



DRIPLINE



PNDU

Parenteral Nutrition Down Under

I hope you enjoy the latest issue of Dripline, with a mix, as usual, of members' stories and issues, medical information of interest to HPNers and PNDU events to be aware of and maybe become involved in. Read the uplifting story of Jordan's Starlight Wish, see if Laurie's story of cruising with HPN gets you on a boat. From a practical point of view, member, Belinda, has shared her fluid balances chart with us and an AuSPEN member has kindly written an article especially for Dripline on enteral feeding with HPN. Read about HPN Awareness Week '18 and how you can vote for the PNDU awards. Our youngest adult member has written two articles for this issue – one about life without eating (A Day in the Life...) and the other about being a teenager on HPN (Teen Talk). And loads more ...

Gillian – Editor

CONTENT

- [Jordan's Starlight Foundation Wish](#)
- [Alternative Access Sites](#)
- [Two Sydney events for all HPNers and carers – December 2018](#)
- [Teen Talk](#)
- [Cruising with HPN](#)
- [Enteral Feeding with PN](#)
- [Emily's Motility Test](#)
- [A Day in the Life of an HPNer – Food, Glorious Food – but I can't eat!](#)
- [Daily Fluid Balance Chart](#)
- [HPN Awareness Week– 14-20 October 2018 – let's get ready!](#)
- [PNDU Annual Awards – start nominating soon!](#)
- [Birthday Corner](#)
- [Fay's Story](#)
- [A Follow up to how long have you had your line?](#)
- [The Spoon Theory](#)
- [Upcoming Events](#)
- [Planning Overseas Travel with HPN](#)
- [Thank You](#)
- [PNDU Information – membership; giving; contact details](#)

ISSUE 24
MAY – JUL
2018



Jordan's Starlight Foundation Wish

Words by Chris

Spending as much time in hospital as Jordan has over the past 9 years, there is a wonderful place for children to go to get away from the long mundane days spent on the ward. The Starlight Room, a place where children can forget about their problems and treatments for a while, interacting with the wonderful starlight volunteers, enjoying a multitude of activities from singing and dancing, arts and crafts, playing video games or watching a movie. Starlight helps you forget for a while that anything is wrong.

'The Starlight Children's Foundation has a mission: 'to brighten the lives of seriously ill children and their families'. One way in which Starlight does this is through the wish granting program.

A Starlight Wish is a once-in-a-lifetime experience for a seriously ill child and their family.

An incredible gift of hope during the toughest of times, Starlight Wishes help sick kids and their families dream big and leave the pain of treatment behind.

From the moment a child is told their Starlight Wish is to be granted the excitement begins. Dreaming, planning and talking about the wish is a great distraction from treatment and surgery. It's the light at the end of the tunnel that lifts spirits and brings families together.'

A dream come true.

Jordan has always enjoyed wildlife programs on TV, especially Steve Irwin "The Crocodile Hunter" and his daughter Bindi. Jordan would often tell us he wanted to be just like Steve Irwin.

During a long stay in Westmead Children's Hospital, Jordan learnt that Steve Irwin had passed away (before Jordan was born). Jordan was distraught by this news, his hero was gone. The overwhelming emotions expressed by Jordan touched more than just his close family members and a social worker nominated Jordan for a Starlight Wish. When Jordan's wish was granted it wasn't hard to determine what Jordan's wish would be, "Zookeeper for a Day" at Australia Zoo, (A little Steve Irwin).

The proposed date for Jordan's wish coincided with his 9th birthday. A decision was made to keep all the plans a secret and surprise Jordan on the day he arrived at Australia Zoo. The planning process began, and with the help of Starlight and their travel partner Virgin Airlines, all the required medical clearance forms in order for both Jordan and little brother Logan (also on HPN) to fly, were obtained, completed by our medical team and submitted to Virgin Airlines. Suitable HPNer accommodation in a high-rise apartment at Mooloolaba was arranged and booked, complete with enough fridge space for 8 bags of PN. Our homecare company, Baxter were contacted and arrangements made to deliver the boys' PN to the Mooloolaba accommodation. The family were now able to settle back and wait for the great four day adventure to arrive.

On the morning the adventure started, three curious boys Dylan (older brother), Jordan and Logan, realised something special was about to happen as they watched Mum and Dad (Brooke and Mick) carefully packing suitcases, backpacks and cooler bags with clothes, medical supplies and bags of PN, under the careful supervision of Nana (Tanya) and Auntie Katie. Jumping out of their skin with excitement, realising they were all going on a holiday, the repeated questioning continued, where are we going?, what are we doing?, who are we going to see? The surprise of the mystery destination was kept secret.

Arriving at the airport, the excitement of the three boys, Dylan, Jordan and Logan, couldn't be contained. They were bursting at the seams. Dylan and Jordan had flown before and recently had a private behind the scenes tour of how their local airport operated, and so both Dylan and Jordan wanted to be the first to tell Logan what to expect and how an airport operated. Now under the supervision of our two airport experts, Dylan and Jordan, the family were directed through check-in and then through security. Having a letter from the boys' medical team explaining the medical supplies and PN, along with copies of this letter in all the extra cabin luggage, ensured a smooth transition through security. The family were now ready to depart on the adventure of a lifetime.

A special thank you to Virgin Airlines, who made the family feel welcome and comfortable during the flight. Jordan and Logan were given a special treat, being able to sit in the captain and co-pilot seats, proudly wearing their flight caps, after landing at Brisbane and also back in Newcastle; the family were off on their adventure.



Welcome Aboard Virgin Airlines, Captain Jordan ready for take-off

Arriving in Brisbane, the family had a hire car waiting with a car seat fitted for Logan and the GPS programmed to their accommodation. The family drove north to Mooloolaba and settled into their accommodation. The next day the family drove to Beachmere near Bribie Island, visiting the boys' extended QLD family. A wonderful time spent with great grandparents and cousins that they rarely have the opportunity to see. The hours passed quickly catching up with family and soon it was time to return to Mooloolaba and prepare for the next day at the zoo. On arrival back at Mooloolaba, it was a great relief to find the arranged PN delivery had arrived safely and the boxes had been placed in a refrigerator by the apartment staff. The family relaxed and enjoyed the comforts of their accommodation for the night.

The big day finally arrived with an early start, as the family packed the necessary supplies into the car and headed to Australia Zoo.



Jordan the Zookeeper had an amazing time at Australia Zoo -to be a little Steve Irwin for the day was a dream come true for Jordan.

"CRIKEY" was the excited scream from the three boys as the car pulled up at the zoo. Still unaware of his surprise wish, Jordan and his brothers were delighted just to be at the zoo. A quick meeting with the zoo staff revealed this indeed was a special wish; Jordan would be a Zookeeper for the day and the whole family would be involved in the zoo experience. Jordan had a trip through Bindi's boot camp and emerged wearing his own set of khaki Zookeeper clothes ready to escort his family around Australia Zoo!

The entire day spent at the zoo was truly a dream come true for Jordan. Access to all the shows and exhibits, as well as the ability to interact with and feed animals, ensured Jordan's wish to be just like Steve Irwin had been fulfilled, with memories that will last a lifetime.



A very special thank you goes to the amazing 'Di', Social Worker, Westmead Children's Hospital for nominating Jordan for a Starlight Wish; to The Starlight Children's Foundation, for granting Jordan's wish and the wonderful support arranging everything HPNers need to travel; to Virgin Airlines, Starlight's travel partner, for making the flight special for Captain Jordan and Co-Pilot Logan; to Australia Zoo, making Jordan's wish to be a Zookeeper just like Steve Irwin a very memorable experience that Jordan will remember for the rest of his life.



Jordan loved sharing his wish with his family.

THANK YOU CAPTAIN STARLIGHT! From Brooke, Jordan's mum

Jordan would like to say a big thank you to the Starlight Foundation for granting his wish "to be a zookeeper for the day". Jordan had an awesome time away and was grateful to have his family join him. The experience was amazing.

Alternative Access Sites

Editor's Comment: Something that some HPNers fear, is running out of central vascular (vein) access for their CVAD (Central Venous Access Device). Some of PNDU's members have had central veins 'shut down' and no longer support a CVAD to supply their PN (Parenteral Nutrition). Some have been told by their doctor that they are on their last central vein. This article shows what solutions some members' teams have adopted in order to supply them with their life-giving PN.

Please note: This article is not providing medical advice. There may be reasons why these types of access are unsuitable for some people. As always, this medical information needs to be discussed with your medical team.

One member writes about using an A-V Fistula for HPN:

Since 2000, I have had an A-V fistula to use as my method of access for HPN and for my infusions of IVIG (Intravenous Immunoglobulin) for treatment of Myasthenia Gravis. My fistula access is only for those two uses. So, for example, it cannot be used for blood collection for pathology or for giving I.V. antibiotics.

My A-V fistula was created by a Vascular Surgeon but other specialities do the surgery too. A-V means Arteriovenous. It is surgically created in an operating theatre under general anaesthetic. It involves joining an artery and a vein. An A-V fistula is usually used for haemo-dialysis. There was a brief period where using an A-V fistula was trialled at my hospital for HPN. I was fortunate enough to have the opportunity to have a fistula created at that time. Like everything, there are advantages and disadvantages. For me, my immune system does not appear to cope with "artificial" devices such as a PICC or Hickman lines. My fistula is my

own vein and artery joined and so that is a personal advantage. However, there are also artificial fistulas, made from synthetic material, that go under the skin and can't be seen.

Prior to any fistula being created, 'mapping' of one's arms (and sometimes, upper legs) is done to see which area is the most appropriate to use. After surgery, it is a minimum of six (6) weeks before the fistula is able to be cannulated.

I spent time as an in-patient being trained as to the correct cannulation procedures – the same as every HPNer. The crucial point for A-V fistula use, is whether one is willing and able to insert a cannula directly into one's self. (Having never had an implantable port, I don't know how this differs from accessing a 'port' for HPN.) The cannula that I use is a 20G (25mm) pink Saf-T-Intima™ cannula, so relatively small and soft especially when compared to dialysis cannulas. However, my only available fistula site is my right arm and I am right hand dominant. I was taught how to cannulate left handed – in a way it is back-to-front and up-side-down! Being right hand dominant; using my right hand and arm constantly, and in years past for heavy work, made my AVF very prominent. Like every HPNer, there are sterile and aseptic techniques for cannulation procedures. As with all "devices", it is possible for an A-V fistula to become infected. Except the AVF cannot be removed!

The point where the vein and artery join is called the anastomosis. Touching that site gives a "buzzing" sensation called a "thrill." That "thrill" must be present as a sign of a functioning fistula. There are other significant "fistula words." For example, a "bruit" is the whooshing sound of the blood flow heard through a stethoscope.

My fistula has been surgically revised several times, including for an A-V fistula "steal" i.e. where there has been insufficient blood flow. Recently, after 18 years, my fistula was revised because the blood flow was too high and was significantly affecting my heart and blood pressure.

As with every type of access, positive and negative aspects abound, especially with long-term use. Overall, in my circumstances, an A-V fistula has been the best option for me.

**Acknowledgements:
Metro South Health
Dept of Nephrology
Patient Health Brochure A-V Fistula/Graft*

Editor's Comment: *There is also an article written by a member in Dripline, Issue 4, called 'What are AV Fistulas?', which can be accessed on our website under 'Resources', 'Dripline Newsletter' <https://pndu.org/>*

Fay writes of Femoral Vein access (read all of 'Fay's Story' in this issue)

My PN has been delivered via Hickman catheters almost all the time, except for a short period when I had a PICC line after a bad infection. All my upper body veins have been used and become occluded, so I now have femoral vein access. This involved cutting into a smaller side vein in the groin then feeding the catheter into the femoral vein and up towards the heart. This vein has been in use now since 2013 and I find it quite convenient to both access, and cosmetically.

Jane writes of Femoral Vein access

Traditional sites didn't suit my body, so after a year of several replacement lines after line sepsis, I had my a Broviac line put in my femoral vein. I've now had lines put in my femoral veins in both my legs over the space of 18 years. Currently it is in my right leg, about 2 inches from my stoma bag outlet. For many years I had infections, but these stopped when I began to lock off with Taurolock™ two years ago.

Another member writes of back access

My daughter has had at least 30 lines, and maybe more, put in since birth. She has had them inserted through her ribs at the back and cut downs on her legs. Lots! The one through the back rib cage went directly into her heart. It wasn't easy getting it in there, but the surgeon managed to. He came out looking 10 years older and I thanked him for not giving up on her. His words were 'I would never give up on her'.

And that is the important part - a surgeon or doctor not giving up. That line lasted for six years. These days they can use ultrasound to find open veins and arteries and a Specialist Radiologist actually puts the line in. My daughter has lots of scars, but as far as she is concerned, they are what has kept her alive for so many years.

Another member writes of an intra-atrial line

My son had clotted off all his SVC and IVC veins by the age of 5yrs old. We were told we really didn't have any other spots left. They did try a transhepatic line, which is put in by an intervention radiologist and the line is fed through the hepatic vein that runs through the liver then fed up to the heart. It is risky and unfortunately it fell out of the heart into the peritoneum. We then got an intra-atrial central line put in and that was done by a cardio thoracic surgeon (they are the only ones who can do it). It is inserted via a Thoracotomy in between the ribs and sewed straight into the right atrium of the heart, so you bypass all the other major veins. This was our last hope. He has had it there since he was 5 and he is just about to turn 16. It's very risky from the point of view that any infection you get in the line can cause endocarditis.

Editor's Nurse

I asked my PN nurse whether a PICC line could be used permanently, rather than as a temporary measure.

Her reply was:

'As PICCs are not implanted or tunnelled with a Dacron cuff, they are not considered a permanent option. In saying that, if the patient has no other option, anything is an option! I have known PICCs to be in-situ for up to 18months. The difficulty with PICCs is their small size, limiting flow rates.

In addition, PICCs take away the use of both hands, and in order to be able to use both hands for set up, etc, an extension set would be used, further limiting the flow rates and increasing connections, thereby increasing infection risk.

Many years ago, I had a patient with a tunnelled Hickman via the Inferior Vena Cava (not the Superior Vena Cava), exiting in the abdomen. Not often seen but it worked for a couple of years for her.'

Two Sydney events for all HPNers and carers – December 2018

Words by Karen

As you will have seen on our recent 'save the date' email, AuSPEN's HPN consumer workshop AND PNDU's annual social gathering will this year be held in Sydney – 1st and 2nd December 2018.

These are not-to-be-missed annual consumer opportunities. The AuSPEN HPN consumer workshop is a unique opportunity to learn more about our HPN from expert clinicians working in the field. The social gathering provides valuable opportunity to meet with others who totally 'get' living with HPN, and learn more about PNDU. And all of this for free! We hope as many HPNers and carers as possible make the most of these opportunities.

We are very grateful to AuSPEN for once again holding the consumer workshop specifically for HPNers and carers. Way to go AuSPEN!!



AuSPEN HPN consumer workshop

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

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

Venue: Sheraton on the Park, Sydney

Register: To Be Advised.

AuSPEN HPN consumer workshop

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

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

Venue: Community Hall located right near Central Station, Sydney (email contactpndu@gmail.com for more details)

Register: To PNDU at contactpndu@gmail.com or (+61)0413715187 by Sunday 18th November

Travel sponsorships to attend the 2 Sydney events

PNDU has two travel sponsorships of \$600 each on offer to PNDU HPNers and carers, prioritising any PNDU members who haven't before attended an AuSPEN workshop + PNDU annual social gathering. If you have attended before, you can still apply.

To apply, please write two paragraphs describing how you believe attending the events will affect your life and send your email to contactpndu@gmail.com. (One sponsorship per family. Travel must be completed and receipts received by PNDU before reimbursement can be made.) And if you're not yet a PNDU member, complete the membership form on our website TODAY.

Closing date for applications: Saturday 18th August 2018

Winners announced: Saturday 1st September 2018

Teen Talk: What is it like being a teenager on TPN.

Words by Annie

Well I think this could be different for everyone but I'll tell it from my perspective.

Firstly, HPN (Home Parenteral Nutrition) is the most amazing thing to ever been invented - it's my liquid gold. My partner in crime. My one true love. My soul-mate. HPN is the reason I'm alive. HPN is the reason I'm thriving. HPN is the reason I'm not malnourished. I'm so thankful for this life-saving medical intervention.

However, HPN comes with lots of downfalls as a teenager and it's mainly socially. It affects the way I dress, go out and it also affects my individuality of who I am.

As a teenager I'm embarrassed to admit I'm sick. I have put up a wall around me where I don't let others in. I don't tell anyone I'm sick. I never told my school mates - I just faded out of their lives because at the same time, they didn't understand. They wouldn't visit me because they were "busy" and I even got messages saying "I should get over myself because what I'm going through is nothing", yet I never had talked about my life-threatening and life-limiting illness. So I'm glad I no longer know those girls. But at the same time, it pushed me further away from wanting to be honest and open about my illness. The last thing I wanted from people my age was pity. So, it's been socially very lonely.

Due to HPN and my intestinal failure, I was unable to attend school for the last couple of years. HPN isolated me from the best part of school - friendships. Instead, whilst my HPN was infusing, I was sitting connected to a pole at the kitchen table, attending an online class once a week. Then spending 6 hours by myself studying for the rest of the day.

HPN has taken away my freedom in many ways. Not only HPN, but my disease has caused me to have lots of tubes, pegs, drains, catheters and stoma bags. This has affected the way I dress. I'm constantly worried people can see my lines or tubes. I can't wear strapless dresses or tops. I can't wear low cut things, because my line is obvious. All anyone will look at is my line in my chest.

It's also taken away my freedom as a teenager. I can't just go out till 3 in the morning, because I have to be home to hook up to my PN. I can't just go somewhere spontaneous with my friends because of my HPN. I can't just hop on a plane or go on a car trip with a day's notice, because of my HPN. It makes me feel like a kid with a curfew. It makes me lose all sense of independence, the most important thing to a teenager. Especially when you're sick, you spend so much time with your parents.

Even though it's socially isolating, thank goodness for online support groups such as PNDU. I've met some of the most gorgeous, supportive, caring and friendly people. I even met my best friend online who also is on HPN. We have been talking for years. She's from warm sunny Brisbane, whilst I'm in little old Adelaide. So, we had never been well enough to meet. We finally met last month and it was the most amazing week of my life! I'm so thankful for the support from all of you in PNDU and especially my gorgeous friend. For the first time in years I felt so happy meeting Mikayla.

HPN has taken away moments when I should be making memories and exploring the world. But I wouldn't be here without it, so HPN definitely outweighs the negatives. I'm so thankful for it. At the end of the day, my life is more precious than all of these problems. They may be a huge nuisance sometimes, but it's given me more time to spend with my family, and that's the most important thing. So even though HPN is a pain in the butt, it's the best pain in the butt I could ever have at the moment.



Mikayla and Annie



Annie and Mikayla

Cruising with HPN (on a private power yacht in the 15 metre range on the west coast of Canada)

Words by Laurie

My wife and I had a recent adventure of cruising among our local gulf islands. I've never considered travelling with HPN as an insurmountable task no matter what the travel form; it just takes planning, so I thought others might wish to hear how we managed this with my nightly HPN commitments.

I have been on HPN for 29 years. I hook up every night for about 10 hours. While onboard a boat of this size, there are usually numerous places to hook up; a head (toilet, wash basin, shower), but the countertop will be quite small by home standards; a salon or dining table – however you may not wish to commandeer

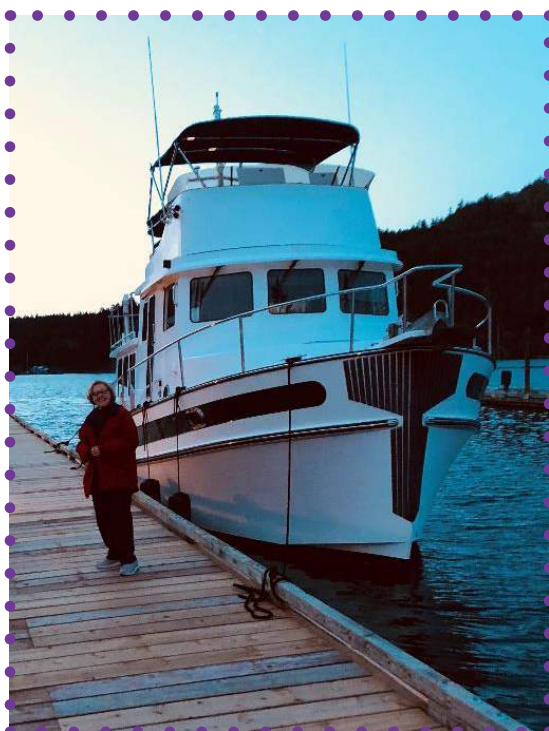
the public spaces if you have, or are, a guest; on occasion I have used a baking dish as a work surface (all 15 inches by 9 inches, or 7 x 4 cm). There is warm water in either the head (washroom) or the galley (kitchen), and you can grab something appropriate to use as your own waste basket. If at all manageable, I would not be hooked up while cruising (on the move), and since I generally hook up at night this is not an issue. If I have a trustworthy mate onboard, I would have no hesitation in pumping saline for several hours while underway. Close friends, those who might be onboard a boat, will have my intravenous feeding regimen explained to them.

It might help to visualize our operating environment if you understand the following. We are cruising in generally protected waters as opposed to open ocean. There are a myriad of islands and inlets on our coast, including an "inside passage" that runs all the way to Alaska. In this case 'inside' means that the route or passageway runs between islands/inlets as opposed to in open ocean waters for most of the way. (There is a web link at the bottom of this article that offers photos and maps of our coastal waters.)

Don't get me wrong, there are places where the winds have a 100 km plus of open waters to pick up a head of steam, and it can present uncomfortable conditions. We generally consider winds of less than 20 knots manageable. If winds are in excess of that, it is not a good time to be out of the marina.

It seems to amaze people that I could get my Captain's certification and pilot a yacht. Let me explain; I've been a boater all my life, so the only issue was becoming comfortable as captain on a boat of this size and type. We hired a skipper, who is also a former charter boat business owner and now teaches boating and the various certifications commercial boaters must have. My objective was to satisfy both myself and he of my skills such that he felt comfortable advising a boat charter company of my suitability to charter one their boats, and secondly that I felt comfortable in command. The three night outing, living onboard with local cruising, was adequate to review navigation, anchoring, engine room operations and troubleshooting, management of electrical alternatives (shore power, generator and battery power) etc, etc. At the end of this process I was much more confident, as was he.

The type of boating I was contemplating and did command was going to be a trawler yacht from 45 to 50 ft (13 to 15 m) in length with two to three staterooms and all the other comforts of home - to a degree. My wish was to see more of our 1000 km coastline and likely continue into Alaskan waters at some point. Ownership, or charter, of a larger boat is a bucket list item which I've avoided pursuing until now, as my enthusiasm for the coast is not shared by my wife. Over my past 50 years of discontinuous boating, I've cruised our coasts inside and outside (east and west sides) of Vancouver Island for all of its 600 km length. My current goal is cover the waters north of this



Laurie's wife, Shirley on board and next to the boat skippered.



Laurie enjoying the fruits of Canadian west coast waters.

to the Canadian / Alaskan border and beyond, into Alaska. This is some of the most picturesque and remote parts of our coast and far less travelled and crowded than more southern waters.

I had reviewed whether it was more practical to try to bring refrigerated PN solutions onboard and maintain them in what would likely be a 2nd refrigerator; or to use non-refrigerated solutions and not worry about the added electrical load of a second refrigerator; or maintaining them in an icebox. Any of these solutions would have been doable for the short term, however, as I contemplated weeks onboard a boat cruising, it becomes much simpler to manage with non-refrigerated solutions. You just need to store them and not worry about temperature (at least in our west coast of Canada climate). Even in a hot climate, if you can move solutions closer to the bottom of the boat where it picks up the ocean temperature this will likely maintain the non-refrigerated solutions at near room temperature.

After this short experience on-board I am feeling confident in cruising up our Canadian west coast to enjoy the scenery of the more remote inlets and passageways that it has to offer.

If you have any questions, or plan to visit our coast, do not hesitate to contact me if you think I can be of assistance.

<http://ahoybc.com/bc-coast/>

Editor's Comment: The following article is an invited contribution from AuSPEN (Australasian Society of Parenteral and Enteral Nutrition) for which PNDU is very appreciative.

.....

Enteral Feeding with PN

.....

Emma Osland AdvAPD
Advanced Dietitian: Specialist Nutrition Support
Dept of Nutrition and Dietetics, Royal Brisbane and Women's Hospital

You've probably heard parenteral nutrition be referred to as TPN – Total Parenteral Nutrition. I hate that term. The reason that I hate it is that unless there is a very good medical reason to make PN the sole source of nourishment, we know that even a little bit of nutrition going into the gut is a good thing, so we never really want PN to be total if we can avoid it.

The benefits believed to be associated with having nutrients come directly in contact with the gut lining (the 'intestinal mucosa') include:

- Maintaining the physiological processes within the gut. This is protective to the liver and the gut lining;
- Preserving immune function in the gut and other organs such as the liver and lungs;
- Reducing inflammation; and
- Controlling the balance of gut bacteria¹.

Some form of oral intake, even in small amounts, is the usual way to ensure the gut is getting some stimulation with nutrition, but there are situations when this may not be safe or feasible. These can include swallowing problems, motility changes in the upper gut (such as gastroparesis), or when parts of the gut are no longer connected after surgery or trauma. In these cases, tube feeding into the stomach or small bowel may be an option to offer the benefits we believe are associated with stimulating the gut with nutrition. For long term enteral feeding, a gastrostomy tube with or without an additional extension tube into the small bowel would most commonly be used to facilitate enteral feeding, though everyone is different and sometimes other options are more appropriate.

For small volume enteral feeding and for all feeds being delivered into the small bowel, pumps similar but different to your PN pump is used to infuse small volumes into the gut (basically the same way PN is delivered into the blood supply). Sometimes faster rates or small volume boluses can be given into the stomach to avoid the need to be connected to a second pump for long periods.

While providing enteral feeding as a supplement to PN has many health benefits, it also brings some challenges with it. Some practical approaches that some of my patients have found useful for reducing the hassle with having two different nutrition regimens include:

- Having your PN and tube feeding regimens run concurrently so that when you come to your break time you're free of any connections and can make the most of your time off infusions.
- If infusing during the day, take advantage of the backpacks offered by most companies to keep you mobile.

I have one patient who has fashioned her own backpack set up to be able to include her PN and tube feeds fitting into the same back pack. (It's quite amazing what you can do with Velcro and zip ties!). This allows her to do the things she needs and wants to do without being tied down to a pump stand. The only down side is that it can be heavy if a new bag of PN and enteral nutrition are hung at the same time (so she staggers them as much as possible).

What works best is different for everyone (because we are all different!). If you are using tube feeding in addition to your HPN talk to your dietitian about how best to juggle what you need nutritionally and what will work best for your lifestyle.

¹Seres et al. (2013). Advantages of enteral nutrition over parenteral nutrition. *Therapeutic Advances in Gastroenterology*, 6(2):157–167. [Accessed at: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3589130/pdf/10.1177_1756283X12467564.pdf]

.....

Emily's Motility Exam, Part 1

.....

Words by Emily

Editor's Note: *Emily is a young American HPNer who spent some time in Sydney in 2015 and attended a PNDU social gathering, as well as cruised on the Hawkesbury with myself and Karen, our President (read 'Cruising the Waters with International Friends' issue 14 www.pndu.org) Emily now writes a regular article for Dripline.*

In December of 2016 I had a motility exam. Another one. I get them, at this rate, about every ten years. It's a test that is known for never going well despite the fact that the test has improved overtime.

Let me explain what a motility exam is.

Let me explain what motility is.

Motility is the movement of your digestive tract. It's how your body moves food throughout your body. It includes swallowing, peristalsis, bowel movements. It's pretty important stuff you'll take for granted until it's gone. Hopefully, that will never happen. In 2006, when I was 13, the motility exam used water sensors. These water sensors were placed into the digestive tract while under anaesthesia, down the throat and up the rectum. The water sensors connected to a machine that would track the flow of the water. How the water moved was supposed to represent how your motility was. And then you just wait on your back. For 6 hours.

Well, if you're lucky. I wasn't. It took me 18 hours. My digestion is that slow. The rule of thumb, determined by my dad, "for however long it takes a person of normal physiology, multiple by three for her." This goes for exams, such as endoscopies, contrast exams, and oral medications.

Party trick: this is also his rule when asking someone how much they've had to drink
But that was the test then. There was simply no end time. The exam was over when it was over. We'll get there when we get there.

In 2016, I was called upon by those-who-know-best saying that I needed another motility exam. "It's important to track the duration of your condition; for all we know, you could have improved over these past 10 years." Hmm, I think I wudda noticed!

I wasn't surprised. My first one was when I was 3 years old. I entered year 23 with apprehension. What I didn't know was that the motility test, unlike me, has changed over the past 10 years. The older version was found to have major flaws that, when at extremes, could provide false negative results. The first problem was that the test began immediately after the sensors were placed. The sensors were placed under anaesthesia, which causes temporary paralysis and, although very helpful when cutting into a person with a scalpel, a little counter-intuitive during a test that measures digestive tract movement. So, the new test doesn't begin until after the anaesthesia wears off. No, not when you wake up. After the last administration, patients typically wake up in 20-30 minutes but it can still affect motility. Nope, the test begins the next day. The test is no longer a same-day procedure. The sensors are placed on day one, the test is on day two. The sensors are different! Ditching this third-party crap, they now use electrodes, which are more sensitive and more accurate. Plus side, the test will take 6 hours no matter how low the motility you have.

So, the new test, despite being longer, is more accurate. A little more bang for your buck. Unless you don't have a buck to begin with like me.

December 2nd I went into the Gastroenterology clinic knowing I was getting the sensors placed. Now, at the time, I did not understand that the test would not begin until the next day. I was simply not fully informed until right before I was given the paperwork to sign and, as anyone who has ever had something as simple as an endoscopy knows, they don't give you that paperwork until right before you go under. This is why it is important to fully explain the procedure and make sure the patient really understands what is going on way in advance. Up until that point I was only vaguely informed by my fast speaking motility specialist. Let me tell you about my first experience with this doctor. I was finishing up my junior year of college and slated to spend the summer in San Francisco, then a semester in Sydney. I was in clinic for my regular appointment with HPN and they asked me if I'd like to see this doctor and just chat for a moment. I really didn't know who he was, why he wanted to talk to me, how he found me, or why it mattered, but I said yes. He came in, pants ironed in such a way that a crease is created down the centre of the leg. (Henceforth I'll refer to him as Dr CP, for creased pants!) Shoes way too nice for a hospital, I seriously doubted if they were non-slick.

"Your quality of life is low, but, I believe I can improve it."

Yup, that's what he said to me. Let's recap. I've just finished my third year at a top tier university, am preparing to spend yet another summer in California at the same neuro-tech company, only this time they'll pay me, and afterwards I'll fly halfway around the world to study in Australia for three months.

This guy is an ass!

Flash forward 9 months...
(To be continued...)

.....
: **A Day in the Life of an HPNer – Food, Glorious Food (but I can't eat!)** :
.....
Words by Annie

Editor's Comment: Annie has written this for Dripline whilst in hospital – many thanks, Annie!

One question I get asked often is what's it like not being able to eat?

Well my usual response is "you just do what you have to" just like when you're asked 'how are you with a chronic illness?', the usual response is "I'm okay" when it can be far from the truth.

I haven't been able to eat for about 3 years now. At first, I was so unwell it wasn't a struggle. One year down the track when things stabilised and I was at home more than in hospital I started experiencing the downfalls. First off, not being able to eat or drink is extremely socially isolating. Most girls my age are going out for a drink every weekend. Most of their outings consist of dinner, brunch or going out to a bar. People stop inviting you because they feel awkward eating/drinking in front of you. When I sit down at a table, I don't feel awkward- I'm happy to be there chatting, catching up on gossip and being out of the house.

Instead, the whole time, people are just apologising for eating. I think we forget how much socialising mainly involves eating/drinking.

The second hardest thing is that I still crave food; I still get hunger pains and I still get boredom hunger, except there's nothing I can do about it. I struggle to sit with my family at dinner time, because I want to eat what they're having. My mouth still salivates and it's a constant battle in my head trying to not touch it. In summer, the incredible thirst overwhelms me. I almost become obsessive about drinking. I'll go for a walk in the sun and all I can think about is the water running from a sprinkler in someone's back yard or the fountain in the shopping mall. All I notice around me is everyone guzzling down an ice-cold drink. Sometimes I get so frustrated about wanting to drink I end up crying. It causes me to be stressed out. No amount of IV fluids can stop this awful feeling. It's almost a subconscious thought.



Annie in Hospital

I miss the routine of eating. Getting up in the morning to make a hot cup of tea. Feeling the warmth in between my hands as the sun rises. I miss cutting fruit up and making smoothies and fruit salads on a hot summer's morning. I miss the healthy routine that I once had. You don't realise how much time you have on your hands when you don't eat. Breakfast, lunch, dinner and snacking take up a big portion of the day.

There are times I give in to eating ...I'm human after all. This usually ends up with me screaming on the floor having to get my dad to pick me up. My mum holds my hair whilst I projectile vomit into a vomit bag. My stomach becomes distended. My stoma becomes blocked. I then spend the next 24 hours dry heaving, throwing up and crying in pain. Even though I know this will happen every time, I still do it. I have no will power to stop, even though, as I'm throwing up, I'm screaming "never ever again" and I do it again.

I also love to cook. I think this is what keeps me sane. On special occasions such as Christmas or birthdays, I find spending the whole day cooking takes my mind off eating the food. I'd rather spend the day baking a cake, even for my own birthday. I have found this helps me cope. Most nights I cook dinner for the family. I enjoy watching their faces enjoying the food I've created each night. I honestly think I couldn't cope if I couldn't cook.

I still struggle with Christmas. I also struggle with going out for dinner. I feel like a restless toddler who needs colouring in pencils and a drawing book. I find it awkward just sitting there, bored out of my brain whilst others spend hours talking and eating. It has gotten worse as time has gone on. I find it a mental battle watching everyone eat food in front of me. I also struggle with family understanding. I think a lot of us who can't eat deal with this. Sometimes the ones I love say things like "I need to get used to it", but it's not that easy. It gets harder as time goes on.

Recently I have discovered chewing and spitting food. This has allowed me to be a bit more normal. I can have a mini plate of food and just chew it, get the taste and then spit it into a spew bag. Yes, it's not as satisfying as eating but it's something. This doesn't always work and can still lead to nausea, vomiting and pain.

So now you have an idea on what it's like not being able to eat. It's one of the hardest parts of coping with my intestinal failure.

Belinda's Fluid Balance Chart

Editor's note: We thought this was too good not to share. PNDU member Belinda has created her own fluid balance chart to record her son's details, and has received many positive remarks from clinicians about her great record-keeping, as well as requests from other carers to use her chart for their child.

NAME	INTAKE (Mark Which Type "As Needed" Meds In Other)							WEIGHT	OUTPUT				DATE	()
	TIME	FOOD & FLUIDS	GRM/ ML	JEJ	IV FLUID	TPN	MEDS	OTHER	TIME	URINE	BOWEL	PEG DRAIN	VOMIT	COMMENTS
	7PM								7PM					
	8PM								8PM					
	9PM								9PM					
	10PM								10PM					
	11PM								11PM					
	MIDNITE								MIDNITE					
	1AM								1AM					
	2AM								2AM					
	3AM								3AM					
	4AM								4AM					
	5AM								5AM					
	6AM								6AM					
	7AM								7AM					
	8AM								8AM					
	9AM								9AM					
	10AM								10AM					
	11AM								11AM					
	NOON								NOON					
	1PM								1PM					
	2PM								2PM					
	3PM								3PM					
	4PM								4PM					
	5PM								5PM					
	6PM								6PM					
	TOTALS								TOTALS					
									TOTAL					
COMMENTS									MLS/KG		Previous MLS/KG			

HPN Awareness Week– 14-20 October 2018 – let's get ready!

Words by Karen

"HPN: our food for strength"

HPN Awareness Week is a wonderful opportunity each year for HPNers and carers, HPN hospitals and industry to not only celebrate this life-saving yet complex life-support therapy keeping many of us alive, but also, as the name suggests, increase understanding and awareness right where we are amongst those most important to us – family, friends, work colleagues.

This will be PNDU's 8th HPN Awareness Week and we have been really excited and encouraged by the growing involvement of members, HPN hospitals and industry friends. PNDU's Management Committee has already been hard at work for a couple of months now preparing resources and liaising with our industry friends to ensure you all have what you need to make this the best HPN Awareness Week yet.

Resources

We will be providing our HPNer and carer members with a video to share, social media profile, Twibbon, example post, stickers, and example newspaper article to write your own story and send to your local newspaper. For hospitals and industry friends, we will be providing an 'HPN AW resource pack' with ideas and information regarding the resources available (including video, stickers, posters, flyers, game).

PN Pharmacy Tours

And once again, we are working with Baxter Healthcare (in both New Zealand and Australia) and Biomed (Auckland only) as they open their compounding pharmacy doors to HPNers and carers, so we can see all that goes into making our life-sustaining Parenteral Nutrition. Biomed welcomes tours any day of Awareness Week. Baxter will be offering tours on the following dates:

Auckland:	Tuesday, 16th October
Christchurch:	Friday, 19th October
Brisbane:	Thursday 18th October
Sydney:	Friday, 19th October
Melbourne:	Tuesday 16th October
Adelaide:	Thursday 18th October
Perth:	Tuesday, 16th October

There will also be opportunity for HPNers and carers to tell their HPN journey to the pharmacy staff. These Baxter pharmacy tours are also open to HPN clinicians. If you'd like to find out more information and book your place now, email us at contactpndu@gmail.com

Keep a look out for more information as we post it about all that's happening for HPN Awareness Week 2018 (plus World HAN Day on 15 October 2018).



PNDU Annual Awards

Words by Karen

Is there someone you think does a marvellous job when it comes to HPN care or PNDU? Here's your opportunity to let them know! This is PNDU's 5th year of bestowing awards on dedicated people nominated by our members. Join with us in celebrating what's great in the world of HPN 'down under'!

There are a few different categories and you can nominate as many times as you like. For the HPN Professional Awards categories, you can even nominate winners from previous years (see PNDU Annual Awards page on our website for a Roll of Honour listing all winners):

- **Lifetime Membership Award** is a special award for any PNDU member who, as an HPN consumer or carer, has given their time "over and above" for PNDU.
- **HPN Professional Awards** recognise positive efforts by health professionals and industry to provide high quality service to HPN consumers (your favourite HPN clinician and/or a helpful soul at your homecare company; you may even nominate your work colleague!). These awards are decided by two independent judges working in the field of HPN. There are 3 categories of HPN Professional Awards you can nominate for:
 - **Adult Parenteral Nutrition Professional of the Year**
 - **Paediatric Parenteral Nutrition Professional of the Year**
 - **Commitment to Patient Care - Company Employee of the Year**



ONLY SIGNED-UP MEMBERS of PNDU (HPNers, carers, clinicians, industry employees, those 'just interested') CAN NOMINATE, so you must have completed the [membership form](#) on our website. If you haven't done that yet, do it today so you can nominate!

And nominating is super easy with a simple on-line form. Nominations will open on Tuesday 17th July, closing 3 weeks later on Tuesday 7th August. All winners will be announced at PNDU's AGM on Tuesday 21st August. For more information, go to our [website](#).

A reminder of our 2017 PNDU Award winners:



Azmat Ali (on left)



Katie Howard



Caroline Moussan (on left)



Kath Angstmann (on right)

Miranda and Gillian

Prof Gil Hardy (on right)

Birthday Corner

Words by Chris (grandfather/carer)



Thanks everyone for Logan's birthday wishes. Logan (HPNer) had a wonderful day with his family on his birthday and of course, he loved the Aunty Katie birthday cake, covered in his favourite confectionary "freckles and Emojies"

Logan had a birthday party at the local park on the Saturday, joined by a dozen or more of his school friends. They all enjoyed a fun-filled day of activities and games, a sausage sizzle for lunch with plenty of cake and lollies. It is wonderful to see how far Logan has progressed in the past 6 years, even more since starting school this year.

Recently, Jordan (HPNer), Logan's brother, also had a birthday, turning 9. (Read about Jordan's amazing day in the article in this issue entitled 'Jordan's Starlight Foundation Wish'). These two amazing birthday cakes were donated to the boys from Variety, The Children's Charity Rare Care Program. Jordan loves Batman and Logan loves Paw Patrol, so both boys were very excited when they received these special birthday cakes. It was wonderful to see them overcome their oral aversion and actually try the cakes. Both boys seemed to enjoy the black icing.



Fay's Story

Words by Fay

In 2001 I had surgery to remove my colon. That was when my whole life changed. 16 days after the surgery I was taken back into emergency and admitted after an abscess which had formed where my bowel was joined had burst. This was when I had my first time on PN for 6 weeks giving my bowel time to heal. Wow, not being able to eat a thing for 6 weeks- I didn't think I would cope. Of course I did, but my bowel never recovered. I had another surgery exactly 12 weeks after the first to try to see what the problem was, but nothing conclusive came out of that.

I spent 4 ½ months in hospital and lost lots of weight (I could afford to lose a bit, but only a few kilos) and was diagnosed with a pseudo obstruction of the small bowel. Over the next couple of years I was on all sorts of medications and on and off PN with bouts of hospitalisations and lots of pain. Eventually they decided to give me PN at home. I had no trouble learning how to do it as I was a nurse in my early years of working (before children).



The following years were a mass of hospitalisations for obstructions and infections. I think the obstructive episodes were the worst because when my bowel stopped then so did my stomach and I just vomited bile constantly until my oesophagus was so ulcerated I could not even swallow water without crying. I lost count of how many times I was hospitalised with a NG tube to relieve the distention in my gut. Of course infections were pretty bad as well but here I am 17 years later and still able to have a slightly restricted normal life.

My PN has been delivered via Hickman catheters almost all the time except for a short time when I had a PICC line after a bad infection. All my upper body veins have been used and become occluded so I now have femoral vein access. This involved cutting into a smaller side vein in the groin then feeding the catheter into the femoral vein and up towards the heart. This vein has been in use now since 2013 and I find it quite convenient to both access and cosmetically.

A few years ago, I heard about faecal transplant and after discussing it with my specialist, I attended the Centre for Digestive Diseases in Sydney. After a consultation, I decided to undergo the treatment to see if that might help my condition. That turned out to be a bad decision because in order for the treatment to work I had to go off all antibiotics. That in itself caused me to have torrential diarrhoea and I ended up severely dehydrated with extremely low sodium levels. I lost all control of all aspects of my body and do not even remember the next 2 weeks. Another 2 weeks after that I was having rehab and slowly regained my legs.

HPN not only affects the patient but also the carer (my husband in my case). In fact the whole family can be affected. My husband and I have travelled extensively over the years, both locally and overseas. We have been to so many wonderful places and seen so much. It has been cumbersome organising and carrying all my HPN gear and ancillaries but certainly not impossible.

I turned 70 the year before last and have decided I won't travel long haul overseas anymore because the jetlag is too much to get over. We have a beautiful unit in on the Sunshine Coast in Queensland so that is going to be our main holiday destination now. We will still travel within Australia and maybe NZ or Singapore.

I have been a member of PNDU for many years and have recently joined the Management Committee. I had no idea how hard those people work for us!

A Follow up to 'how long have you had your line?'

Editor's comment: *The following is a response from my HPN nurse following on from the article in Dripline issue #23.*

'If you are interested.....

The longest line I had in one of my home PN patients was 17 years!!

It was a single lumen Hickman. It was repaired more than once, decontaminated several times, and very well used, with simultaneous pain relief (continuous morphine) and cyclic PN overnight.

Unfortunately, the Hickman outlived our beautiful patient, but it served well.'

The Spoon Theory

Editor's Note: *The Spoon Theory was thought out by Christine Miserandino and is sometimes mentioned by PNDU's members when discussing how they are coping with life. It is a clever, visual representation of the limited energy levels that people coping with chronic illness and pain often have to deal with in their daily lives. It is a visual way of trying to explain this to friends and family, who often just don't understand. [Read The Spoon Theory here.](#)*

UPCOMING EVENTS

17 July	Nominations open for PNDU Annual Awards
7 August	Nominations close for PNDU Annual Awards
18 August	Applications close for travel sponsorship to AuSPEN HPN consumer workshop + PNDU Annual Social Gathering
21 August	PNDU's AGM & Announcement of PNDU Annual Award Winners
1 September	Winners of travel sponsorships announced
15 October	World HAN Day
14-20 October	HPN Awareness Week
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 presenting)
1 December	AuSPEN HPN consumer workshop - Sydney
2 December	PNDU Annual Social Gathering - Sydney
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 donation:

Baxter Healthcare Pty Ltd

\$3,000

PNDU Membership for Aussie and Kiwi HPNers and carers:

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

Benefits:

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



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

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

Donations

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

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

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

Donating via direct deposit

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



Australia (\$AUD)

Bank: Westpac
Account Name: **PNDU Inc.**
BSB: 032 056
A/C No.: 482 738

NEW ZEALAND: (\$NZD):

Bank: ANZ
Account name: IPANEMA
A/c No: 06 0273 0308799 00
Please include reference "PNDU"
IPANEMA (Charities Commission Registration CC21178) is a NZ charity

Management Committee Members

President - Karen
Vice-President/Editor - Gillian
Secretary/Public Officer - Miranda
Treasurer - Chris
Committee Member - Fay

Contact Us

Parenteral Nutrition Down Under Inc. ABN 49742201085
contactpndu@gmail.com | www.pndu.org
Registered address: [128 Rainbow Street, Randwick NSW 2031, AUSTRALIA](#)
PNDU Inc.'s privacy policy is available on our website www.pndu.org

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

Designer: MBE Hurstville