as a result was left with short bowel syndrome. He has been on HPN and enteral feeds since he was a few days old and we were trained on HPN in the hospital when he was 8 weeks old. When we first took Dominic home we were a nervous wreck! I kept going over and over in my head how to hook up PN and how to disconnect and I even wrote a step by step guide and stuck it on his wall above his 'PN set up trolley'. On top of learning HPN we also had to navigate our way around a very wiggly baby with an NG tube and running continuous feeds. Once we got into the hang of everything; it was actually quite easy and he was connected 16 hours a day.

The first few months at home were tough, learning to get into our own routine, attend countless hospital appointments, manage all his feeds and HPN and then still care for a normal baby that wanted to roll, eat and not sleep! I was very nervous about going portable with his PN. One afternoon I was so bored at home, I thought I'd be brave and put his PN and pump in the backpack and hang it on the side of the pram. We'd only been home for a month at this stage and I thought 'yeah, you got this Mum!'. Dom settled into the pram for an afternoon nap and I walked towards Coles and thought I can grab a few bits and pieces. Shortly after starting my shop his pump started beeping! I was frozen, I had no idea what to do. Everyone was looking at me! Oh gosh! I hope no-one asks me if I need any help, how do I explain HPN?!

I opened his backpack and pulled the pump out and saw the sign saying 'DOWN OCCLUSION'. This was the first time it ever happened and right there I lost it and started crying and had no idea what to do. I put the groceries down and rushed out the store and back home whilst the entire time the pump was beeping.

I felt so embarrassed and so upset that I couldn't go to the grocery store and my day was ruined. I cried all afternoon BUT I promised myself I would try it again the next day. And I did. We went for a walk to the park instead and had a lovely time in the sun. As Dom got older, I started getting more confident with transporting his feeds and PN and slowly we dropped some hours so he was only connected at night time when he slept.

Dom is now 2.5 years old and we are now down to 13hrs of PN and 13hrs of feeds overnight. Right now, I've just connected him to his PN and feeds and he's sitting in his high chair (see pic) watching his iPad and will have dinner shortly. Our night time routine means we do hook up first and then dinner and he actually looks forward to the time in his high chair as he gets to use his iPad. He'll be too big for his high chair soon so we'll be setting up his play pen in the lounge room so he can have a bit of freedom before bed time. Dom has had many surgeries over the last 12 months, the most recent one being a bowel lengthening and tapering procedure which has gone amazingly well and helped so much with his appetite and absorption. Whilst in hospital he was on PN for 24hrs and a bigger volume as he wasn't eating and we were waiting for his bowel to heal, however we've slowly weaned back to 13 hours and hope one day in the future we may even get a night off!

Some days with Dom are a complete mess with ostomy bag leaks, high output/vomiting or unexpected CVL dressing changes and then other days are a complete breeze and you forget about all his extra 'accessories' and it's those days that make us slow down and really appreciate how far Dom has come. We actually find HPN the easiest to do out of everything else! We are so lucky to have such amazing life-saving nutrition for our Dom. It's given him the support he's needed to grow and gain weight and will for many, many more years and we will always be grateful for that.



Dominic has come a long way!

Like Books?

Words by Karen

Do you like reading books? Do you like buying books? How about books as gifts for Christmas? Did you know you can help PNDU simply by buying books from The Book Depository?



If you click on The Book Depository link on PNDU's [website](#) home page, and buy something from The Book Depository's on-line store, PNDU receives 5% commission! You must use the link on our website however.

An easy way to help PNDU!

Congratulations to our 2018 PNDU Award Winners

Words by Karen

We had the pleasure once again at PNDU's 2018 AGM in August, of announcing this year's PNDU Award winners. This is a very special opportunity for PNDU and our members to say a very big 'thank you' to those who do great work for all living with HPN 'down under'. There are many dedicated people working to improve HPN lives, and it's a privilege to recognise and applaud these people and their work.

So, on behalf of PNDU HPNers and carers, congratulations and thank you to all our winners for your work and dedication. All winners' names are included on PNDU's Roll of Honour (on the [PNDU Awards page](#) of our website) and have each received a special Award Certificate.



Thank you to our Professional Awards judges. This year Prof Gil Hardy was joined by Dr Sharon Carey in this difficult task – thank you to you both. And thank you too to our runners-up and all who nominated.

PNDU's Professional Award winners (judged by our PNDU Professional Awards judges):

- Outstanding Achievement Award – **Dr Andrew Holt**, Intensivist, Flinders Medical Centre, Adelaide
- Adult PN Professional of the Year – **Francine Tanner**, Pharmacist, Austin Hospital, Melbourne
- Paediatric PN Professional of the Year – **Gai Lovell**, Occupational Therapist, HNE Kids Health, Newcastle NSW
- Commitment to Care - Company Employee of the Year – **Mary Dillon**, Baxter Healthcare, Melbourne

We look forward to acknowledging the great work of HPN professionals as well as PNDU volunteers again in 2019.

Below are some short excerpts from the nomination(s) received for our winners:



Dr. Holt receiving his Award Certificate from Annie

Andrew Holt

"[Dr Holt] has been every type of doctor possible through this awful transition from the children's [hospital] struggling to find specialists to care for me... He has been caring, nice and empathetic towards me. Being so young this means more to me than anything."



Francine (centre) receiving her Award Certificate from Renée and Philip

Francine Tanner

"[Francine] is always advocating for me, and speaking to my specialists on my behalf to better my care... She continues to teach me about my condition and living on HPN... She was the only person who understood how scared I was so went out of her way... She celebrates my triumphs and picks me up from my lows. Francine is not only supporting me in my care, but my family also."

"Her ability to ensure patients and carers understand their medical needs, even if they are new to HPN and confused by some aspects of it, means we are all touched by her phenomenal effort."

Gai Lovell

"Gai has made regular home and school visits, identified supports, equipment and home modifications required... Gai has coordinated all the allied health professionals, required..., to ensure minimal appointments (all professionals can be seen on the same day)... the boys enjoy a far better quality of life because of Gai Lovell's dedication and caring nature."



Mary (centre) receiving her Award Certificate from Karen, with team member Francine Lama (left)

Mary Dillon

"[Mary] has been an outstanding consumer liaison, genuinely listening to what PNDU has to contribute, assisting Baxter to take on board PNDU's matters of concern, and where necessary, assisting towards a mutually satisfactory outcome on matters... I know the significant time and effort she has put into making [the HPN Awareness Week] pharmacy tours a success."

The Search for a Suitable Medical Play Toy for PNDU Children

Words by Chris

When you are the parent or carer of a child with a complex medical condition, you face many challenges each day. One of those challenges is having to continually explain your child's condition, not only to close family and friends, who, over time, may begin to somewhat understand your child's condition, but also to other people, who just don't have any idea of the challenges you face, let alone begin to understand. It's human nature to be inquisitive and when we see something different, we want to know more.

How do we simplify the explanation when the person asking has no background knowledge of the complex medical condition, or no understanding of the many different prosthetic medical devices our children have attached to them? What if the people asking are children themselves? What if it is your child asking why am I different?

When confronted with this situation, there are no simple answers or explanations for adults and there had to be an easier way to help a child understand.

A little bit of research indicated that there was a great benefit to children from engaging in medical play, especially if the child had an interactive toy that helped explain their condition, but where could we find a medical play toy with such rare prosthetic devices, that closely resemble the medical devices required for children living with Intestinal Failure requiring Parenteral Nutrition? It seemed like a quest for the holy grail.

The solution to our problem was found in the UK. The International Children's Ostomy Educational Foundation (ICOEF) UK. A charitable organisation set up by Liz and Phil Prosser in 2011. Gastronaught puppets were being manufactured with bespoke medical devices to closely resemble those of children with bowel and bladder diversions. Liz and her organisation were more than happy to make bespoke puppets for PNDU children and include a central line in their range of products. The QLD Stoma association were already importing Gastronaught puppets into Australia and a supply agreement was set up between QLD Stoma, PNDU and ICOEF.



PNDU placed their first order in June 2015 and, despite a misunderstanding with custom officials, resulting in the first order being destroyed, soon member children under 10 years of age started receiving a very special gift from PNDU; a new interactive play toy with medical devices that resembled their own, a new HPN friend who could help explain their complex condition and share their daily life, living with Intestinal Failure and Parenteral Nutrition.

Another order was placed and more PNDU children were excited to welcome their new HPN friend into their family. It seemed PNDU had found the holy grail. Unfortunately, from February 2017 things started to get complicated, our puppet friends started to go missing in the European postal system and more were destroyed by customs officials. When the one puppet order was eventually lost four times, a total of sixteen puppets, it was no longer viable for PNDU or ICOEF to continue supplying Gastronaught puppets, a new local toy supplier had to be found.

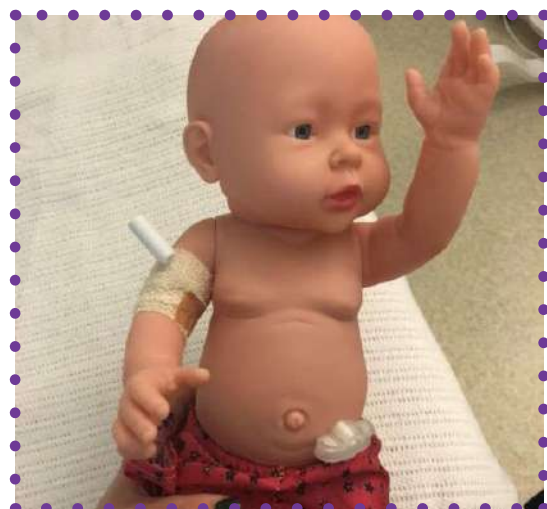
PNDU are happy to have found a local Australian manufacturer, [Just Like You Dolls](#).

Just Like You Dolls have worked closely with PNDU over the past few months, to develop additional prosthetic medical devices that closely resemble those required for Intestinal Failure: central lines with a choice of single or double lumen PICC Lines, and Mic-Key gastro buttons; as well as redesign their nasal gastric tubes. They also offer stoma bags and PEG feeding tubes. These medical devices can all be attached to the JLYD range of products. The wonderful owner and manufacturer, Jade, delights in making these amazing toys mirror each child's situation, 'Just Like You'.

PNDU are now proudly supplying these new medical play toys, free of charge, to eligible member HPN children under 10 years of age. The responses and photos from the recipient families tell the story of how delighted our children are to welcome their new HPN friend into their family.

Hayley writes:

Thank you so much! Noah loves "Tom". He's looking after him while we have an unexpected hospital admission....Thanks PNDU! They will certainly get up to some mischief together that's for sure! Such a great idea. Thank you again."



Noah's Toy Tom

Shannyn writes:

Konrad loves his 'just like me doll'. At first, he didn't want to touch the lines as he knows he isn't allowed to touch the ones on his own belly, but after mummy said it was okay, he wouldn't let him go!



Konrad with his new friend

Audrey writes:

Chandler loves playing with Joey (his doll) and was playing pretend shop with him in the photo attached. Thank you PNDU for organising this.



Chandler and toy 'Joey'

Carol writes:

Thank you so much for the baby doll!!! It's perfect.

I plan to save it till Xmas and make a wardrobe of clothes for it in the meantime.

I'm sure she will love it! (Hallie's grandmother, Carol)

Eileen writes:

Thank you, PNDU. Mayana's baby arrived today. She loves her and has named her Lilly. Mayana is in hospital, so has good company.



Mayana and Lilly

Jessica writes:

Ilah was very excited to open her gift once it arrived. It took her awhile to remove the wrapping paper but eventually she got to the box. Her first words were "mum, she looks like me". The message on the box itself was very sweet and it honestly made my day! Ilah was mesmerised by the doll's lines and compared them to her own. She was very quick to undress the doll to have a good look at what was underneath! We are very, very thankful for her new toy, so thanks so much to everyone involved for her gift.

Here's a photo of Ilah & her new little friend.



Ilah & her new little friend

Lauren writes:

Thank you so much to PNDU for Dom's new little man from 'Just Like Me Dolls'.

He's so fascinated with this toy, complete with central line, g-tube and stoma, just like Dom.



Dominic and his new friend

HPN and the Birth of Kelly's Business

Words by Kelly

My name is Kelly and I live in Western Australia. I have been on HPN (Home Parenteral Nutrition) for 18 months now. Prior to this, I was on intestinal feeds, which I failed at miserably.

My story began many years ago, but as my symptoms slowly got worse, constantly being told I had gastro... the GP decided to do an ultrasound to check for gallstones as the pain, bloating and continuous bouts of gastro were so frequent. The scan showed I didn't have gallstones, but instead kidney cancer and a bonus lump on my gallbladder. They thought they had found the cause of my stomach problems.

Shortly following my partial nephrectomy, it was clear that the cycle of vomiting, bloating and pain were still occurring. My GP arranged for me to have some scopes done. I battled with the prep, vomiting most of it back up. Despite this, my stomach was over half full of prep when they did the scope. More surprises were found in my colon- multiple polyps and one much larger mass too. Now they were sure they had found the cause of my ongoing stomach issues. I was booked for a subtotal colectomy.

Following the surgery, I failed to successfully progress back to food and fluids. I kept getting obstructions, and my symptoms were worse than ever. After a month or so, I went onto PN for a few weeks as an inpatient, trying to figure out what was going on. I was transitioned onto NJ feeds and had a Peg placed - diagnosed with gastroparesis. Despite this, I still didn't tolerate the feeds and would vomit them back.

I am immunosuppressed due to a genetic fault and rely on regular blood infusions of Immunoglobulins, but being so run down, I developed Aseptic Meningitis some months later. During this admission, some further testing showed that the jejunal feeds were tracking back to my stomach, which I then would vomit... so I was put onto PN for home (HPN). It took another year before I was diagnosed with Chronic Intestinal Pseudo Obstruction along with the Gastroparesis.

Looking at photos going back to even before my children were born, I would take pictures of my stomach when it would swell up, making me look pregnant... now I know what it was all along, just slowly getting worse as the years rolled by. The positive to my CIPO and Gastroparesis is, that if I didn't have these conditions, my cancer and all would never have been found. These don't tend to show any symptoms until it's too late. It sucks not being able to eat or drink, and rely on HPN... but at least I get to live my life and watch my children grow up. My aim is to grow old and grey with my hubby.

I have spent a lot of the past few years in and out of hospital. From surgeries, to infections and everything in between. During this time, I held down full-time employment, but once it reached a level of 50/50 being home or in hospital, it was impossible to continue in my job.

My husband and I purchased a laser machine at the end of last year and my business, Custom Laser Crafts was born. I quit work in January this year and have put all my efforts into my little home business. I make personalised chopping boards, cheese boards, glassware, lamps, dog tags, cake toppers and more. People come to me to have decorations for weddings and other special occasions made.

I am busy and work most days, having recently added an additional laser machine to my collection. If I am having a 'bad day', I can take the day off. Being home, I can do IV Antibiotics as an outpatient, instead of more horrible hospital stays (I hate being in hospital!). I now have the flexibility to work when I feel well enough to. My job is also very rewarding, working with my customers to come up with designs that have a deeper, more personalised meaning to them, at affordable prices. My products are all over Australia, with some items even making their way to the UK!

I can be found on Facebook.... [Facebook.com/customlasercrafts](https://www.facebook.com/customlasercrafts)



The Power of a Picture

Words by Chris, Jordan's 'Pop' and a carer

They say a picture is worth a thousand words.

We all take many photographs over the years; most photos are just happy snaps, but, to us they are irreplaceable memories, kept safe in photo albums and frames as a pictorial record of the lives of our loved ones.

In some cases, for reasons that are not always obvious to us, one photo will capture a moment in time that appeals to a wider viewing audience. This photo of Jordan seems to have had that effect.

As an advocate and active campaigner for rare diseases, I have shared stories and photos of Jordan's rare disease journey, with many rare disease organisations. Always hoping that one day Jordan's story would help to bring about change for those people, who like Jordan live with a rare disease.

In 2016, I submitted this photo of Jordan in the EURODIS rare disease photo competition. (EURORDIS-Rare Diseases Europe is a unique, non-profit alliance of 810 rare disease patient organisations from 70 countries that work together to improve the lives of the 30 million people living with a rare disease in Europe.) Although the photo didn't win the competition,



polled very well and attracted the attention of many rare disease patient organisations around the world. In Australia the photo is now used by Rare Voices Australia, to help promote the 'Fair for Rare' patient campaign. (You will find Jordan's Photo at the bottom of the home page www.fairforrare.com.au)

In May 2018, I received a request from the communications team at EURODIS- Rare Diseases Europe, on behalf of the European Patients Forum – a non-profit federation of patient organisations that work closely with EURODIS. The European Patients Forum (EPF) were in the process of creating a brochure that showed the impact of EPF activities, and the EPF believed that Jordan's photo told a powerful story of how a patient's life could be impacted, without the need for words to describe the picture. Of course, we agreed.

Jordan's photo now appears in the EPF Impact report 2018; the EPF represents the interests of 150 million patients and carers in Europe.

The power of one photograph!

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: **Choosing the Right Central Venous Catheter for Parenteral Nutrition** :
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Dejan Micic, MD, Carol Semrad, MD and Vineet Chopra, MD, MSc
Summary by Karen

Below is an amateur summary of a really interesting 2018 article that appeared in the American Journal of Gastroenterology (July 2018 <https://doi.org/10.1038/s41395-018-0203-8>), and has been shared with us by PNDU's friend, Dr Vineet Chopra. The full article appears with permission on PNDU's website (<https://pndu.org/dashboard/clinical-info/>) and has some interesting history, and evidence-based facts about various catheter type risks. Thank you Dr Chopra and co!

Micic, Semrad and Chopra have written Choosing the Right Central Venous Catheter for Parenteral Nutrition as a guide for gastroenterologists. While it is a medical article, with numerous citations of evidence-based studies, the language isn't overly technical, the article is short, and it is a great read for anyone on HPN or with an interest in HPN.

The authors start with a brief summary of the history of Parenteral Nutrition (PN) delivery and explain that a Central Venous Catheter (CVC) with the tip leading directly to the heart (superior vena cava (SVC)/right atrium) is needed for PN because of its concentration. Advances in CVC production material and sterile insertion techniques, they explain, have contributed to increased use of PN in hospital and long term, at home (for Intestinal Failure). However, they note that choosing the right CVC, its location and insertion remain important factors in minimising risks.

Micic et al go on to describe what CVCs are now made of and stress the importance of understanding a potential CVC recipient's full medical experience, what the CVC will be used for and for how long. This is followed by general descriptions of the various types of CVCs – tunnelled CVCs, PICCs and implantable ports (ports) – what each is best used for, and the advantages and increase in possible complications with each type of CVC. With tunnelled CVCs, which the authors explain are good for long term therapies, there is a decrease in possible thrombosis, but an increase in possible malfunction of the CVC. PICCs, they explain, have the advantage of nurses being able to insert, and lower costs, but an increase in possible thrombosis. And lastly, the authors explain that ports are best used for periodic infusions, whereby they provide a lower infection possibility and better opportunities for pursuits like swimming. As an aside, they mention that port use for regular PN has also been shown to be safe.

There then follows a more in-depth look by the authors at the various aspects of choosing a CVC specifically for PN use, starting with, again, the importance of considering the patient's medical situation, and the purpose of CVC use, in balance with the pros and cons of each CVC type. Also for important consideration, Micic et al explain, is the number of lumens, with single lumens being preferred in order to avoid an increase in possible thrombosis and central line infection. They describe why it's better to avoid ports for PN (the

needle continually in, with an increase in possible infections, and the difficulty involved in removing a port) and why PICCs are better for PN usage of less than 3 months, as long as there are no pre-existing thrombosis risks. The authors explain that for long term HPN, PICCs have a greater tendency to shift as they don't have a cuff, and it's difficult for patients to connect up by themselves with it being in one arm. For "... longer-term or life-long PN, single-lumen silicone tunneled catheters are favored..." is Micic et al's advice. Regarding the placement of a CVC for PN, the authors explain that, in contrast to the inferior vena cava, having the tip at the meeting of the SVC and right atrium reduces the possibility of thrombosis and infection. IF the SVC isn't an option, they advise of reports of translumbar, transhepatic and tunnelled femoral options for PN. By tunnelling a CVC under the skin, they explain that the possibility of infection and CVC movement is reduced, the CVC can be less obvious under clothing, and the patient can look after it his/herself.

Next, Micic et al describe the things that can go wrong (positioning, functioning, infection, and thrombosis-related)! Central line infections, they explain, can have various causes, but can also indicate inadequate CVC care. The authors explain that the greatest infection risk to the CVC is from the skin, so appropriate skin preparation products and dressings should be used, with specific recommended branded products listed. Good handwashing and cleaning of the CVC access point with 70% ethanol and saline lock when not using, they explain, will all help reduce the possibility of central line infections.

In conclusion, to minimise CVC problems with PN, Micic et al again stress the importance of carefully considering all aspects: duration; patient experience of bloodstream infections and thrombosis; CVC type; and tip location. They also iterate their recommendation for single lumens, PICC (if suitable) for short term PN, and tunnelled CVC for longer term PN. Meticulous care of the CVC; appropriate patient education; and the CVC never being used for blood draws or other infusions, they explain, have also been shown to reduce the possibility of problems. The authors finish with: "Application of evidence-based principles has the potential to improve both safety and quality of PN delivery."

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: **Emily's Story, Part 2** :
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Editor's Note: Last issue we read Emily's story of how she was approached by a doctor, who she calls Dr CP (because of his perfectly creased pants) who wanted to do a motility exam, something Emily had undergone, with bad memories of it, in the past. Not everyone's HPN/IF journey is easy. Here's one of Emily's experiences that shows just how difficult the journey can be for some.

"Here I am for this long-dreaded exam. I don't want to do it, I really don't want to do it. I could, in fact, I could just flee the scene! I could make a run for it right now, I mean, I'm AN ADULT so I do what I want," I tell myself.

But, as we all know, being an adult is really about doing the things you don't want to do. So, I went in. I'm ready for a hell of a bad few days. But, unlike last time [a test which Emily was told would last for 6 hours, but took 18 hours], the test will only be 6 hours, so that can't be too bad.

I go into the procedural unit and am promptly visited by the nursing staff to begin paperwork. It is only then someone explains to me that the test won't start until the next day after all the anaesthesia is out of my system. This means that, yes while the test is still only 6 hours long, the sensors are stuck in my body for at least 30 hours! Just to be clear, I don't care if the sensors are on and actively measuring or crunching numbers or whatever - I care that they are in my body! Already, this is going badly.

Before going under, Dr. CP (his pants are still suspiciously crisp) stops by and I make doubly sure that thanks to nerd advances in technology, this test will only take 6 hours once someone presses the 'on' button. I'm already questioning if this is someone I should trust, given the lack of the 'informed' part of the informed consent. It was more like a vague consent. I even go so far as to explain to him how earlier tests took much longer with me. With confidence, he assures me that even if he doesn't get full results after 6 hours, he will end the test.

Honestly, fool me once shame on you, fool me twice, well, shame on me. But I'll get to that later. I go under the anaesthetic, I come back up, I got the sensors, hell has begun. Let me paint the scene for you. I actually cannot get up out of bed and I'm stuck like this for the next 30 hours and I'm groggy from the anaesthesia. Oh, and I couldn't sleep...not that I wasn't allowed to sleep, I just couldn't. I don't know why. I don't notice it at first, until I realize that my hands and legs have gone all pins and needles. The warden sends in someone to do a neurological exam to see if I've had a stroke (lol, as if) and determines I'm having an ANXIETY ATTACK. They give me literally the weakest medication they can because most benzos can affect motility. So that entire night I didn't sleep, which has never happened to me before; even during my most stressful nights I have never gone completely without at least two or three hours of sleep. A definite factor was that hospital rooms are never completely dark, what with the computer and monitors and flimsy curtain putting in a 5% effort to keep out the light. Every hospitalization is stressful, simply because I lose sleep.

The next day at 7am I ask my nurse to put a sign on my room's door stating that from approximately "8am to 8:15am DO NOT ENTER – IMPORTANT CALL IN PROCESS". I actually had a phone call with an HR department in regards to a job, which I scheduled naively thinking my request to be left completely alone for a whopping 15 minutes would be respected. I hounded my nurse reminding her all evening the day before. She told the entire nursing staff. But lo and behold at 8:01am there was a knock on my door because nothing is sacred, not even the patient. So there I sat, arms crossed in my bed, on a call with HR while two beefy guys with a wheelchair stared at me for 15 minutes straight trying to coax me to come with them. I simply turn my head anyway from them. No, I didn't get that job.

The test was pretty straight forward until the very end. I watched movies while counting down on the clock. I was sleep deprived, offended, and angry. The second the sensors were removed, I was going to bolt. In the last 30 minutes, five people come into the room, one of which is Dr. CP. They're looking at the results when Martha, Martha, someone who called me three times prior to this procedure just to confirm my medication list three separate times, starts telling me about how I should start doing enemas once every three months.

I look dead into her eyes and say "I'm going to let you know right now, that's not going to happen." Martha, Martha, turns to Dr. CP and says, "Oh, this could result in colon cancer, right?" and cocks her head back at me when Dr. Literally-Too-Busy-For-Patients-CP hastily confirms without so much as looking up at me. Me, as an intellectual who does not respond to threats, replied, "Then I guess that's how I'll go." If I never see that woman again it'll be too soon, because how dare you suggest I do an enema every three months while I've been stuck on my back, vulnerable, sleep deprived, for 30 hours.

They leave and soon after the tech comes in and says Dr. CP wants an additional 3 HOURS!

Honestly, as I write this, I am reliving this horror. Where the hell is he? How DARE he! You're gonna hide behind a tech? We had an agreement! What do I do? I'm this far in, if I pull out now will I have to repeat this entire fiasco? WE. HAD. AN. AGREEMENT.

That was the moment I snapped, I kid you not. I started screaming. Actual screaming bloody murder. Two more nurses rushed in, trying to assure me that it wasn't that bad. I calmed down long enough for them to leave and started hyperventilating. I called my dad screaming, I couldn't even get my words out, "I...can't...do this. If I die then I die, that's it, this isn't worth it." I scared him. Once I finally explained everything that had happened, he was infuriated. He's a doctor himself and was ready to call up the director of the entire hospital, a card he NEVER pulls. Martha, Martha, was what shook him the most. I told him not to. I said it was all too late, I don't know what I meant, and yet I still do. I was mistreated as a patient, it happened, it was too late.

I made it another 2 hours and 30 minutes before I lost it all over again and started screaming. The head nurse came in this time and I told her I wanted out. She told me she could remove the sensors in ten minutes, because she needed an aide, and I told her it absolutely had to be exactly ten minutes, not ten minutes starting in two minutes, not maybe ten minutes. She, apparently the only trustworthy person of the day, glanced at the clock and said it would be now only eight minutes. The nurses were the only people who really took care of me for the whole duration of my stay; only they heard me.

On the Uber ride home, I thought about flowers. There was a flower bed near my old college dorm. Someone would walk by, see how beautiful the flowers were, and take a petal from one of them. Then someone else would walk by, see how vibrant the colours were, and want a petal too. Not wanting to disturb the other flowers, they'd pick a petal off the flower already missing one because, well, it's already been taken. The next person would do this, and so would the next, until you'd see this bush of flowers, with one barren, ugly flower without any petals left. Because everyone else took them. Why that flower? Why not any other? Simply, bad luck. It was chosen first.

Dr. CP, he was the one who wanted to improve my horrible, horrible life. My life he didn't know, or ask about, the life he saw in a chart somewhere. But as someone living with intestinal pseudo-obstruction, I'm actually high functioning in comparison to the norm. I live independently, I attend college, I take care of all my medical needs. He didn't want to improve my horrible life because it wasn't horrible. He wanted to improve my life because he wanted an impressive case on his record. Whether it was putting me on an experimental drug to increase motility, placing a pace maker in my stomach, or removing my ostomy and using my small intestine as a colon as well. It wasn't about me. I was a Rubik's cube, an opportunity for a shiny gold star on his lapel. I allowed it. What I've learned is that I am a highly specialized patient treated by individuals in a highly competitive profession, and there are professionals there for all kinds of reasons. Some really, truly do want to help people, and some have other goals. Bedside manner matters and your gut reaction to someone matters too. Being told I have a low quality of life by a stranger should have been the first warning sign.

The biggest lesson is that now I have no reservations about telling a doctor where to get off. I will never let anyone let me feel like that again. I don't care if you're the head surgeon or if you're a doctor with degrees from five medical schools. You may be an expert in intestinal physiology, but nobody is an expert in me but me. If you don't treat me right, you don't treat me at all.

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: **Hospital Meals for Carers** :
: :

Words by Belinda

When I was stuck in the hospital for 9 months, it was hard to come up with meal ideas for myself, let alone actually being able to afford take-away, so I came up with this list of meals. Easily cooked with a microwave and a few basic ingredients.

EASY HOSPITAL MEALS:

Baked Sweet Potato or Potato

- Can use Baked Beans
- Also do a Salsa version with sour cream
- Single rice meals e.g. Uncle Ben Tomato and Basil Rice
- For meat add chicken, ham, or dice up some other meat

Corn Chips

- Salsa, Sour Cream and Chicken
- Baked Beans
- Salsa, Sour Cream and Mince

Cold meat and salad

- Baby Corn
- Baby Cucumbers
- Tiny Tomatoes
- Tiny Capsicum
- Pineapple
- Baby Spinach

\$3 On the Menu Meals (Coles) with a side of steam microwave vegetables

Risotto

- Cook in stock
- Add chicken or ham and a side of vegetables

2 min noodles (or equivalent)

- Add vegetables and diced meat for an easy stir fry

Eggs (such a versatile microwave meal)

- Omelette – add vegetables and bacon with grated cheese
- Scrambled Eggs

Stuffed Capsicums

- Filled with Salad
- Single sachet Rice Meal e.g. Uncle Ben's Tomato & Basil Rice

Salmon

- Add vegetables and rice

Fried Rice

- Add ham and vegetables

Chicken Fajitas

Soup

- Potato Soup
- Pumpkin Soup

Quesadillas

Toasted Sandwiches

KITCHEN STAPLE TRAVEL PACK:

- Own Cutlery
- Small Tongs
- Sharp Kitchen Knife – I picked up a lockable one so it didn't have to go to the nurses station
- Large Plastic Microwave Mug with Lid – I use Sistema To Go Soup
- Microwave Plate
- Toast Bags for Toasted Sandwiches

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: "Some days are diamonds, some days are stone, :
: Some days the hard times just won't leave me alone" -Dick Feller :
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.....

Words by Belinda

In July 2016, Aidan went to Sydney for an outpatient clinic appointment, with Gastro and Surgical/ Urology. Aidan had just completed a stay in our local hospital for a UTI, where he was discharged on IV Antibiotics. The Gastro team were concerned as he can't digest properly, so the plan was to admit him to the Children's Hospital for IV antibiotics for 5 days. We had nothing packed for a stay and we were 5 hours from home. I also had plans for the next few weeks as my husband had only had surgery in April and was seeing specialists, trying to get full function back in his leg plus we had all of Aidan's appointments. I spent a good few hours ringing everyone and cancelling everything we had on. Shane (husband) decided to stay home as it was only going to be a week.

It was during the first week, Aidan had a full-blown stomach bloating episode, these can range from 70cm up to 85cm in circumference. We had seen these heaps of times over the past few years so as a parent I wasn't overly concerned by them. This was the one time that we were made aware of the fact that these episodes were actually restricting his breathing and were actually quite serious, despite numerous hospital admissions in our local hospital who had assured us it was normal for Aidan. Surgery for the Gastrostomy was discussed as was the need for an Ileostomy, in the meantime, a lot of tests were run and a Nasal Gastric tube was inserted. It was starting to look like a bit longer trip than one week but no one could tell us what to expect or how long.

Aidan ended up in isolation originally due to his inability to cope and his meltdowns that he kept having, but after the surgeries, he developed Klebsiella, which developed into Extended-Spectrum Beta-Lactamase (ESBL). This is a superbug that cannot be completely cleared from the system and as such you remain colonized and isolated for life with it when you are admitted to the hospital.

With the help of hospital volunteers and child life therapists, we decided to decorate the room and give Aidan a feeling of homeliness and he was getting extremely homesick and lonely. We used wall decorating stickers, a digital photo frame from home, pictures from magazines, his drawings, cards that had been sent to us, and items from the packages sent from school. One of the volunteers was really good at drawing and would often come into the kid's rooms and draw on windows and whiteboards for them, Aidan had a large glass window that was transformed regularly into all sorts of different designs. We were in the hospital for just over 3.5 months, and on discharge, we went home with several boxes and suitcases, I think from memory it was 4 -5 boxes, 2 large suitcases and a couple of backpacks.

After returning home Aidan's gastrostomy started to play up again, we were in and out of the local almost weekly with electrolyte imbalance due to heavy losses from his stomach. After 2 – 3 weeks of this we were airlifted back to Sydney for review. This lasted over 4 months – our Christmas holiday was cancelled, his birthday and Christmas with family and friends was cancelled. He was devastated, the NUM organised with the help of the hospital an Xbox with games for him and with the help of Starlight Captains, we managed to have it hooked up so he could play it.

Once again, we decorated his room with the help of volunteers, Starlight captains, nurses, and child life therapists. We had a variety of Birthday decorations, pictures from magazines, posters, and Christmas decorations. One of the nurses suggested we get him Nerf guns and set up targets for him to shoot at to get rid of frustrations. Though I wasn't a big fan of weapons and guns, after talking it over with Dad we decided to get him two small guns, which somehow got bigger over time. We had a large number of nerf guns which were given to him and we would often go out to the basketball court nearby and play nerf wars. At one stage we had several nerf guns, this resulted in many nerf wars between staff, Starlight captains and volunteers.

During these 2 admissions, Aidan ended up with over 10 surgeries in total, a Gastrostomy, Ileostomy, Jejunostomy, PICC line (which was removed during the first admission), and a Hickman Central Line. We also had over 15 tests – not including blood tests and several infections. We left the ward in March, heading to Bear Cottage Respite for a week of adjustment. Once again, we headed home with lots of boxes (Shane had already taken home a full car load of gear already), 2 suitcases, backpacks and other bits. I have also decided travelling with a large body pillow and 2 blankets, was not clever!!

We all thought after this trip we would have time to settle down and try to find our normal. Three days after returning home, we had a stoma prolapse and were back in the hospital in Sydney for another 2 weeks. I didn't do a lot of decorating this time though, as I was just so exhausted from everything.

We have a folder now at home with photos, pictures, and other bits



can use when he is in hospital. I have a suitcase packed ready to go with his consumables we can't get in the hospital.

We also have a favourite blanket and cushion which go with us every trip, I am trying to be more organised and get a doona everyone can add messages to so that he can read through the messages when he needs a pick me up.



• Making long hospital stays more personal •

Words by Gillian

Aiden, one of our 10 (now 11) year old members, had these decorations to improve the look of his hospital room. This colourful display and cartoon would certainly brighten his day somewhat.



Aiden's Room

Karen:

During my most difficult ClubMed admission, my family went about putting up photos of friends and family all over one wall, creating 'Karen's world'. They asked friends and family to send in photos, drawings, etc and they all went up on the wall. It had an incredible impact on me, and helped me to remember life beyond that room. My dripstand also became 'Stan the Man' with a face on it. I wouldn't want it every admission, but it was very important that time. It wasn't quite redecorating the ClubMed room, but it did make it more human for me.

Teresa, a past member who sadly died in 2017, brightened up her hospital stays by getting permission to have her young cat, Victory, spend time with her. What compassionate nurses and doctors!

Gillian:

When I had my major operation, I ended up spending 2 months in a private hospital, then 1 month at the public hospital to be trialled on, and later trained in, HPN. This all was very unexpected, to say the least, and I found it helped having a personal touch to connect with my life outside. I asked my husband to make a copy of a recent family photo and have it enlarged, so blu-tack on my wall. Then over time I ended up with about 2-3 dozen cards on display plus hand-drawn cards from one of the kindergarten classes that I taught (I was an ESL teacher until retirement a couple of years ago). There were so many cards that one of the nurses taped cords across the window and put the cards on these to display them – so thoughtful of her, and such a lovely effect. I think I took photos, but they are 'lost' somewhere on my computer!



My family photo – 12 years ago. I'm about 8kg skinnier now!

Emily's Backpack Saga

Words by Emily (an American HPNer)

Editor's note: Backpacks have been discussed on our email group in the past. Just remember to check with your medical team before changing from the one provided with your pump, as there may be important reasons why a different backpack isn't suitable.

I've been on HPN for about 20 years and only just now got a new backpack. My last backpack was old. It has stains on it, rips, and this massive hole conveniently the size of my pump, so it was always trying to make a great escape. This was nasty. I have had this exact same backpack for as long as my dog has been alive. A lady never reveals her age, but my dog has a lot of white around her nose! So why? Why didn't I ever change the backpack? I mean, my home health company offered, my parents annoyingly hinted, why? WHY?

Because that backpack was so difficult to get in the first place. Let me explain. There are two kinds of backpacks that my supply company offers. One is black and stiff and honestly, I believe it was made by someone who is definitely not on HPN themselves. Firstly, the PN bag is held up by a loop of Velcro. Velcro! Do you know how long Velcro can hold up my three-litre bag of PN? As long as a command strip can hold up a mirror. Second, there were two flaps of fabric to hold the PN bag in place, but nothing to support it from underneath. I don't know about you, but my PN needs to be refrigerated (lol everyone's PN needs to be refrigerated) so when it leaves the fridge, condensation forms on it, making it slick. This backpack is really banking on that loop of Velcro.

The backpack I had for more than a decade is blue. It was definitely better than the black one on offer, but still left more to be desired. The PN bag was held up by a buckle () and had four flaps of fabric to support it from all sides. It was a little more relaxed fabric, too. There were some extra features that gave me the feeling that the design team behind this backpack was a little more informed and thoughtful, but ultimately, I found some of the features useless, such as a compartment to strap IVs down and extra straps to buckle the backpack around your waist. I'm sure other people might find that useful, but I didn't.

So now I'm 25 and this backpack has been nearly everywhere with me; Australia and Paris, college, up mountains, the beach etc. etc. I still sometimes find sand in it! It's in really rough shape, to the point that throwing it in the wash isn't helping it any longer, but actually damaging it. I can't just ask for a new one; I've tried that. They just keep sending that black kind. I literally have no idea where this blue one came from or how I got it. Furthermore, while it has been helpful for as long as I've had it, it is not a convincing looking backpack. It doesn't look like anything you'd find hanging up on a hook in an elementary school. It looks...different.

What I'm saying is, this backpack is not cute. Where are the cool designs? Where are the sparkles? And that got me thinking...why don't I make my own backpack? Like, just go to Walmart and choose one?

That is exactly what I did.

I went looking for something I knew I was going to have to alter a little bit on my own. I knew I'd have to add a buckle to hold up the PN bag and maybe something to hold the bag in place. I definitely wanted a smaller separate pocket to hold a screwdriver and hand sanitizer and other stuff. I wanted to get one of those cool girly backpacks with the sequins that change colours depending on the direction to smooth them out (mermaid sequins?) but I knew if I had to cut that fabric at all I'd ruin it completely. I found one that was cute AND it had an inside pouch in the main pocket that I think is supposed to keep books or a laptop in place (do kids need laptops for school?) which ended up being perfect to hold the PN bag. The only alternations I made were adding the buckle and I did remove a layer of fabric that separated two pockets to make it one big pocket – plus my little one for my



screwdriver and hand sanitizer.

It was really easy; all it took was a little creativity and really thinking about what I need for a PN backpack. I did this little project with my stepmom and it was a great bonding experience and a way to make it my own.

• • • • • PNDU exhibiting, and presenting TWICE at the 44th AuSPEN Annual Scientific Meeting • • • • •

Words by Karen

We are once again very grateful to AuSPEN for allowing PNDU to exhibit free-of-charge at its [annual scientific conference](#) for clinicians on 30 November -1st December 2018 in Sydney. This is a really valuable event for PNDU each year: to be seen, reconnect with PNDU friends and supporters (clinicians and industry) and meet other HPN clinicians – to promote what PNDU does and how we can help support their HPN patients and carers.



But this year is extra-special! For the first time ever, a PNDU Management Committee member has been invited to present during the conference! Chris, PNDU's Vice President and Treasurer, will be presenting on the Saturday morning on "'I Live with a Drip" Home Parenteral Nutrition – a Carer's Perspective'. But wait... that's not all! PNDU submitted an abstract for scientific poster presentation of our most recent [member survey](#): Swimming Practices and Experiences. Well, it wasn't accepted for poster presentation,... but was accepted for oral presentation! Miranda, PNDU's Secretary, will be giving that presentation on the Friday afternoon.

We are thrilled and are very grateful to AuSPEN for these opportunities for PNDU to represent our members and all HPNers and carers throughout New Zealand and Australia as we give the consumer perspective of 'living with a drip'.

If you are an HPN clinician, we hope you'll be attending AuSPEN Conference 2018, and invite you to come and visit us at the PNDU exhibit.

• • • • • Explaining to little ones how we get our 'good stuff' • • • • •

Words by Karen

Intestinal Failure and HPN is difficult even for adults to comprehend. So when I was approached to be interviewed for the kids' talk at church recently, our dilemma was how to explain it to little ones, the youngest of whom may not understand nutrition, etc, in a way they could understand. My wonderful interviewer friend gave a brief explanation to the kids about how normally, when someone eats broccoli, it gets 'mooshed' up in the stomach and then goes into the small intestines. It's in here that all the 'good stuff' in broccoli is taken out into our blood, and then the blood pumps the 'good stuff' around our body to feed our cells and keep us alive.



I then went on to explain I don't have enough small intestines to get enough 'good stuff' out of food so I can live. Obviously I'm alive, and I can still eat, but I get my 'good stuff'...differently! I get my 'good stuff' in a bag each night. A tube goes from the bag to a needle in my chest and straight into my blood. It's tricky because there are a lot of steps to do it each night, and it needs to be done just right. I have a little pump and I put the pump and the bag of 'good stuff' into a backpack so it can keep going all night. I do that every night, so if they see me in the evening sometime, they'll see me with my little backpack of 'good stuff'.

A Day in the Life of an HPNer: One Problem Leads to Another

Words by Gillian

One of our members posted about this problem on our private email group, and as it is fairly typical of the sorts of run-arounds we cope with because of the complexity of HPN, I thought it warranted as being considered as 'a day in the life of an HPNer'.

Our member posted:

'I know HPN/IF is complex, and we all live with it on a daily basis, but I had another reminder of it recently. Like many here, I've got osteopenia (from pre-HPN days) and it's been quite a balancing act getting enough calcium for my bones without exacerbating kidney stone problems. My endocrinologist also told me long ago that because of the changes at menopause, I would probably need to go onto HRT at menopause to try and protect my bones from further deterioration. So, we are now investigating the options in readiness. The problem is that I'm on Clexane because of DVTs from my CVAD, so I have to see the haematologist to discuss this because the increased risk of clotting (I can't afford to have more DVTs). Also, there is a slightly increased risk of breast cancer, but I can't have mammograms because my port is in breast tissue. So, I need to discuss with my GP alternative screening options. And then it was all hit on the head anyway by my migraine doctor last week, who said HRT would be too risky with my history of migraines + DVTs. So, it's back to the drawing board to look at other alternatives!

I'm pleased that my specialists are happy to look at this ahead of time, and not take the 'let's wait and see' approach. My migraine doctor assured me that he and the endocrinologist will have to try and come up with an alternative. I'm currently the only one on HPN at my hospital, so I'm just really pleased when specialists understand the complexity and are happy to try and work through things.'

UPCOMING EVENTS

25 October	Baxter HPN Coordinator Workshop – Sydney (PNDU will be presenting)
16-17 November	Rare Disease Summit – Melbourne (PNDU will be taking part)
29 November – 1 December	AuSPEN 2018 Conference – Sydney (PNDU will be exhibiting and giving 2 presentations)
1 December	AuSPEN HPN consumer workshop – Sydney (PNDU will be presenting)
2 December	PNDU Annual Social Gathering – Sydney (including 10th Birthday celebrations)
6 January	PNDU's 10th Birthday

Planning Overseas Travel with HPN?

As a founding member of [PACIFHAN](#) (International Alliance of Patient Organisations for Chronic Intestinal Failure & Home Artificial Nutrition), PNDU can put you in contact with sister organisations in various countries overseas (UK, USA, Czech

Republic, Denmark, Italy, France, Poland and Sweden) which may be able to assist with any HPN travel questions in those countries. Just ask us at contactpndu@gmail.com.

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.



THANK YOU

We wish to thank the following for their generous gifts:

A Newbold

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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.)

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