



# DRIPLINE



# PNDU

Parenteral Nutrition Down Under

Wishing all our members a healthy New Year! As usual, Dripline has a mix of members' stories and opinions; medical information, which can be discussed with your hospital teams; and information on cruising with HPN. There is a tribute to Nat, one of our members who died last year, as well as learning about one of our youngest members, Mayana. We farewell Sydney's Baxter couriers and learn about 2 member gatherings, in Sydney and Melbourne. We read about medical research on blood thinning patches and catheter infection reductions, and well as learning about the role of glucose in our HPN and the effect of sugar in our intestines. Read and enjoy!

Gillian - Editor

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# Remembering Nat – one truly amazing young woman

## WORDS BY KAREN

We shared the very sad news in the last edition of Dripline that 3 very precious members passed away last September - Carol, Sam and Nat.

Nat was 27 years old and PN dependent for 9 years as a result of a progressive neurological disorder, and lived in hospital for her last 6 years. Previously she'd had over 60 admissions in a children's hospital and 2 adult admissions. Nat could no longer eat or tolerate any oral feeds, and had 5 IV pumps with 10 lines attached to her central line administering IV fluids, PN, medications and pain medications 24/7. To the credit of those who cared for her, primarily her mum, Lyn, Nat only ever had one central venous catheter for the whole 9 years and no line infections. The catheter itself had 5 repairs and remained 'open'.

Nat's biggest wish was to get home, which the family were able to achieve for a few days in 2015 despite the incredible obstacles. Heartbreakingly, more complications arose after that brief spell and increased until her passing.

That was the medical aspect of Nat's life. But there was so much more to Nat! In the words of Lyn, Nat had such a positive attitude to life! She had so much living to do! During the years in hospital, Lyn would take Nat out on 'gate leave' everywhere...concerts, parties, New Year's Eve, Luna Park, the Voice, as many Cronulla Sharks rugby league home matches as was possible, etc, etc, etc. Nat loved to socialise and had such an attractive, happy personality that she couldn't help but draw new friends all the time. And singing – oh did Nat love to sing and write songs, especially with her friends.

Nat's hospital room was filled with artwork, posters of pop stars, and scores of photos of the various events she went to, friends and all the famous people she would meet. It certainly didn't look like a hospital room! Nat radiated such fun despite her circumstances. We were privileged to have Nat and Lyn in PNDU.

Her beautiful nature and appeal was evident at Nat's funeral, attended by some 600 or so people, with refreshments held afterwards at her beloved Cronulla Sharks Club. People involved in her medical care, past and at the time of her passing, attended, some giving beautiful eulogies about this amazing young woman.

For Nat's loved ones, this time of grieving is particularly difficult as her passing has left such a great big hole. We continue to send our love and heartfelt sympathy to Lyn and the family and all those whose lives Nat touched, and thank Lyn for being part of the PNDU family and sharing life with us. Nat was one truly amazing young woman, and may her memory live on.



*At Cronulla*



*At The Voice*



*At The Sharks*

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# Goodbye to our wonderful Sydney Baxter drivers!

## WORDS BY KAREN

January is a sad month for many Sydney HPNers as we say farewell to two small teams (Team Jim & Dimi, and Team David) of dedicated, highly respected and caring drivers who have delivered PN to HPNers and hospitals across Sydney, Team Jim & Dimi having done this for the past 13 years. Jim, Dimi, Peter and Mikey (Team Jim & Dimi), as well as David, Ashleigh and Sioni (Team David) – we thank you and salute you for your amazing work! You



recognised how important your role was for those living with life support therapy and carried it out with great professionalism and genuine care. For that we are so very grateful. We hate to see you go, but wish you all the very best for the future, wherever it takes you. PNDU is especially grateful to Jim, Dimi and the family for their encouragement, support and enthusiasm for PNDU's work and mission, and in their genuine care for the HPNers and carers they delivered to each week, letting them know of PNDU's existence to support them along their HPN journey. PNDU and so many of our Sydney members will always appreciate you.



*Jim and Dimi with one of their delivery vans*

From a few Sydney PNDU members:

**Gillian:** Jim is almost part of the family, knowing when I've been in hospital and asking how I'm going – giving personal service, not just delivering boxes, sign here, gone, as couriers from other companies do. Jim also introduced me to PNDU, by encouraging me to enter a 25 word competition about life on HPN that PNDU was running. I not only won a book and met Karen and a wonderful, supportive group of people via our chat forum, but joined PNDU's management committee and began Dripline! Thanks, Jim!

**The Einstein Family:** Thank you David for your work over the years and for bringing to us Ariel's vital nutrition safely every week!! Your warmth and dedication makes a huge difference to us and we will really miss seeing you. We wish you all the best for the future. Thank you from all of us.

**Ann-Marie:** I would like to say a big thank you to Ashleigh. It was so nice to see a friendly face each week. When we suddenly stopped HPN we didn't get to say a proper thank you to her. So a big thank you Ashleigh. Daniel wishes you well for next year and he certainly does miss his weekly hellos to you.

**Renee:** Thanks for the opportunity to express my gratitude to Dimi (and the other Baxter couriers). When I first started on HPN it was naturally a bit overwhelming and Dimi's smiling face was always so reassuring and supportive. She was so confident I would be ok and it really helped having someone holding that light for me when I could not see it at the time. She always gave outstanding service with a smile, letting me know when she was coming and also responsive if I needed to make changes. Best of all, Dimi told me about PNDU and I was able to meet Karen. That was the beginning of a very special friendship and a support group that is precious beyond measure.

Thank you Dimi, and all the couriers. You will be sorely missed and your work really made a difference to our lives.

We hope you find fantastic jobs where you can continue to serve your community with such distinction.

**Sonya:** Milla and I would love to pass on a big huge thanks to Ashleigh for always putting a smile on our face each week. Ash, we loved the chats and will miss the surprise some weeks of new chosen funky hair colour. You have been such a treasure and we will miss you!

**Helen:** I too am very sad to lose my lovely delivery man David. He has been so kind and such a gem, delivering the same time every week, unpacking my boxes and being very understanding of the contents importance. I was not feeling well recently and he asked if I was feeling better. That is service!

**Karen:** Dimi is not only my PN courier, but a dear friend! This has only happened through great service, understanding (and seeking to understand) the life of an HPNer, and genuine care and kindness. Dimi truly cares about the people she has delivered PN to over so many years. I've loved sharing life while boxes are delivered and a

signature given. And other members of the family I've met along the way (Peter and Mikey) all share the same amazing work ethic. Dimi – I'm so sorry to see you all go, but thank you for impeccable service and warm friendship!

**Sal:** Many thanks to Ashleigh for her years of warm smiles every time she delivered my PN.

**Jane:** Dimi – I'm really sorry you're going. You are the one who introduced me to Karen and as a result I got involved in PNDU. I really appreciate that. I'm really sorry I won't see your smiling face for Baxter.

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## Congratulations to our 2016 PNDU Award Winners

PNDU Award giving is a particularly special time of year for all PNDU HPNers and carers as we get to say thank you to those who do great work for all those living with HPN 'down under' – giving credit where credit is due! There are many dedicated people working to improve HPN lives, and this is our opportunity to recognise and applaud these people.

We had award winners in 3 categories this year. The names of all our Professional and Lifetime Membership Award winners are on our Roll of Honour, and they have already received an Award Certificate for proud display. In addition, our Lifetime Membership Award winner will have her name engraved on our perpetual Lifetime Membership Award trophy.



### **PNDU's Professional Award winners:**

Adult Parenteral Nutrition Professional of the Year – **Declan Gibney**, Pharmacist, Prince of Wales Hospital, Sydney

Commitment to Care - Company Employee of the Year – **Di Chiang**, Registered Nurse, Home Support Services, Brisbane district

### **PNDU's Lifetime Membership Award winner:**

**Karen**

We also give special commendation to our runners-up. We wish there were enough awards for everyone!

### **Adult Parenteral Nutrition Professional of the Year:**

- Dr Sharon Marks, Monash Health
- Rachel Berry, Royal North Shore Hospital
- Rachel Pons, St George Hospital

### **Commitment to Care – Company Employee of the Year:**

- Jim Chrisafis – Baxter Healthcare
- Caroline Moussan – Baxter Healthcare

Thank you to our Professional Award judges - Prof Gil Hardy and Prof Patrick Ball. And thank you to all who submitted nominations. We look forward to acknowledging the great work of HPN professionals as well as PNDU volunteers again in 2017.

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

### **Declan Gibney**

As a pharmacist and one who would usually have a more unseen role within the HPN care team, Declan's involvement and care for his patients is obvious and outstanding and he is a very active member of my HPN care team. I know I can fully trust Declan's attention to detail in all aspects of my PN.

As the one through whom I organise my holiday deliveries, Declan is always on the ball, supportive and encouraging. Sometimes this has required lots of follow-up with various parties, and even advocating on my behalf, which Declan has always willingly done. He will also never hesitate to raise concerns/questions with my homecare



*Declan receiving his Award Certificate from Karen*

company on my behalf, following them through until a satisfactory answer is received.

Declan not only receives PNDU's newsletters but also shares them with his staff as a way for new pharmacists to understand life on HPN from the patient perspective, and is actually the person who introduced me to PNDU.

### Di Chiang

Di has been my Nurse in my home for close to two years now. In that time, she has been nothing short of amazing. There is never any issue with any organisational work. Di manages her time and medical/nursing stock with great efficiency. She has excellent communication skills as well as a delightful sense of humour. She possesses that lost quality that was once known as "Common Sense" in spades.

Di spent time learning initially how to cannulate my fistula to provide access for my Home PN. Di is acutely aware of the need for a completely aseptic technique and ensures that she does this 110%. Di takes enormous interest in knowing about I.F. to the extent that she attended and enjoyed learning from the 2015 AuSPEN Conference in Brisbane.

She is great company to have in my home and keeps me up to date with what is happening "in the outside world" with humour and intelligence. She shows great compassion and dedication and is truly passionate about her profession and the outcomes of her care for her patients and the effect that she and her work will have on their lives. She is observant and aware of any changes, however small, there may be in my health or outlook. Di has an exceptionally high standard of care for her clients and an understanding that the work done by medical professionals, such as herself, has consequences for the clients that she deals with.



*Carmel presenting Di with her Award Certificate*

**Karen**, nominated by Jacqueline, and Ryan

I know of a few people who do a lot of work behind the scenes, but when I see the list of names that are on the Roll of Honour and Karen's name is not on there, it feels like an injustice to the amount of time and effort she has put into PNDU, bringing support to those on HPN, growing the HPN support community and increasing awareness of HPN in the great medical and public community. And I know she has involvement in the wider HPN community and brings that knowledge back for the benefit of PNDU. I'm sure with the contribution of other members the efforts that Karen goes to for the PNDU community would easily fill a large book! (Or several!)

Karen works diligently for the good of PNDU; has a grasp of all that is happening in relation to Management Committee, members, upcoming events, surveys, minutes, assisting with Dripline, liaising with companies and other organisations and representing PNDU on the world stage by convening PACIFHAN.

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## Can You Eat?

**Editor's Note:** *Karen made the following comment on our email forum, and we had many interesting answers.*

*I think it would be really interesting to know how many members can eat, and if so, how restricted? Let us know!!*

*From my understanding, many of our PNDU adults can eat something, but some are very restricted. Lots of the littlies however can't eat or have food aversion.*

*For me, I can eat and drink, but with restrictions – low fibre, cooked, not sweet drinks, etc.*

*Is there anything people crave that you can't have? For me it's fresh fruit. I loooove the smell of it. I can have a little, but too much and I get partial blockage symptoms.*

**Jodie says:**

I can eat small amounts. My team encourages me to eat as it really helps my liver in light of the harshness of PN on the liver. However, if I eat too much of anything, I get very symptomatic. Which can be difficult, as I love food and the amount I can happily tolerate varies greatly.

I get symptoms every day from food. If I'm lucky, it's just some bloating. More so at the end of the day than the beginning (slow motility issue - it all builds up).

Some foods give me more problems than others. I try to keep my diet low in gluten / wheat, low dairy and low sugar.



Low FODMAPS food seem to travel through better too. Eating and tolerance of food is all a bit hit and miss and random for me though, with CIPO. It depends what's happening in my small intestine at the time - which is all guesswork and varies greatly.

Sometimes I can eat junk for a short season. I went through a 2min noodles phase earlier in the year. Other times, I will react to the smallest treat. It's very hard to explain this to people. They like to know concrete rules - not wish washy changing needs that go with my CIPO. I'm very hard to cook for!

My guts would love nothing more than to go food free (I feel best, emptier). I had a 4 month period many years ago after an operation where I was only allowed a small amount of liquids and I remember loving having such a flat tummy! I used to make my visitors eat around me so I could smell their food and enjoy it vicariously.

My willpower is weak. I go through seasons of being a fat person in a skinny person's body. The CIPO doesn't appreciate it. I especially struggle with eating when I'm out of the house. In a social situation, it's 'normal' to eat. And almost every social situation contains food and/or drink.

I have a thing with always wanting to be 'normal'. Only because I don't like people to always know about my illness (I don't like to be defined by it). Not eating with others has brought me unwanted attention so many times. I'm sure a lot of PNDU members understand. I hate that sort of attention! It's draining and sometimes even demeaning (I'm very sensitive).

When I was growing up with CIPO from the age of 8, my Drs and family were always trying to get more food/calories into me via mouth and nasogastric tube. No wonder I was always so sick with so many gut symptoms! These days, for example, I rarely vomit. Back then I would vomit daily.

I do the same each morning - test how bloated I am. And my day often unravels in a way quite dependant on that morning bodily state. I am most empty in the morning and so breakfast is my fave meal of the day. I don't put up with hunger pains very well. I never started getting them until my late teens. I am super grumpy when hungry.

I don't drink coffee anymore because it makes me very shaky. There are some other definite no's for me - like KFC (for example). Or like a bowl of pasta or a milkshake. Some things I just stay clear away from, even if I'm sorely tempted. Quite randomly, I was affected yesterday from having a soy hot chocolate. I thought I'd be fine but I was very sick at the end of the day. Sigh. So hard to manage!

BUT I am truly grateful I am able to eat a bit. I guess we all get used to what we have to do / not do in order to maintain as best health we can.

#### **Lara says:**

I can eat really small amounts and a very restricted diet, but the amount and how well I tolerate it varies hugely from day to day. The first thing I do when I wake up each morning is run a hand over my stomach and see how bloated it is... the bigger it is, the worse my day will be.

The less I eat, the better I feel generally, but even after all these years my willpower is weak. And I get such strong hunger pains, and low blood sugar sometimes, it's a tough balance to maintain. I usually keep to one tiny, solid meal per day and stick to fluids the rest of the time.

I remember seeing (a fellow HPNer) in Brisbane eating a sandwich and I got so jealous! I really crave a big salad sandwich sometimes. My cravings have really changed over the years... I used to want EVERYTHING but now most foods (like salad sandwiches!) I look at and my brain just links it to how sick it will make me feel, and the craving sort of disappears.

I tend to skip breakfast. I love it, but I'm usually at home by myself for it, and I prefer to save my stomach space for lunch and/or dinner when other people are around. The social side of things is very tough. I used to try and hide things, but I've given up now. My friends are getting used to me turning up at things lugging my ugly backpack. But sometimes I find myself at events, ordering food and eating it even though I know it's going to come straight back up later. (shrug) It's not logical, but sometimes I just want to fit in and worry about the consequences later.

Once I bought dozens of different flavours and types of tea to try and trick myself that they were like meals. Didn't work.

#### **Daniel says:**

I can't eat or I'll vomit. I can suck on a few boiled lollies and that's about it. With drinking, I can only handle a few sips at a time.

#### **Sal says:**

Some days some foods are ok and others they are terrible. It's so hard to explain to my dietitian as it so unpredictable.

It is very hard to cook for the family and not get to enjoy it, or if I do taste it, then end up doubled up in pain for the rest of the night. I totally understand what (people on the forum) were saying about social events always being based around food. It is hard and I don't think anyone not in this situation will ever truly understand unless they were made

to be food-free at a social event and see what it is like.

When I couldn't eat at all, I used to imagine my PN was all sorts of gourmet meals, and my family would ask me what I was having each time. Sometime it was just a pina colada, because you have to admit, PN does look like it!!

I am just so glad we can share with each other how we feel and know that we are understood; it's nice not be alone.

**Carmel says:**

It is fascinating to read your "food stories". I relate to all of them.

I used to go through phases where I could manage to eat something eg steamed fish, and then a couple of weeks later the very same thing would cause me to obstruct.

I have had periods on Ensure® or Resource Plus® and then same thing: pain, nausea, full or partial obstruction. It can be so frustrating. Especially as I just love food!!

I would just love to eat a big, red juicy apple! And a piece of white bread with butter and crunchy peanut butter.....  
Mmmmm

**Renee says:**

With respect to diet....I am one of the fortunate ones who can eat on HPN. My diet was actually more restricted when before I was on PN. The reason for this is that I have had short-bowel syndrome since 1976 but there was no treatment at the time. So I struggled with absorption of all nutrients (as I did from the time I was diagnosed because my disease was so virulent) and particularly electrolytes. The end result was that I was in hospital fortnightly for years...having IV infusions of various things. (When my son was 15 months old my husband brought him to visit – he said: "Ooh, we're at the hospital, Mommy lives here!!". The idea of the dietary restriction was to minimize diarrhoea and maximise absorption. Obviously this is not such an issue on HPN as I get most of what I need there. Still, things like high fibre, spice, sugar etc do not help. What I eat varies hugely depending on how I feel, sometimes almost nothing, other times quite a lot. Mostly it goes straight through though. I do absorb a certain amount, particularly carbs. I truly feel for those of you who cannot eat....very difficult indeed and I would miss the social aspect enormously.

**Lisa says:**

I can't eat at all - only sips of water. I can't even have sips of coffee or lollies. I'm envious of those of you who can! Still, I'm grateful for every day I have.

My biggest cravings are for seafood, sandwiches and pasta. Never going to happen though!

When I'm out with people I focus on who I'm with, not the food.

**Celena says:**

It's amazing to hear from you all and how we manage our lifestyle when it comes to the most culturally involving activity in the world: eating. I also make up PN Cocktails. I find it hilarious that others need to imagine what you could be having so as to make it compute. Like most of you have experienced, I am always interested by how people are flabbergasted that you could "not eat".

I don't eat at all. I have Sprite and water so it's nice to socialise for a drink, although depends on the day, or rather if my stomach is emptying well. I haven't really eaten since I was 3 years old (I'm not quite 40 years now). I don't really have a lot of food memories, which I think has made it easier for me. I'm not bothered by not eating; in fact the idea of sticking something in my mouth, having to chew it AND then swallow it disgusts me. J But I love food. I love chopping food, I love cooking and do so without tasting it. I have only ever had one complaint when I got a bit heavy-handed with the chilli! I prefer savoury to sweet.

**Jane says:**

My favourite is Coles cookies and cream icecream . They are\$1 each and yummy. I crave fried onion, beans and gravy ,cabbage and cauliflower cheese - mostly savoury stuff and high fibre!!!

**Gillian says:**

I'm extremely fortunate in that I can (and do) eat anything I want, so I have normal sized meals with a variety of food. Of course, it doesn't get absorbed and provide nutrition for me, so the down-side is that I have to empty my ileostomy bag fairly frequently during a long, protracted meal, such as at a restaurant, or just fairly soon after family meals at home. I often think that if people at a restaurant notice me heading off to the toilet yet again, for the third or even fourth time during the night, and see how slim I am, they probably suspect I'm bulimic!

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## PNDU Sydney Social Gathering

### WORDS BY GILLIAN

PNDU had its second Sydney social gathering for the year on Sunday 30th October, this time out west at Sal and Matt's home. 7 HPNers were there with their families, three of them young children. As well as Sal, there were Karen,

Jane and Gillian (adult HPNers) and Ariel, Logan and Milla (paediatric HPNers). It was a great opportunity to chat in person and catch up on news, both health related and otherwise, and strengthen our growing friendship. Although Logan and Milla are too young to be very aware of other children's needs, Ariel, aged 5, asked me if was on PN, showing this awareness and interest, as well as allowing her to realise that there are other children with the same health treatment as her. I believe this contact will be invaluable for the children as they grow older and get to know each other better.

Although we have read about Sal and Matt's holiday bus ([See Dripline issues 6 – Eromanga, west of Quilpie, Qld, and 14 – Tasmania](#)) and seen the accompanying pictures, it was great to climb aboard the bus and see how comfortably Matt has finished it so that all 6 of the family (4 young adult and teenaged children) can live in it to enjoy family holidays together, while Sal has all that she needs for her HPN.

We were also greeted by their 2 dogs – 1 only interested in guzzling up dropped tidbits of food, while the other couldn't get enough of chasing his ball if he could persuade one of us to throw it for him.

The cubby house in the back yard proved popular with the young ones, as did a racing car track. Matt's restored truck and the boys' car restorations in progress proved popular with the men.

Luckily the rain held off until we left, allowing us all to have a lovely day and feel very welcomed by Sal and Matt.



*Eadie and Logan (HPNer) on the infamous bus*



*Fun at the race track*



**Back row:** Callum, Bradden, Juliette, Matt, Sal (HPNer), Miranda, Chris, Gillian (HPNer), Ray, Jane (HPNer), Dave, Karen (HPNer)  
**Front row:** Sonya, Milla (HPNer), Ariel (HPNer), Logan (HPNer)

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## New self-regulating smart patch releases blood-thinning drugs when necessary

**Source:** North Carolina State University

Published on November 29, 2016 at 7:05 AM

An interdisciplinary team of researchers has developed a smart patch designed to monitor a patient's blood and release blood-thinning drugs as needed to prevent the occurrence of dangerous blood clots - a condition known as thrombosis. In an animal model, the patch was shown to be more effective at preventing thrombosis than traditional methods of drug delivery. The work was done by researchers at North Carolina State University and the University of North Carolina at Chapel Hill.

Thrombosis occurs when blood clots disrupt the normal flow of blood in the body, which can cause severe health problems such as pulmonary embolism, heart attack or stroke. Current treatments often rely on the use of blood thinners, such as Heparin, which require patients to test their blood on a regular basis in order to ensure proper dosages. Too large a dose can cause problems such as spontaneous haemorrhaging, while doses that are too small may not be able to prevent a relapse of thrombosis.

"Our goal was to generate a patch that can monitor a patient's blood and release additional drugs when necessary; effectively, a self-regulating system," says Zhen Gu, co-corresponding author on a paper describing the work. Gu is an associate professor in the joint biomedical engineering program at NC State and UNC.



"Two years ago, I spoke with Zhen Gu about the significant clinical need for precise delivery of blood thinners," says Caterina Gallippi, a co-corresponding author and associate professor in the joint biomedical engineering program. "We, together with Professor Yong Zhu in the mechanical engineering department at NC State, assembled a research team and invented this patch."

The patch incorporates microneedles made of a polymer that consists of hyaluronic acid (HA) and the drug Heparin. The polymer has been modified to be responsive to thrombin, an enzyme that initiates clotting in the blood.

When elevated levels of thrombin enzymes in the bloodstream come into contact with the microneedle, the enzymes break the specific amino acid chains that bind the Heparin to the HA, releasing the Heparin into the blood stream.

"The more thrombin there is in the bloodstream, the more Heparin is needed to reduce clotting," says Yuqi Zhang, a Ph.D. student in Gu's lab and co-lead author of the paper. "So we created a disposable patch in which the more thrombin there is in the blood stream, the more Heparin is released."

"We will further enhance the loading amount of drug in the patch. The amount of Heparin in a patch can be tailored to a patient's specific needs and replaced daily, or less often, as needed," says Jicheng Yu, a Ph.D. student in Gu's lab and the other co-lead author of the paper. "But the amount of Heparin being released into the patient at any given moment will be determined by the thrombin levels in the patient's blood."

The research team tested the HA-Heparin smart patch in a mouse model. In the experiments, subjects were injected with large doses of thrombin, which would result in fatal blood clotting of the lungs if left untreated.

In the first experiment, mice were either left untreated, given a shot of Heparin, or given the HA-Heparin smart patch. The mice were injected with thrombin 10 minutes later. Fifteen minutes after the thrombin injection, only the mice who received no treatment died.

In the second experiment, the thrombin was injected six hours after treatment. Fifteen minutes after the thrombin injection, all of the mice with the HA-Heparin smart patch were fine, but around 80 percent of the mice that received the Heparin shot had died.

"We're excited about the possibility of using a closed-loop, self-regulating smart patch to help treat a condition that affects thousands of people every year, while hopefully also driving down treatment costs," Gu says. "This paper represents a good first step, and we're now looking for funding to perform additional preclinical testing."

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## ~~Sneaky~~ Creative Ways to Feed Fussy Toddlers

BY CARMEL

***Editor's Note: this article came as a result of a carer of an HPN dependent child, who was being encouraged to eat by her hospital team, wanting ideas to tempt her child to try different food. However, it is always advisable to ask your team for approval before trying new ideas.***

I wouldn't have a clue about little ones coming off PN, but I do have a few hints about little fussy eaters, if that helps at all?

Does your child like Milo? And does she like to help in the kitchen? I would make a Milo drink mixed with Ensure® and Vanilla Ice-Cream. The more calories the better! And thank goodness for blenders!

All mum's need to be sneaky - oops, I mean "creative" - with food. Is there something that the doctors want her to eat that she doesn't like? Can you cook eg vegetables, blend them and add them to the gravy or the bolognaise or the rissoles? If she has to have fibre, add fine bran with bread crumbs when you crumb meat or anything else. Even add it to biscuits with the flour.

My nearly-3-year-old grandson (not on HPN) loves to help in the kitchen. So maybe instead of toast, he and I will make "french toast". He thinks he is "the bee's knees" being allowed to beat the eggs and milk with a fork. He is allowed to "dunk" the bread in the egg mixture. I put it in the pan; we both butter "his cooking" and add honey if he wants it.

Do you have a vegie garden where your daughter can choose what she wants to pick to eat?

I think that making food fun may be the go- ignore the mess-it is only a temporary inconvenience!

There is using reward charts: when you eat A, I will put a star/sticker on your chart. 5 stickers and you can buy X from the shop. "Do we have a deal?," I ask. My grandson shakes my hand, bless him but he knows he has to earn his stars!!!!

I would think you may be working back the front to most people-you want to add every calorie possible. Maybe, your daughter can have fun with a shaker of sprinkles on top of yoghurt- she can "draw with sprinkles" before she gobbles it up.

Above all else, there is "Constructive Negotiation" (read "bribery") - just because sometimes that is what works!!!!

But your daughter may also find that the "food fairies" have visited. There may be little treats that pop up unexpectedly in unusual places around the house. And what little girls want the fairies to cry by not eating their special "fairy treats".

Another thing that worked when my daughter was ill and losing weight: we would have, for example, an "S" day. Everything we played and ate that day needed to begin with "S".

I sincerely hope all goes well for you both and that she soon enjoys food. I hope that she has some fun with her food and you never know, with all this creativity with food, we may be seeing the beginning of a career as the world's top chef!

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## PNDU Annual Social Gathering - Melbourne, 2016

### WORDS BY JODIE

I was one very lucky (and appreciative) recipient of the 2016 PNDU travel sponsorship. This covered the cost of my flight from Perth to Melbourne and my flight from Melbourne to home again. Without the sponsorship, I would not have been able to attend the PNDU social gathering. Ryan and I didn't have enough money at the time to cover such a trip.

I arrived in Melbourne the evening before the social gathering on Wednesday the 16th of November. As I'd been travelling most of the day from Perth to Melbourne, my pump was in need of a decent charge-up session but I couldn't wait for the battery to fill – I had to connect to PN upon arrival at my accommodation. So, I had a small problem to solve.

I'd learnt how to connect my PN without a stand (which held the bag up) before my trip. This came in super helpful (I'm never going back to my old way of setting up again). I put the pump (still in its charger) in my bag with the line connected to PN, zipped it up and left it on the floor, leaning against the end of my bed so the Bodyguard power cord could reach the wall socket. I didn't have as much freedom to move in bed as usual but I had enough leeway to get a decent sleep. When I woke up to use the toilet, I just unplugged the power cord from the wall for a short time.

I was delayed in getting out the door on Wednesday morning and ended up sitting to eat a proper breakfast at a café near the NGV in Federation Square around 11am. A meal and taking things slow were what my body told me were immediate priorities for the day. Arriving at the PNDU gathering had to come second place.

The meal service took much longer than I expected. It also took much longer than I expected to walk from Federation Square to the Royal Botanic Gardens. So I arrived at the Rose Pavilion 45mins late (after getting lost, asking a stranger for directions and finally calling Karen). Karen's idea to use Google Maps on my phone was genius and I finally found the group of people I'd been so longing to meet. What a walk!

The Wednesday PNDU social gathering was fantastic. I could hardly get my head around meeting all these wonderful people I'd been talking to online for over two years. Slowly, all the pieces began to click together in my mind.

Poor Emma was sporting a cast for her broken ankle and giving the wheelchair -look a new kind of beauty. She was one of the first of the PNDUers who captivated my attention, with her gentle open face of compassion and strength. We chatted at length. What an amazing, intelligent woman Emma is. Definitely one of my superheroes.

I was keen to give hugs all round and they were received well. One of the important things I wanted to do on this trip was give Graeme a super big hug of compassion after the loss of Carol earlier in the year. It was so lovely to have him there and I really hope he will continue to involve himself as part of our PNDU family.

Little Ariel was having difficulties leaving daddy to take her little sister for a walk and play. She ran after Dave in tears. I scooped her up for cuddles and gentle talk, then delivered her back to her mum, Miranda. What a privilege it was to connect with such a brave little soul.



Above: The Rose Pavilion  
Below: Jodie (HPN), Emma (HPN),  
Karen (carer), Daniel (HPN)



Clare (carer) and David (carer)



Clare, Lara and I chatted at length also. It was cold in the pavilion so we sought out some grass and sunshine together. Clare had a million questions for me, which I gladly answered and Lara joined in with accounts of her experiences too. I was excited to learn that Lara is a bookworm, like me, and a keen writer, like me! We have since stayed in touch via text messages and I've had lots of laughs with her.



*Graeme (carer), Renee (HPN), Lara (HPN), Ariel (HPN) and Eadie*



*Chris (carer), Peter (carer), Theresa (HPN), Jill (carer), Miranda (carer)*

Beautiful Clare – my kindred spirit in PNDU travel sponsorship for 2016. What a beacon of absolute strength and determination. A true super mum! I felt a deep joy to meet her. We enjoyed some additional time together on Thursday, shopping and walking and by the end, resolved to get our families together in the new year. We even joked about her dropping Bertie and Elsie off at my house so she could have a much needed holiday / break with Mike. Who better to look after PNDU children than a mother and old hand at PN set up?

Renee sought me out early and lavished affirmations and kind words upon me. What a positive, amazing woman with a wonderful story of overcoming hardships. I instantly connected with her gentle soul.

It was good fun to stir up Chris and get a couple of hugs from him. Amazing man! He's like a walking encyclopedia of medical information and politics, but with a huge heart and generous smile.



*All the gang, HPNers and carers*





*HPNers*

**Back Row:** Daniel (Vic), Jodie (WA), Lara (Vic), Ariel (NSW), held by Renee (NSW), Karen (NSW)  
**Front Row:** Emma (Tasmania) and Theresa (Vic)

By 3pm it was time to leave and Graeme was kind enough to drop Emma, her mum and myself back to our accommodations in the city.

[Because the annual AuSPEN HPN Consumer Workshop originally planned for the following day was postponed – see next article,] Between Clare, Karen and I, we organised (online) another social catchup for the Thursday morning at a Starbucks in the city. Miranda, Dave and the girls were able to make it, as well as Chris and Daniel. We talked about lots of things but one of the most relevant topics was perhaps the issue of a PNDUer (whether with ostomy bag or not) needing quick access to a toilet. Clare and I were busting for a wee but the toilets were closed for cleaning and we had to keep going back and forth to check whether we could finally use the ladies...

It was impossible to get enough time with each person present on the Wednesday and Thursday and I dearly regret that I didn't get to speak long to many people and not at all to others. Though saddened by this, I also look forward to meeting again the PNDU group in person again and getting a chance to talk with those I didn't get to this time.

Gosh, I was just taken by everyone I met! What a wonderful group of people. I'm so blessed by PNDU's presence in my life.

Thank you PNDU for the generous sponsorship and for my PNDU family who has honestly changed my life. I love you all.

## AuSPEN's HPN Consumer Workshop postponed, and PNDU at AuSPEN's Annual Scientific Meeting in Melbourne

**WORDS BY KAREN**

With our annual PNDU social gathering on Wednesday 16th November 2016, we were all very saddened that AuSPEN's HPN consumer workshop planned for the following day had earlier been postponed. Despite the disappointment this time, and various members (including our travel sponsorship winners) missing out on the workshop, we are encouraged (and very thankful to Sue Larsen in particular) that AuSPEN has now found a way to better keep this valuable annual HPN consumer event going for years to come.

PNDU continues to be very supportive of these annual AuSPEN HPN consumer workshops, the first of which took place in 2014 in Auckland, New Zealand, and are not aware of any other Parenteral & Enteral clinical society worldwide that provides such events for HPN consumers. In support of the workshops and to allow HPNers and carers to talk to each other face to face about life on HPN (something some HPNers and carers rarely get to do!), we

hold our annual PNDU social gathering alongside the workshop (on a separate day), and provide 2 travel sponsorships worth \$500 each to 2 PNDU HPNers/carers who haven't before attended both events. Beforehand, we also provide AuSPEN with a list of suggested workshop topics our members would like to know more about from HPN clinicians.

With these 2 events again able to continue, we look forward to announcing soon when and where the next ones will be held. So, watch this space!

Back in Melbourne, PNDU's activities didn't stop after our annual social gathering however, and Karen, Chris and Miranda exhibited for PNDU at AuSPEN's Annual Scientific Meeting at the Crown Casino Convention Centre on Friday and Saturday, 18th-19th November. We are very grateful to AuSPEN for allowing us to exhibit free of charge, and were stoked with our excellent spot – no-one could miss us!



*Karen and Chris exhibiting at AuSPEN ASM 2016*



*Location, location, location!*

It was a long couple of days, but so very worthwhile as we reconnected with our friends at Baxter Healthcare, Fresenius Kabi and Niche Medical, as well as existing and new HPN clinician and AuSPEN friends. After the disappointment of the HPN consumer workshop postponement, the exhibition was a great encouragement, and we received lots of positive feedback. We were able to continue spreading the word about current PNDU resources and activities (giving out lots of resources), and encourage more clinicians to let their HPN patients and carers know about PNDU. And that's one of the main reasons PNDU exhibits at these events. That mission will be accomplished when, as some already do, all Australian and New Zealand hospitals automatically provide all new (and existing) HPNers and carers with information about PNDU.



*Karen and Chris with our Baxter Healthcare friends*



*Chris with our Fresenius Kabi friends*





*Chris and Karen with our Niche Medical friends. These Micrel HPN infusion pumps and wheely backpacks are being used by Biomed in New Zealand and trialled by Baxter Healthcare in New Zealand.*

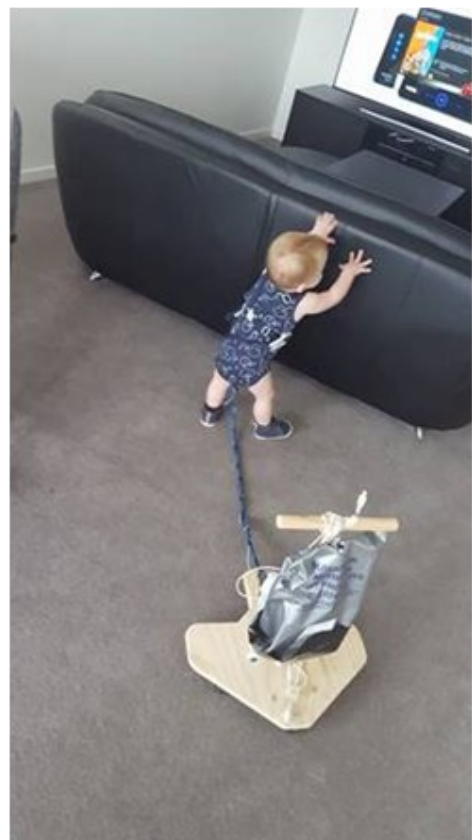
## Getting around on HPN

**Editor's note: one of our members, Amy, recently shared her husband's creative talents.**

Thought I would share with you what my husband made to give Zander a bit more independence. The toddler harness and lead means that he pulls the walker with him if he walks away from it without pulling his CVL or PN cord.

Yes he thinks it is awesome, even using it as a scooter! Here is a cheeky pic of him pushing buttons on the pump: that has been the only downfall. Will take some tweaking. [Another member was able to advise that if you press the blue info button and hold for a few seconds it locks the key pad. Very helpful for those with little ones on HPN.]

**Editor's Note: Read the instruction booklet to find out how to turn the lock on and off again.**





# What's in your Bag? Glucose

WORDS BY PROF GIL HARDY

**Editor's note:** *This article and the next are both written by Prof Gil Hardy for Dripline. Prof Hardy is a retired Professor of Clinical Nutrition, who helped found PNDU and is a Life Member. Together with colleagues at St Mark's hospital in London he invented the first 3 litre bag for PN in the 1970's and has collaborated with Nutrition Support Teams in UK and New Zealand ever since. He has published over 250 papers on parenteral nutrition and has written several articles, and adapted others, for Dripline. He is currently Chairman of the international clinical nutrition section (ICNS) of the American Society of Parenteral and Enteral Nutrition (A.S.P.E.N.).*

**As with all medical information, if you have questions or concerns, these need to be raised with your medical team.**

Glucose is the carbohydrate, or sugar, used in Parenteral Nutrition (PN) formulas. Glucose is the body's main source of immediate energy and a vital fuel for many essential functions. It is stored in the body as the carbohydrate polymer, glycogen, then released when required to feed the cells, heart, nervous system and particularly the brain, which alone requires about 100gram per day.

Because glucose utilisation may be inhibited in diabetes or liver disease, other energy sources have been investigated. The carbohydrate we know as table sugar is called sucrose and consists of a mixture of glucose and fructose, another simple carbohydrate. But fructose has a lower renal threshold than glucose and when processed in the liver it can cause acidosis and other adverse effects. These limitations deter us from infusing fructose or sucrose intravenously.

In nature Glucose exists in two forms, the D- form, often called Dextrose and the L-form, which is not used very efficiently by the body. Dextrose solutions of varying strengths are therefore the only sugar solutions used in PN. Ideally, we should try to avoid confusion by not referring to glucose or dextrose simply as 'sugar'. However, some health professionals still incorrectly use the term 'Blood Sugar Level' (or BSL) when it is the glucose level (BGL) that is actually measured.

In the sedentary adult the daily energy expenditure is approximately 2000 kcals (or 8372 kjoules if you have been trained to use this unit for energy). Energy expenditure increases when we exercise and decreases in the hospitalised patient at bed rest. Under normal circumstances glucose is the body's main source of immediate available energy, but if necessary it can also obtain energy from other carbohydrates and fats (lipids) or proteins.

Body fat is by far the largest and most efficient source of energy as we each carry about 150,000 kcals of fat compared to the relatively small amount of 500 kcals of glucose, stored as glycogen. We also carry approximately 15,000 kcals of energy in a fixed pool of protein, but unlike fats/lipids and carbohydrate, the body is not able to totally utilise protein for energy, without first breaking down muscles with potentially catastrophic results. Protein is therefore in reserve as a 'last resort' for energy.

In starvation, malnutrition or illness the limited glucose energy store of glycogen is exhausted after about 15 hours, but a glucose deficit adversely affects the balance and distribution of electrolytes in the various fluid spaces of the body. Hence the need for rapid replenishment, initially if necessary by a simple Dextrose 'drip', but for longer term energy and nutrition support, PN is required.

A Dextrose drip is normally a 5% solution of glucose (sometimes abbreviated to D5W) and provides approximately 200 kilocalories in one litre (or 837 kjoules ) and is "isotonic", meaning that it has approximately the same consistency as blood and can therefore be infused into the small "peripheral" veins in our arms or the back of our hands. However, adult PN patients usually need about 1000 glucose kcals a day, in addition to the other nutrients, which would require infusion of over 5 litres of D5W!

Dextrose solutions up to 70% strength are therefore manufactured to combine with amino acids (the intravenous source of protein), lipids and electrolytes, into the PN bag to minimise the infusion volume. Unfortunately, these very strong "hypertonic" solutions are much more concentrated than blood and would destroy small peripheral veins. Consequently, when incorporated into a PN bag with the other nutrients, they need to be infused into a large "central" vein near the heart where blood flow is rapid enough to dilute the hypertonic solution before it damages the inner surface of the veins. Your PN bag label probably has the Warning: THIS SOLUTION IS HYPERTONIC.

Uncontrolled hyperglycaemia (very high BGL) associated with too much dextrose administration can lead to increased infection risk. This is likely to be caused by depressed immune function as hyperglycaemia affects production of immunoglobulins and other cells of the immune system and enhances microbial virulence. For this reason some clinicians include insulin in the PN regimen to ensure that BGL are controlled within acceptable limits.

A typical 1.5 litre PN bag for adult HPNers will usually contain:

Glucose	100 -150 g (400-600kcal)
Lipid	20-60 g (200-600kcal)
Amino Acid	25-85 g (100-340kcal)

Plus electrolytes, vitamins and trace elements.

However, as you will know there is no 'typical HPNer' so your PN regimen and bag label might look different as it will be formulated specifically for your individual requirements. Nevertheless, it will contain sufficient glucose and the other nutrients to meet your needs.

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## Why is sugar bad for the intestines?

WORDS BY PROF GIL HARDY

**NOTE: The following comments relate to normal gut function. The situation may be irrelevant or more complex for PNDU members who are totally dependent on PN for Intestinal Failure (IF) where the gut won't be functioning 'normally'. However, there are degrees of IF and different reasons for the underlying causes of IF, so for those with only partial IF who are able to eat a little, some of this information may be of interest. As with all medical information, if you have questions or concerns, these need to be raised with your medical team.**

When eaten as part of a balanced diet, sugar (sucrose) is not bad for the intestines and is a valuable natural source of energy. Problems occur when we ingest too much sugar in 'fast food', lollies, chocolate, sweet desserts and high energy sugary drinks. Apart from the fact that excess sugar can rot our teeth and cause us to put on too much weight, there are other serious health issues that need to be of concern.

The quantity of refined sugar in the diet can significantly influence gut function and the composition of bowel contents. Studies have shown that in volunteers on a high sugar diet their mouth-to-anus transit time was significantly prolonged, the faecal concentration of bile acids increased significantly, and their breath hydrogen, involved in production of duodenal ulcers, increased when compared to those on a low sugar diet.

Sugar therefore has a huge impact on the digestive system, because that is where a large part of our immune system is housed. Consuming too much sugar can affect immunity, cause metabolic problems, insulin resistance and lead to diabetes. It can feed Candida (yeast) infections, and result in diarrhoea, bloating, gas and other unpleasant digestive effects. Excess sugar can weaken the lining of the gut, which by making the intestine more permeable enables harmful bacteria to leak through the gut lining to infect the bloodstream (leaky gut syndrome).

### How does sugar cause all of this?

Sucrose is made up of the two simple carbohydrates: glucose and fructose. That part of ingested sugar which is converted to glucose enters the bloodstream and circulates until it is eventually taken up by cells throughout the body where it is burned for energy. Fructose, on the other hand is only converted to energy via the liver where, in excess, it can produce a lactic acidosis. Consumption of large amounts of sugar is thought to be a contributor to non-alcoholic fatty liver disease (NAFLD), especially in children.

Under normal circumstances the body copes well with sugar, but when too much is consumed, the liver converts it into fat. Overproduction of fat causes the sex hormone binding globulin (SHBG) to shut down. Since SHBG regulates the male and female hormones, when there is less SHBG, there is more circulating testosterone and oestrogen, which can cause acne, infertility, polycystic ovarian syndrome, and uterine cancer in overweight women. This can also lead to an increase in cardiovascular disease, especially in women.

### Mineral Depletion

Mineral depletion also effects digestion. Our body requires minerals, such as: potassium, calcium, magnesium, zinc and chromium for the enzymes that break down fats, proteins, and carbohydrates such as sucrose and other sugars for energy and nutrition. However, by a phenomenon known as osmosis, a high sugar diet can increase losses of essential electrolytes and micronutrients causing a reduction in the production of these essential enzymes. With a reduced supply in the bloodstream then the other functions in our body can suffer. Thus people with low blood pressure, kidney stones, osteoporosis, or rheumatoid arthritis, when consuming too much sugar, may well experience mineral depletion and digestive problems.

All of these factors are interconnected. Sugar depletes minerals, which deplete enzymes, which cause digestive issues, which cause immune problems, which leads to other health problems. It is a vicious cycle!

### So what can be done?

- Be more aware of just how much sugar you are consuming
- ALWAYS check the nutrition label to see how many grams of sugar are in the food and drinks you are buying.

- Check out the serving size. The label may say 5 grams of sugar per serving, but if there are 10 servings that's 50 grams of sugar!

Of course, the 'sugar' in PN is pure glucose and the quantities are adjusted for your individual requirement by your Nutrition Support Team, ([see 'What's in your Bag? Glucose' page 15](#)) so these side effects of excessive sugar consumption are less likely for most HPNers.

## Mayana's Story

**Editor's Note:** This story was written by Julia Jensen and published on news.com.au. (Source: Caters News Agency). Mayana's carer/grandmother, a member of PNDU, has given her permission for the article to be reproduced in Dripline.

### Girl with short gut syndrome unable to eat a full meal or drink a glass of water

DECEMBER 18, 2016 12:38PM



Picture: Caters News.

*Mayana loves to play like other kids her age, but her condition means she can't go for a swim or eat a full meal, and even having a glass of water will leave her dehydrated*

TWO-year-old Mayana from Queensland is just like any other kid her age, except that she's not allowed to swim, eat a proper meal, or even drink a glass of water. Born with gastroschisis, a congenital condition that causes the intestines to form outside of the body, Mayana now suffers from short gut syndrome and only has 30 centimetres of intestines — a far cry from the average 250 centimetres that a typical child her age would have. She now lives with part of the organ hanging outside of her body, and although she is able to urinate, she is unable to complete bowel movements and relies on a colostomy bag to collect solid waste.

Her condition means that she's unable to digest food properly or even retain fluids. In fact, a glass of water would flush out her system too quickly and leave her dehydrated.

Instead, Mayana relies on a feeding line that delivers vital nutrients to a vein near her heart. It's a job that Eileen, 45, has been taking care of ever since her granddaughter was born — when she volunteered to be Mayana's primary carer.

"I've been caring for her since day one" Eileen said.

"When my son and his partner found out there was something wrong with Mayana, they worried that they'd do something wrong and accidentally hurt her.

"So I asked them if I could take care of her. I was nervous at first, but I don't think at their age they could have handled it, as they're only in their early twenties.

"But it doesn't mean that they don't love her and I've never judged them for it. That's what families do. They help each other out."



It was clear that Mayana had health issues from when her mum was 26 weeks pregnant. The ultrasound showed that her intestines were developing on the outside of her body, but her family had hoped for a miracle. But when Mayana was born she was rushed straight into a three-hour surgery, during which doctors had to remove all but 30 centimetres of her intestine.

When Eileen met her granddaughter the next day, she knew she had to help. That meant leaving her two teenage sons at home in Townsville while she moved to Brisbane to be by Mayana's hospital bedside for the next 14 months.

"Initially, it was hard being away from my sons, but I wanted to make sure she was getting the best care" said Eileen.

"I tried to make her life in hospital as normal as possible and made sure she had heaps of toys and decorations around.

"She needs dressing changes every week for her colostomy bag and central line, so it was helpful to learn how to do these things in hospital.



*Eileen has been caring for her granddaughter Mayana since she was a baby. Picture: Caters News.*



"I was so nervous at first, but now it's just our normal. Some people change dirty nappies, but I change dirty bags."

For the most part, Mayana is just like any other girl her age — the main difference being her diet. While she can technically eat, her digestive system is so fast that food has no effect on her body. This means that when Mayana does eat, she has to eat high fat, high protein foods that take longer to digest.

"She doesn't have to eat because she doesn't absorb anything out of it, but she likes the way things taste, especially chicken nuggets and strawberries" said Eileen. "Instead, she gets her nutrients from a bag that pumps into a vein near her heart. I hook her up every night so she's not running around with a pump all day. That way, she can get her nutrients while she sleeps."

"It's really not good for her to drink, either. It comes out of her like a waterfall and pushes everything out, which dehydrates her. "She's always asking for drinks though, so I'll give her an ice block or a Hydrolyte ice block to suck on."

To make sure she's getting the proper nutrients, Mayana's nightly feeding line is supplemented with monthly injections of iron and vitamin D. She also has routine blood tests and takes medications four times a day.

Hopefully with natural growth, her intestines will grow long enough where she'll be able to start on a normal diet. If not, Eileen says an intestinal transplant could be an option. But for now, Mayana has all the love and support she needs.

She's even getting a dry suit, which will allow her to take a proper bath for the first time. "With her bag and central line, she can't be immersed in water or she will develop an infection. "I give her daily sponge baths in a centimetre of water. But we've just ordered her a dry suit from the UK that will allow her to take a swim for the first time and splash around in mud puddles, which she loves. "She'll finally be able to enjoy summer."

Eileen, who has been in the Royal Australian Air Force for over a decade, says she's going to discharge in order to be able to give even more attention to her granddaughter. She said: "In the beginning, CPR was my limit, but now I'm doing dressing changes, giving her medications, and changing her bags. "I'm hoping to take a teacher aide course so I can go to school with her and help out in the classroom."

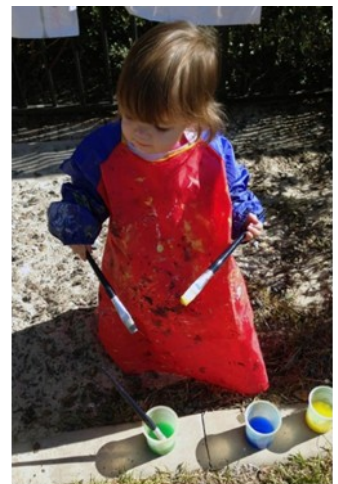
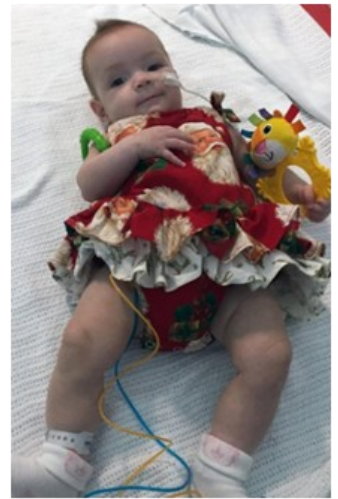
"Overall Mayana is a very happy well rounded toddler. Everyone who meets her loves her. She loves people and life and enjoys singing, dancing and socialising. Mayana is has an old soul; it is like she has been here before and she is here for a reason."

*Photos by Caters News:*

*Top: Mayana spent 14 months in hospital as a baby.*

*Mid: Mayana gets nutrients pumped into a vein near her heart every day.*

*Bottom: Mayana loves art and craft like most kids her age.*



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## Cruising for HPNers

WORDS BY GILLIAN

In November, Ray and I went on a 9 night cruise around a few islands in Vanuatu and New Caledonia, but rather than write about my holiday, I decided to write about the pros and cons of cruising as a holiday whilst on HPN (Home Parenteral Nutrition). I know that one of our retired readers in Canada, Laurie, and his wife, regularly cruise and enjoy it, and other PNDUers have cruised before, and although we haven't become cruisaholics, Ray and I would consider another cruise in the future.

The information in this article is based on a November 2016 cruise on Royal Caribbean Line's 'Explorer of the Seas', but I am in no way implying that it offers a better service or cruise experience than any other line. For more information for consideration when cruising with HPN, please see PNDU's [Travel Information Booklet](#) ('3. Cruising') available on our website [www.pndu.org](http://www.pndu.org) (go to Travel page). And always discuss with your hospital team and ensure your HPN needs can be met BEFORE you make any bookings. There may be reasons why cruising is not suitable for you.

### The 'cons' of Cruising

**Travel insurance** is, unfortunately, a concern and challenge for Australian and New Zealand HPN travellers, but

necessary considering any visit to the on-board doctor will not be covered by our national healthcare schemes, and the cost of an emergency medical evacuation from the ship would be exorbitant. Sadly, many HPNers 'down under' simply cannot get travel insurance for pre-existing illness. Even with companies which seem to cover our potential HPN and underlying disease related problems, complete cover may not be certain unless a claim is made, and then it is too late ... and we are left with a medical bill in the thousands or more. I went through a computer check with my travel agent and read the accompanying leaflet with all the 'small print' details, so I and my doctor believed that I was appropriately covered. To have greater assurance, you may choose to have a personal meeting with a health assessor. It's also important to take out appropriate cover for your medical equipment ie pump, charger, backpack (as required by Baxter Healthcare if leaving Australia/New Zealand). Ask your hospital to enquire of the equipment value for this purpose.

**Vaccinations** were recommended by my GP for both myself and Ray. We both had 2 injections which covered several diseases, but each of us had slightly different ones. You would need to discuss your needs with your own doctor.

**Activities** are endless on a ship, with things to do, both structured and unstructured, most of the day and night if you choose to avail yourselves of them. Unfortunately for HPNers, eating, drinking and swimming feature largely. Adult HPNers would probably be able to cope with this, but children on HPN might find it difficult. This is unfortunate, because a few friends with children have commented on how wonderful cruising is for the whole family, because there is something to do for everyone, and the children enjoyed joining in the organised and supervised activities for their age group.

**Food is included in the ticket price**, so if, as an HPNer, you cannot eat or have a very restricted diet, you pay costs for something you won't use. It may be worth checking with the cruise line whether a discount is available in this situation if you provide a letter from your doctor explaining your situation.

**Central line infections**, of course, are a risk for HPNers anytime, anywhere so this risk needs to be thought out. I haven't had a line infection for over 3 years, so, in consultation with my hospital team, decided to take the risk. If I had had a mild one while on this trip [although only cultures will show what sort it is], I was in Port Vila day 5 and Noumea day 7, both of which have airports to enable me to return to Sydney or fly to the nearest tertiary hospital for medical treatment. Also, if within flying range, a helicopter can land on these large ships to evacuate patients. As with any travel with HPN, you need to ensure you have all your up-to-date medical contact details and documentation in the event that you are unwell and need medical attention.

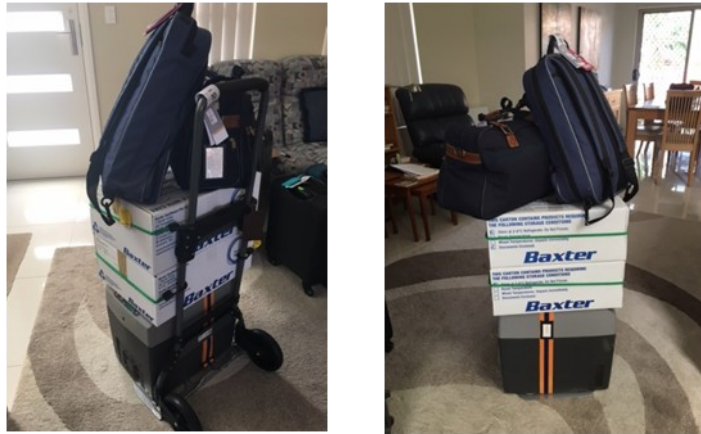
**Abandoning ship** is a highly unlikely event, not least because of the way ships are now constructed, but the possibility of this occurring is taken seriously by the crew, and before you set sail, there is a meeting at your muster station. All crew have a designated spot on the ship to point passengers in the direction of their station. You are told to go straight to the muster station, and not to get anything from your room, so if an HPNer was already connected to PN in an ambulatory backpack, it would be not be a problem. When booking a cruise, it is advisable to declare your medical situation to ensure everyone is aware and your needs will be met in any such event. (The life boats were used as tenders at 2 of our ports, and have a capacity in this use of about 80 people – which is comfortable enough- but when used as lifeboats, they can fit over 100 – which would make them very full.)

**Setting up** away from home can be a challenge, which I'm always happy to meet. 'Where there is a will, there's a way' is so true. Over the 10 years I've been on HPN, I've set up in many basic as well as more fancy motels, hotels, B&Bs, other people's homes and our caravan, so a lovely Junior Suite on a clean cruise ship was no problem. The main thing is to adapt – you don't need to set up near the sink after you've washed (and is advisable if the toilet is near the sink), provided you have a cup or something to prime the line into. As for any holiday with HPN, if you haven't got someone to assist, consider the tap configuration to ensure your hands remain clean when turning off the taps, and ensure you have a clean set-up area using a sterile sheet, travel tray, etc. If you hang your bag for set-up, consider using a coat-hanger or Ocky-strap for the purpose. Also ensure there is access to appropriate power supply in your cabin for your infusion pump's battery charger.

**Refrigerated storage of PN bags** was a potential problem which needed to be addressed in consultation with the cruise line. Baxter made a special delivery to home the Friday before my cruise departed on Sunday (although it may be possible to have a delivery made directly to the cruise ship before departure), which meant that I had my usual 7 night's PN, as well as an additional 5 bags of long life PN. As all these bags need refrigeration, I had organised with the cruise line, through their 'special needs' email, to store some of my PN in the hospital fridge. I always travel with my own electric car esky/fridge, which takes 3 or 4 bags, plus the suite had a small bar fridge, which took 2 bags. The special needs people had also arranged for me to have a small medical fridge in the room, too, which took 2 bags, so no problems storing my PN. All of our luggage was delivered to our suite, then Ray and I took the PN box down to the hospital (only 1 because of the extra fridge in our room). As with all holidays with HPN, always take with you at least one fridge thermometer to ensure it's working at the correct temperature, and take with you spares of everything in case of damage or unforeseen event.

**Travelling with large amounts of luggage** could have been a problem, but again, special needs said that there were pier attendants who would help, and they were correct. When our friend dropped us off with a large case each, hand luggage each, extra hand luggage with peripherals, backpack with that night's PN and pump, our car esky/ fridge and 2 boxes of my PN, the last 3 items stacked on a folding luggage trolley that we had bought, we couldn't

have managed on our own. But while Ray minded our things, I found a very helpful attendant who quickly helped us to carry/wheel our bags to the baggage handlers. The only slight hiccup was having to wait while the handler took my PN boxes and a letter from my doctor explaining my need for it to get approval from his boss. Remember to always have all your paperwork ready and handy (a medical folder with all your medical information, contact details and hard copies of approvals, etc kept with your hand luggage is a good idea).



*The medical portion of our luggage, on our fold-up trolley*

### **The 'Pros' of Cruising**

**Unpacking once** is definitely a huge plus with cruising. Most trips which involve travelling also involve packing up and moving on, but once you're unpacked on a cruise ship, that's it for the duration.

**Freedom** to do as you wish, with the options of organised activities such as art auctions, dance lessons, bingo, trivia, various sports activities; or doing your 'own thing'. If you can eat, breakfast and lunch can be eaten in either the more formal dining room where the meal is ordered, or at the more casual café buffet style dining room whenever you choose or sent to your room at no extra cost. The formal dining room had 2 sittings, but also 'my dining time', which you book for a time you wish as for any restaurant. The casual café/dining room was open whenever you wish to eat.

**Not shopping for food/cooking/cleaning up** is wonderful! Even if HPNers can't eat themselves, their spouse and family do, and the food choice is excellent and varied in both dining rooms, and well cooked.

**Entertainment** was varied and good quality. Each night there was an early and late show at the theatre, which featured a band, dancers, and headline acts such as comedians, illusionists and musicians on some of the nights. Our ship even had an ice-skating rink (available for anyone to use) as well as a terrific ice show with 10 professional skaters. There were movies outdoors next to one of the pools, bands or a DJ playing during the day as well as a featured player at one of the bars at night.

**Visiting several ports** in a short amount of time gives you a taste of other countries and cultures and the opportunity to do a tour that suits your interests.

**Lazing around the pool**, either in the sun or shade, reading a book, snoozing, people gazing or ocean gazing is quite relaxing. Wrapped up sandwich rolls were brought around at lunch time for those who couldn't be bothered moving to a dining room to eat.

**The price of the ticket covers most things**- but there are extra costs if you choose. The most obvious of these costs is drinks. Glasses of water and cordial-type soft drinks were freely available with meals, but bottles of water to drink during the day, soda-type soft drinks and alcoholic drinks were extra and charged at bar prices with 18% service charge, so it's up to the passenger whether to pay as you buy, or buy a drinks package to cover all drinks and service charge. A service charge was also added to your bill daily (or prepaid) to cover tips to staff. There was plenty of food with a wonderful range to cater for all tastes covered by the cost of the ticket, but there are also additional restaurants for those who want to pay for a smaller venue. Port tours are optional, but a good way of seeing around. Spa and hair salon treatments are available with payment and of course the temptation of shopping, both on board the ship and on shore.

**Wheelchairs, walkers and mobility scooters** were all used by passengers on this ship, who seemed to be able to access all areas. There were times that it would be difficult for people with these to get into the lifts because of large numbers of passengers already in them, but with 6 lifts towards the bow and 8 near the stern, a short wait would bring another lift. Wheelchairs were allowed in the ship's tender to go ashore, but not mobility scooters or walkers.

### **Summing up**

As with all holidays, enjoyment of cruising is a personal like or dislike. The information above gives an overall idea of aspects of cruising which could affect an HPNer and their family, but any specific questions or concerns would need to be addressed by your hospital team and the cruise company offering the itinerary that interests you. Ultimately it is



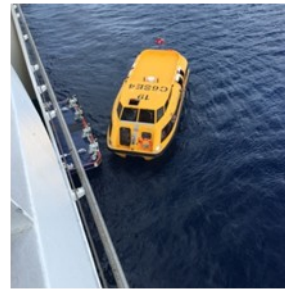
your responsibility to ensure all your HPN needs will be met, so talk with your hospital team and start planning early, and see PNDU's [Travel Information Booklet](#) for more ideas and considerations.



*Near a pool*



*Café/restaurant*



*Lifeboat/tender to port*



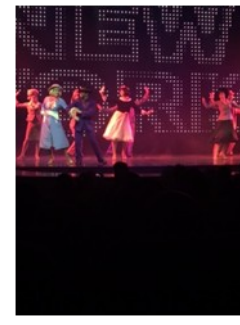
*Island of Maré*



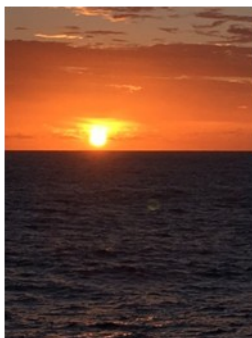
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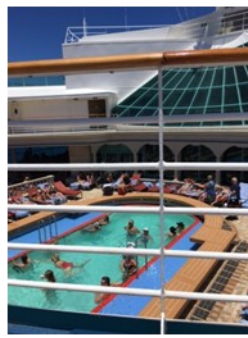
*Mystery Island*



*One of the shows*



*Sunset*



*One of the 3 pools*



*Ice show*

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## A Great Day Out

**Editor's note:** *This is a new semi-regular item for members to share events that are special to them.*

**Daniel**

My great day out started on the 30th October, 2016, when I planned to photograph the 50th anniversary of Steamrail Victoria, "The Vintage Train".

There was a parallel run to Geelong, with both trains booked out, so I had intended to just get a photograph at Tottenham and then at Lara on the return run.

I made a quick visit to Southern Cross Station, where I met some staff members who I knew, who asked if I was coming. I said no as I didn't have a ticket, and they said they could make some room. So I still photographed the out run to Geelong of one train, then caught the clone train. While I was there, I



had time to look around the shops as I hadn't been there in ages.

I then caught up with the guys of the film crew from Railroad Australia for a chat.

I got my ticket and travelled back on train one with mates who had a compartment. Our train had a parallel run with the other train between North Geelong and Little River.

We arrived back at Southern Cross Station about 20 minutes late. My mates wanted a beer, so we continued chatting until we went our separate ways about 5pm.

I got home about 7pm then got all my PN ready.



### Jacqueline

Last weekend I attended the Tasmanian Craft Fair, which is the largest fair in the Southern Hemisphere.

As basketmakers, my group was invited to show and tell for the four days. A new section, lost arts, saw approximately 8 stalls of old arts.

It was a fantastic time with much interest from the public, even from unlikely people, such as a Melbourne businessman.

We sold a considerable amount of our own work, had many people enlist for future workshops and several people joined our group. This is some of the works produced by some of our members.



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## What does an HPNer wish for?

**Editor's Note:** For a presentation Karen recently gave about what living with HPN involves and its limitations on our lives, she asked on the email forum what things members living with HPN wish for – our dreams. Karen read out the following at the end of her presentation:

- Travel, swimming and energy to do more things;
- spontaneity to go out/go away (to be more carefree);
- infuse all that's needed in a short time, not half the day;
- wear whatever I want in summer without having to expose medical peripherals;
- I would like to eat!
- be able to work instead of being in hospital regularly
- not spend loads of money on things medical
- a long hot shower without dressings lifting;

- freedom of movement - not tied to a IV pole or heavy backpack;
- Days off PN would be a dream come true;
- Not having to deal with lifting dressings on a hot day;
- rolling over in bed without getting tangled in my line
- understanding from friends and family that HPN isn't a miracle that fixes everything;
- Going out at night without a backpack;
- Drinking water rather than St Mark's solution

## Recycling our silver bubble wrap...

WORDS BY LARA

Here's a picture of our table all set for Christmas Day. It's hard to see, but the tablecloth is made of my silver bubble wrap from the last month of deliveries. It works really well... shiny and Christmassy, and heat and cold proof. For people who don't understand what a coaster is, it protects the table underneath.



## Self-healing slippery surface coatings for medical devices could help thwart infection

Source: Beth Israel Deaconess Medical Centre

Published on November 1, 2016 at 10:45 PM

Implanted medical devices like catheters, surgical mesh and dialysis systems are ideal surfaces on which bacteria can colonize and form hard-to-kill sheets called biofilms. Known as biofouling, this contamination of devices is responsible for more than half of the 1.7 million hospital-acquired infections in the United States each year.

In a report published in *Biomaterials* today, a team of scientists at Beth Israel Deaconess Medical Center (BIDMC), the Wyss Institute for Biologically Inspired Engineering and the John A. Paulson School of Engineering and Applied Sciences (SEAS) at Harvard University has demonstrated that an innovative, ultra-low adhesive coating prevented bacteria from attaching to surfaces treated with it, reducing bacterial adhesion by more than 98 percent in laboratory tests.

"Device related infections remain a significant problem in medicine, burdening society with millions of dollars in health care costs," said Elliot Chaikof, MD, PhD, chair of the Roberta and Stephen R. Weiner Department of Surgery and Surgeon-in-Chief at BIDMC and an associate faculty member at the Wyss Institute. "Antibiotics alone will not solve this problem. We need to use new approaches to minimize the risk of infection, and this strategy is a very important step in that direction."

The self-healing slippery surface coatings - known as 'slippery liquid-infused porous surfaces' (SLIPS) - were developed by Joanna Aizenberg, PhD, a Wyss Institute core faculty member, Professor of Chemistry and Chemical Biology and the Amy Smith Berylson Professor of Materials Science at SEAS at Harvard University. Inspired by the carnivorous *Nepenthes* pitcher plant that uses the slippery surface of its leaves to trap insects, Aizenberg engineered surface coatings that work to repel a variety of substances across a broad range of temperature, pressure and other environmental conditions. They are stable when exposed to UV light, and are low-cost and simple to manufacture. The current study is the first to demonstrate that SLIPS not only limit the ability of bacteria to adhere to surfaces, but also impede infection in an animal model.

"We are developing SLIPS recipes for a variety of medical applications by working with different medical-grade materials, ensuring the stability of the coating, and carefully pairing the non-fouling properties of the SLIPS materials to specific contaminants, environments and performance requirements," said Aizenberg. "Here we have extended our repertoire and applied the SLIPS concept very convincingly to medical-grade lubricants, demonstrating its enormous potential in implanted devices prone to bacterial fouling and infection."



In a series of trials, the researchers tested three SLIPS lubricants for their anti-adhesive qualities. First, they incubated disks of SLIPS-coated medical material ePTFE - a microporous form of Teflon - in a broth of *Staphylococcus aureus* (*S. aureus*), a generally harmless bacterium found in the nose and on skin, but one of the most common causes of hospital-acquired infections. After 48 hours, the three variations of SLIPS-treated disks demonstrated 98.3, 99.1 and 99.7 percent reductions in bacterial adhesion.

To test the material's stability, the scientists performed the same experiment after soaking the SLIPS-coated samples for up to 21 days in a solution meant to simulate conditions inside a living mammal. After exposing these disks to *S. aureus* for 48 hours, the researchers found similar, nearly 100 percent reductions in bacterial adhesion.

Widely used clinically, medical mesh is particularly susceptible to bacterial infection. In another set of experiments to test the material's biocompatibility, Chaikof and colleagues implanted small squares of SLIPS-treated mesh into murine models, injecting the site with *S. aureus* 24 hours later. Three days later, when the researchers removed the implanted mesh, they found little to no infection, compared with an infection rate of more than 90 percent among controls.

"Today, patients who receive implants often require antibiotics to keep the risk of bacterial infection at bay," the authors wrote. "SLIPS coatings one day could obviate the widespread use of antibiotics and minimize the development of antibiotic resistant micro-organisms."

"SLIPs have many promising medical applications that are in a very early stage of evaluation," said Chaikof.

"Clearly, there's more work to be done before its introduction into the clinic, but this is one of a few studies that reinforces the exciting opportunities presented by this strategy to improve device performance and clinical outcomes."

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## A Day in the Life of an HPNer ... Best Laid Plans

WORDS BY GILLIAN

### The Plan:

Good friends have been travelling around Australia in their caravan for the past seven months. Although they are back in Sydney, they are puppy-sitting for their brother on the other side of the city at Freshwater. They are then off for another month down the coast, so we carefully planned a 2-night stay with them, finally finding dates that suited both of us. Since I have to be home on Tuesdays for delivery, Friday for Ray's tennis and Sunday for my church and Ray's tennis, the only 2 suitable nights are Tuesday and Wednesday, departing after my delivery arrives early in the afternoon (I hope!) Next week was the best week as I had appointments or social activities already slotted in to other weeks, as well as my friends having things planned at times, also.

### The Reality:

The Saturday night before our planned break, I was setting up and noticed that there was a split in the outer casing of my Hickman's catheter. Luckily it wasn't broken all the way through and didn't leak, so I could still infuse and not worry about exposure to germs, and thus the possibility of infection. It isn't something to take lightly in case of further cracking, but of course, the PN nurses at my hospital only work Monday to Friday, day shift and this was Saturday night! So I sent an email with the picture below attached so that my nurses would be informed first thing Monday morning. This meant that unless the Hickman's could be repaired that same day, our visiting plans were out. This, of course, was dependent on their work load for the day, plus the availability of a repair kit. One of my nurses had repaired my previous Hickman's so I knew that it could be done. I spent the next day wondering whether to cancel our plans or expect our friends to be up in the air as to whether to expect visitors or not. Oh well, the best laid plans don't always work out, and they are very good friends who would sympathise with my dilemma.

### The Outcome:

I emailed my nurse Sunday night, with this picture, so that she would have it first thing Monday morning. By 8:30 she had ordered a new repair kit, because, unfortunately, the four kits that they kept in stock were all out of their use-by date by a couple of months – repair kits aren't needed very often, so this hadn't been noticed. The company promised to deliver the next day, so I was able to have the repairs done in the afternoon, then continue on our friends'. Happy result!



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## Exercise for the HPNer

**Editor's note:** Most people nowadays recognise the need for exercise to keep fit and healthy and many try to fit it into their weekly routine, whether walking, jogging, swimming, cycling, sports, gym or classes. Unfortunately, you

need to feel well and have some energy in order to participate in exercise. The following are some comments from people on our email forum about their ability to exercise, as well as the wide variety trialled.

- I went to yoga for the first time in a long while this morning. It was sooooo great. I've really missed it.
- I do lyengar yoga, which is nice and slow and focussed on strength building, but, I came home with a headache and feeling thirsty.
- Mentally, I usually dread exercise because I know it will exhaust me. But yoga feels a little different for me, in that it is more invigorating than draining on my body.
- On good days I'll do a few reps of 5kg, but it makes me thirsty. Otherwise I just go for a walk just close to home, daily.
- I go for a 25-30 minute walk near home. I did have some upper body exercises to do, but they went out the window when life got busy.
- I struggle with exercise. I took up dancing with my daughter in about 2003 and did that for a few years. Then fulfilled a life-long dream and did adult ballet classes. I was the worst ballet dancer but the most enthusiastic! These days, a walk close to home; gardening; running around and playing soccer with my grandson; chores/ maintenance all require some oomph! My physiotherapist encouraged me to try tai chi. Note: one activity per day though these days!
- I did dancing from age 8 until I was 14 years old. I had CIPO then but no central lines until I turned 14, only NG tubes. When I got my first infusaport, I had to quit dancing. It was on the side of my ribs and very much in the way. Dancing always encouraged motility in my gut. I'd arrive home hungry and most often eat my mum's spaghetti bolognese after practice. I got to the age where all the bloating etc was really hard to deal with. Dancing costumes aren't great for covering up symptoms.
- I've enjoyed healthier times in my life when I did weight lifting. It always made me feel good, though exhausted. I'd go to the gym for 30mins in the morning and barely do anything else for the rest of the day! This was quite a while before I got pregnant with my son and there were fewer demands on my time.
- I don't enjoy walking very much. My hips get very sore and my feet go numb when I wear 'proper' shoes. I love some short strolls whilst sightseeing, though.
- I occasionally walk the dog as exercise. My GP told me to walk more, to help the bone density loss in my hips. I do gentle stretches and weights most mornings. Still waiting for the six pack!!!! Surely housework and hanging washing in the line and gardening counts!
- I walk every day and do two Pilates classes a week. Moving certainly helps my health.
- I was into sports before I got sick. I was a good runner up until my late teens/ early 20's when I started to show signs of a connective tissue disorder and my gut problem. By that age I just didn't seem to have enough energy for training high level. Plus, as I was trying to juggle study to get into university, I find that there is nothing better than running to clear your head. I miss it a lot. I used to run every day, even when I was working. My aim for the New Year is get back to running most days. I want my body back. I love the feeling of being super fit.
- For a while, my team weren't really supportive of my running. They were worried about my port. But my port is in my left subclavian so I just make sure I have a really tight sports bra on so it doesn't move around too much. Then of course I'm also careful to make sure that I don't lose too much weight if I manage to get the km's up, which I did a couple of times.
- I did line dancing until this year. I really enjoyed it and hope to go back when I finish this lot of surgery and the required physiotherapy.
- I'm able to walk briskly for half an hour Monday to Friday, giving myself the weekend off. It's also my quiet prayer time. I also do about 50 minutes of Pilates mat exercises, which really improves my strength, flexibility, endurance and balance. I'm lucky that I have the energy to do this, as in doing it, it improves my energy levels.

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## Christmas thank you Gift

**Editor's note:** one of our members, Amy, made these for her son, Zander's, PN nurse for Christmas. She thought it was fitting, as with his PN nurse's support, Zander has doubled in weight this year.



## Birthday Corner

On December 8th, Bryley (HPNer) celebrated her 16th birthday, but not the way she had planned! Unfortunately, Bryley has been in hospital for 3 weeks as an infection set in after an operation, but fortunately there were some positives. Luckily, Gail (her mum), was able to arrange for a nurse to accompany Bryley to the downstairs hairdresser where she had her hair washed for the first time in 3 weeks, as well as coloured. They also gave her a free manicure, so this helped her feel much better. Receiving lots of presents also helped to make the best of a bad situation.

Ariel (HPNer) had a wonderful and epic 6th birthday! We spent the morning at the beach on her new boogie board and then a visit to Dave, her dad's, office for some ping pong, before spending an hour with the kittens at the cat café, followed by a twilight party! Needless to say- she is sleeping like a log now!



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## Planning Overseas Travel with HPN?

### WORDS BY KAREN

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

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

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



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## PNDU's new website launch

Thank you for your patience.

We didn't quite reach our initial plan for a November 2016 launch date of our new website, but progress is still being made and we are hopeful for a launch in the first half of 2017.



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## Thank You

We wish to thank the following for their generous donations which totaled \$5265:

CaPPRe—donation nominated by member who took part in CaPPRe research

Friday Ladies' Bible Study Group, NSW

Shire Australia Pty Ltd, (\$5000)



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# PNDU Membership for Aussie and Kiwi HPNers and carers:

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

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

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



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

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

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## Donations

If you would like to support the work of PNDU, we would welcome your donation, no matter how big or small. When making direct deposits, please provide your name as a reference. If you require an acknowledgement/receipt of your donation, please email us at [contactpndu@gmail.com](mailto:contactpndu@gmail.com).

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### AUSTRALIA:

**Online donations:** PayPal via our website [www.pndu.org](http://www.pndu.org) or **Direct deposit** (Australian dollars only) to PNDU Inc.'s bank account:

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

### NEW ZEALAND:

For our Kiwi members, our sister charity IPANEMA (Charities Commission Registration CC21178) kindly receives donations on our behalf by:

**Direct deposit** (New Zealand dollars only):

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

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