



It is with great sadness that PNDU has lost three of our HPN family members during September. Our hearts go out to the three families as they adjust to life without their loved one and hope that they are comforted with the love of family and friends. Graeme has written a tribute to his wife, Carol, to remember her fulfilling life despite great adversity, and Karen begins this edition with a tribute to all 3 members.

In this issue we also have a great story celebrating one member's artistic talents; we learn about the joy that pets bring to some of our members; we read about several aspects of HPN Awareness Week activities; there are updates on various PNDU matters; results of our PNDU Pump Survey are included; and read an abstract of the latest AuSPEN adult HPN Vitamin Guidelines; plus much more.

Gillian - Editor

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Goodbye to 3 dear members

WORDS BY KAREN

Life with Intestinal Failure is precarious and especially fragile. At PNDU we are all well aware of the reality of life on HPN, but it still hits us hard when a member of our PNDU family passes away. This September was simply a blur as we lost 3 dear members – Carol, Sam and Nat.

We are blessed and so very grateful to have shared a part of these precious ones' lives and to have walked some of their journeys with them and their families. We give thanks for Carol, Sam and Nat – 3 very different souls at very different stages of life – and stand in awe of the courage and grace with which they each lived.

Although rocked and incredibly saddened by such loss in our PNDU family, our thoughts and prayers continue to be for their loved ones. And may we each never forget how precious and fragile our lives are.



My tribute to Carol (HPNer)

WORDS BY HUSBAND, GRAEME

Carol was born in Innisfail, Far North Queensland in July 1949, and lived opposite the showgrounds, and with the Show always on or around her birthday, she and her sisters would spend lots of time there.

Around 13 years of age, her health conditions came to the fore. Today we might describe it as severe Irritable Bowel Syndrome, and it caused distension, diarrhoea, discomfort, and lethargy with which she suffered for the rest of her life. The Doctors in Innisfail sent her to a specialist Gastro-Enterologist in Melbourne who classified it as CIPO, but all that could be offered was symptomatic treatment.

Carol left home at 17 to go to Townsville to train as a nurse, then went to Melbourne in the early 1970's and did her Midwifery Certificate at Royal Women's Hospital, then trained in Maternal & Child Health in Brisbane around 1972. After completing her Certificate, she worked as a relieving Maternal & Child Health Nurse in Bundaberg, Cairns, Innisfail, Bowen and Proserpine. At this time big skies were calling, and a couple of the girls she did Maternal & Child Health with had the hair-brained idea of travelling "overland" to London, and asked Carol to join them. In 1974 they left, and went up through Indonesia, Thailand, Myanmar (then called Burma), and India. They did the Mt Everest Base camp walk, and Carol got within a day's journey of base camp when she was affected by altitude sickness, and had to be brought out on a donkey over the narrow ledges and precipices. Carol flew to London, and worked as a nurse for several months and during this time she had a consultation with an eminent Gastro-Enterologist Dr J E Lennard-Jones who is now regarded as the grand-father of Gastro-Enterology. Whilst he was interested in her rare gut condition, he was unable to help her.

Carol applied to do a Post-Basic Paediatric Certificate in London, but was not accepted. It was through God's providence that she then applied to do the Certificate at Royal Children's Hospital in Melbourne and was accepted. Returning to Melbourne in 1976 she met me.

We married in December 1978, and initially lived in Melbourne, then moved to Traralgon a year later and built a house where we lived 25 years while I worked in the Latrobe Valley Power Stations, mostly at Yallourn.

I was retrenched through an organisational restructure in 2002, and we moved to Cairns in 2003. At that time Carol took the opportunity to retire from work, as her health was constantly becoming a battle. Together we had a wonderful time in Cairns and were blessed with a constant stream of visitors from all over the world. It was a time when Carol was able to return to her childhood roots, including the Innisfail show on several occasions.

In 2010, when I retired, Carol's health was seriously declining, and we returned to Melbourne. Carol was put onto "Total Parenteral Nutrition" (TPN) in March 2011, with a 4 month stay in hospital. The TPN was like watering a floundering plant in the desert, and Carol recovered and flourished.

In 2013 Carol was diagnosed with Scleroderma – a connective tissue auto-immune disease. In her case, the scleroderma had taken away what little peristaltic movement she had in her bowel and had led to total intestinal failure; and also affected her lungs giving her Chronic Obstructive Pulmonary Disease (COPD). With only around 30% lung capacity, any activity was difficult. Especially when combined with copious amounts of uncontrollable diarrhoea.

Carol never took her eye off the prize of heaven at the end of life's journey, and was still hospitable to visitors even up to the last few weeks.

Ultimately the COPD ended her journey late on Friday afternoon 2nd September at Cairns Hospital, and she went to

her reward with the Lord. Well done good and faithful servant. Many daughters have done well, but you excel them all. ([Proverbs 31:10-31](#))



I would like to thank everyone in PNDU for the love, encouragement, support and help from this special group, both whilst Carol was on TPN, and also with the heartfelt wishes on her passing. I have "gone quiet" for a little while, but I will respond soon. Please know that I appreciate all of you thoughts, prayers, and well-wishes.

An HPNer Drips with Talent*

WORDS BY JACQUELINE

****Editor's Note: 'HPNers Dripping with talent' was PNDU's 2016 HPN Awareness Week motto. Jacqueline kindly wrote her story for use in our 2016 HPN Awareness Week media release. Her full story is printed here. A wonderful example of the amazing talents of some of our HPNers.***

After 6 years of vomiting, abdominal pain and distention, aspiration pneumonia, bowel obstructions accompanied by multiple surgeries and large weight loss, I was finally diagnosed with intestinal failure, but the underlying cause of scleroderma came several years after HPN (Home Parenteral Nutrition) was started in 1999.

Over the past 16 years the PN bags, their volume and recipe, have changed many times and although at times it reached 6 bags per week, the infusion time was 12 hours, thus allowing me to work 5 shifts per fortnight in a busy hospital Accident and Emergency Department. However, things changed last July when again the bags were increased to 6 per week and the infusion time is now 17 hours. This forced me to stop work for the interim until things improve. But my time is still busy, not from the fundamental way of earning money but instead by filling my days with artistic expression and creativity. For me, the juggling of ongoing illness is lightened by the creation of something.

Making things has always been an integral part of my life for as long as I can remember. As a child I tried my hand at knitting which grew to spinning, I then started a self-taught trip into sewing, including window dressings, clothes, upholstery and of course the patch-work quilt. But upholstery saw me needing to repair the furniture first, so was borne the interest in woodwork. My first project was the kitchen cupboards in our first self-built house, when my husband and I attended Adult Education classes to learn the basics and have access to the necessary tools.

From there, tiling, painting and stained glass became my focus, where my interest has remained and I still dabble in all these, especially with every subsequent house renovation (6 in total). Simultaneously, I've found an interest in artisan concepts, which has seen me try my hand at pottery, printmaking, leather work, natural fibre baskets, beading, eco-dyeing, paper art, shoe making and calligraphy, but my main focus for the last 14 years has been bookbinding. This ranges from traditional styles using leather bound covers embossed in gold leaf, to artist books, which incorporate most of the fore-mentioned techniques. With already



acquired skills in timber, I make many wooden boxes, books and slip covers and make my own paper, then eco-dye and bind them together using cane toad leather, snake leather and fish leathers. Surface embellishments range from found objects to handmade items such as antler carvings, stone carvings, dried mushrooms and wire figurines.

Belonging to several artisan groups in Hobart facilitates the networking with other artists, their ideas, sharing equipment, offering support and the ability to hold joint exhibitions. I try to attend as many workshops as possible, as well as run my own in book binding and eco-dyeing.

The basket makers group hold two camps per year in the warmer months, where the members have the options of doing their own work, participating in workshops, usually run by visiting artisans, or just spending the four days talking and catching up with friends. I try to attend at least one camp, which allows me to spend four days with like-minded, enthusiastic people who share ideas and always have a positive response to your show and tell.

I've been in the fortunate position to be able to obtain much of the equipment and supplies needed to do my work and of course that requires space to store and work, in which again is a thing I'm very lucky to own...my own studio. I can't think of one skill learnt that doesn't get revisited at some time or other to complete a project. Supporting other artists by attending each other's exhibitions or their openings goes without saying and having free evenings has certainly allowed me to do that. They in return attend my exhibitions and opening and often even purchase items...how lucky is that?

In my spare time I work in the garden, which I have created over the last six years. Totalling just under an acre, I pride myself in a beautiful, peaceful garden with dramatic views of Mount Wellington and of course it contains many of my metal, wire, glass and timber garden sculptures. There's no grass, but two large ponds and waterfall, meandering paths and peaceful hideaways. I even won a garden award four years ago, given by my gardening club.

So with all these interests and so many workshops to take I don't have time to be sick, but, conversely, without being ill, I wouldn't have all this time on my hands to create. How lucky am I to have a portable pump and back pack? This gives me the freedom to work in my studio, in the garden or finish our latest house renovation.



Jacqueline, HPN backpack on, infusing while she works





HPN Awareness Week 2016

WORDS BY KAREN

So how successful was HPN Awareness Week 2016? See for yourself! This is a word-cloud of feedback we received:

Thank you to everyone who got involved and used this week to raise awareness amongst family, friends, work colleagues and more. We were thrilled that a number of hospitals joined the celebrations this year (see article below) and look forward to more hospitals joining us next year. A big thank you too to our industry friends – Baxter Healthcare, Fresenius Kabi and Shire for their support and joining in the celebrations. Karen was invited to talk about HPN at a Shire staff morning tea celebration during Awareness Week, and both Chris and Karen were invited to tell their stories to Baxter Healthcare's Senior Leadership Team.

With the superb [2016 HPN Awareness Week video clip](#), stickers, posters, media release, HPN information flyer, social media profile, as well as the Baxter Healthcare pharmacy tours, there were many ways to get involved across Australia and New Zealand.

From next year, in order to align with the inaugural Home Artificial Nutrition (HAN) Awareness Day on 15 October 2017 (covering both Parenteral and Enteral Nutrition), **HPN Awareness Week 2017 will be pushed back to mid-October.**



HPN Awareness Week 2016 – how hospitals got involved

WORDS BY KAREN

We were really encouraged to have various hospitals join the HPN Awareness Week celebrations this year – Gold Coast University Hospital; Princess Alexandra Hospital Brisbane; Lady Cilento Children's Hospital Brisbane; Royal Brisbane Hospital; Women's and Children's Hospital Adelaide; and John Hunter Hospital, Newcastle.

Below is how some got involved. Others displayed the posters, wore the stickers and used the week as an opportunity to talk about HPN. With some helpful feedback on ideas to help hospitals get involved, we are looking forward to many more hospitals joining in next year.

Many thanks to all the hospital staff who got involved in various ways and celebrated this important week.

Gold Coast University Hospital:

We had one of our home patients in so we used that opportunity to celebrate HPN week in that particular ward – the Gastro ward. We put up the posters and provided the ward with an afternoon tea. We had 6 very inquisitive student nurses there, a dietitian and nursing staff from morning shift and late shift call through for some goodies to eat. We got asked a lot of questions about vascular access, gut failure, PN and we tried to convey the life impact (both positive and negative) gut failure and PN has. We thank you for the posters, stickers etc and next year aim to plan a bit more ahead of time to be able to spread the word further.



Gold Coast University Hospital HPN Awareness Week celebrations. Notice the cake decoration – a bag of PN!



HPN Awareness Week display at Princess Alexandra Hospital, Brisbane.



Lady Cilento Children's Hospital Brisbane – staff and patients get involved

HPN Awareness Week 2016: PNDU Member Activities

WORDS BY GILLIAN

HPN Awareness Week 2016 (AW) started with the release of [PNDU's annual video](#), showcasing four of our members, children and adults, 'dripping with talent', this year's motto. We saw Jordan building with blocks, Jane in her garden and with a few of her artworks, Sal decorating a cake and Ariel playing music while her parents loaded up her pump ready to infuse her PN.

Many members got involved and enjoyed spreading the word and raising awareness for PNDU and HPN amongst their family, friends, work colleagues and hospitals.

To be involved was as easy as wearing the AW sticker all day, which was often enough to start up a conversation.



Chris, a carer of two HPN grandchildren, visited his grandson Logan's preschool, which displayed a poster and flyer and Logan's carer agreed to wear an AW sticker each day for the week. All 3 brothers wore their AW stickers to school/preschool through the week, and the family shared the AW message far and wide, including getting Variety and Lions Club to help highlight the week.



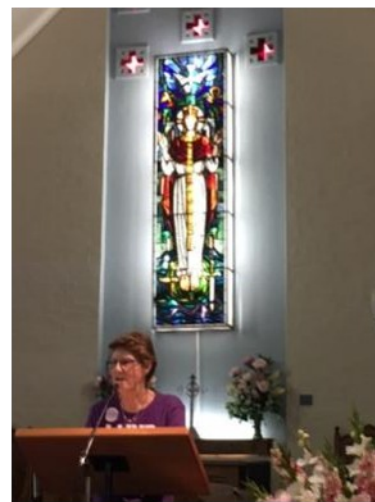
Renee shared the video on Facebook, wore her sticker and also sent the PNDU video to all her specialists involved in her care.

Justine wore her sticker on her backpack whilst infusing, including at her place of work.

Sal shared the video on Facebook, wore her sticker to work at the hearing clinic and showed the video to her boss, who generously made a donation to PNDU. Her eldest wore a sticker on his backpack that he takes to university on public transport.



Ariel wore her sticker whilst touring around the Northern Territory with her parents and sister. Here she is at the Devil's Marbles.



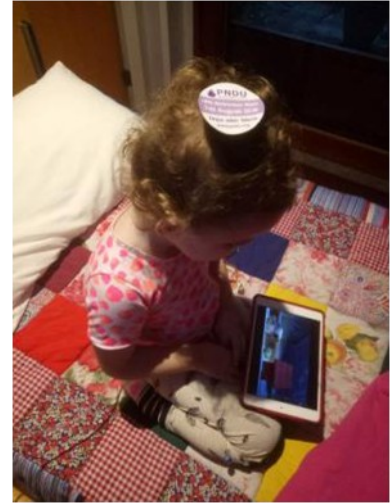
Gillian wore her sticker most days. She sent the PNDU video link to her doctors, nurses and dietitian and put a link on her husband's Facebook page. Her dietitian shared it with all the dietitians at St George and Sutherland hospitals. Gillian also spoke about living with HPN at her Sunday church service.



Karen wore her sticker each day, initiating some conversations, including to church. Like many members, she also sent the AW video to her hospital team, family and friends, and posted it on Facebook.

Little Zander flying the AW flag while in hospital. Mum Amy had hers on her phone case when it wouldn't stick on her shirt.





Milla wasn't so well during her stay at Bear Cottage during Awareness Week but still managed to share her AW stickers! Bear Cottage ran a piece on Milla during AW, with HPN Awareness being the feature on their Facebook page.

HPN Awareness Week 2016: tours at Baxter

WORDS BY GILLIAN



Sydney Baxter pharmacy tour – observing the compounding of parenteral nutrition – ‘looks like something you’d see at NASA!’ Photo courtesy of Baxter Healthcare Pty Ltd

One of the highlights of HPN Awareness Week 2016 was a tour of Baxter's Pharmacy for Aussie and Kiwi HPNers and carers. The tours were organised by PNDU with Baxter in capital cities around Australia and New Zealand.

These visits had a two-fold benefit. Firstly, they enabled HPNers and carers to see how PN is compounded and meet the staff who do this. This is an amazing experience for any HPNer or carer – to see the high-tech facilities, the dedicated and skilled staff and the extreme measures taken to ensure our products are safe. As one member commented, it looks like something you'd see at NASA!

Secondly these tours enabled Baxter staff members to meet real life HPNers face to face – people who use the products they spend so many hours and so much dedication preparing – and hear their stories. This opportunity helps give life to their work and reinforces just what an important job they do. What they do literally keeps HPNers alive.

Brisbane:

In Brisbane, Celena, her father Doug and Sarah (whose daughter, Lara, is in the arms of a Baxter employee in the photo below) toured the facility and shared their stories with the staff. Four clinicians also joined the Brisbane tour.

There was a special meeting, too, for Celena, with a staff member who remembers making her PN many years ago in the Sydney pharmacy!

Some quotes from the tour:

"Every syringe, everything you draw up affects our lives. Your high standards matter, they keep us alive. Thank you very much from us and our families for what you do." Celena (HPNer)

"You have changed my child's life. What you provide is life changing and lifesaving. To know such care is taken preparing her food and to get her meal each night is incredible. PN gives you a life you never thought would be possible. We are grateful to live in a country that gives us this opportunity. Thank you for being such a part of something so special." Sarah (Lara's mum)

"It was so brave of Celena and Sarah to share their personal journey, it was very moving." Marina (Pharmacy)

"Definitely one of the best presentations I've been to. Hearing their stories and how our products help them live has inspired me in my work." Aaron (Pharmacy)



Baxter Brisbane staff with young Lara, Sarah (standing) and Celena (seated)



Celena with an 'old' friend

Christchurch:

Alan (HPNer) and his wife, Ruth, travelled across the country to Christchurch to tour Baxter's pharmacy and had an enjoyable tour of the facilities.

Auckland:

In Auckland, Veronica (HPNer) and husband Ray were shown around the pharmacy. Unfortunately there is no picture available.



Alan and Ruth

Perth:

In Perth, Baxter had a visit from Steve (HPNer), his wife, Sharyn, Clare and her husband, Mike, with both their children Elsie and Bertie (who are both on HPN – read their story in [issue 16 of Dripline](#)).

From Clare: What a brilliant day learning all about PN and the fantastic team at Baxter. Thank you so much for organising today. Sharyn, Steve, Mike, me, Elsie and Bertie learnt lots and were very impressed.

From Sharyn: Steve and I enjoyed the tour and seeing 'Errol' the PN compounder in action. Everyone seemed nice and supportive and I think appreciated hearing real stories from real HPNers. It was also nice meeting Clare, Mike and their children.



Clare with Elsie and Mike with Bertie, with Perth Baxter pharmacy staff.



Sharyn giving the carer perspective of living with HPN.



Mike with Bertie, Clare with Elsie, Steve and Sharyn with Perth Baxter pharmacy staff.

Sydney:

In Sydney, HPNers came to the Baxter Pharmacy from all over the place: Gillian, from the south; Karen, from the north; Justine from further north; Carers Chris and Tanya from the Newcastle area; Geraldine from Canberra; and finally, a mighty effort from Daniel, who flew from Melbourne for the tour! Chris and Karen were generously invited to speak about living with HPN to Baxter's Senior Leadership Team, and then met up with the rest of us where we donned high-visibility vests for the tour.

We were shown around the pharmacy by Vimal and Andrew, observing the amazing facilities, machinery and staff compounding and then labelling both chemotherapy and PN. After this, about 100 staff members came to hear us talk about life on HPN. They were very attentive and we received much positive and interested feedback. After this, the HPNer visitors had a drink and a chat in the café, getting to know each other better.



Left: Chris and Tanya (carers of 2 HPNer grandchildren), Daniel, Jerri, Gillian, Justine and Karen (all HPNers)



Above: Jerri talking to Baxter staff



Left: In the coffee shop – Justine, Chris, Tanya, Karen, Gillian, Daniel (three of us wearing our PNDU T-shirts, [available on our website](#))

This was an excellent activity for HPN Awareness Week, one which HPNers, carers and Baxter staff alike will remember with fondness for a long time. Thank you to Baxter Healthcare and all the pharmacy staff who worked with PNDU to make these tours possible during HPN Awareness Week. There was a lot of organising involved [a big thank you especially to Mary and Karen] and we appreciate all the effort for such worthwhile events.

PNDU on the World Stage

WORDS BY KAREN





Karen with other PACIFHAN members from UK, Italy, Poland, Czech Republic, USA and Sweden

In July this year, in my role as PNDU President and representative in PACIFHAN, and as PACIFHAN's Interim Convenor, I travelled to London for two days of workshops. Travel and both days of workshops were sponsored by Shire. Because PACIFHAN is not yet a legal entity, organising travel and attendance for all of PACIFHAN's 9 member country representatives was no small feat and I am thankful to Greg at Shire, and IS Health's Natalie and Tara for making it happen.

The first day was our own separate and independent PACIFHAN workshop. Working closely with Natalie and UK's PINNT representative in the months prior, we had a wonderfully interesting but also very professional program prepared, with opportunity to reaffirm commitment to our mutual goals; continue work and make some important decisions on our legal set up; decide on an improved communication system; look at how to approach future projects, including the inaugural HAN Awareness Day on 15th October 2017; and film a promotional video. It was an ambitious program and we didn't get through it all, but with IS Health facilitating, it was a productive day and we were able to make positive progress.

PACIFHAN is the International Alliance of Patient Organisations for Chronic Intestinal Failure and Home Artificial Nutrition (a mouthfull!). It began on the sidelines of ESPEN Congress in Geneva 2 years ago and now has 9 member organisations from Australia/New Zealand, Czech Republic, Denmark, France, Italy, Poland, Sweden, UK and USA. PNDU has been part of the Alliance from the outset, and I its first Interim Convenor. Despite involving additional volunteer work to what we all already do, PACIFHAN has been able to launch our first project – a multi-lingual dictionary of HPN and Home Enteral Nutrition (HEN) words which may be needed by patients when travelling. Check it out on our website www.pacifhan.org – type in an HPN word and choose the language you want it translated into. A great tool and example of what PACIFHAN can do.

Translate phrases

From  british/australasian english to  italian

Phrase:

Translation:

The second day was a Shire advisory board day where we were able to give input from a patient's perspective into some of the company's awareness projects.

All in all, a productive even if very tiring couple of days. I look forward to PACIFHAN becoming a legal entity soon at which time I will hand the leadership baton over to PACIFHAN's first President.

Thank you again to Natalie, Tara and Greg, to my PACIFHAN colleagues and to our PNDU members for allowing me to fly PNDU's flag on the world stage in this way.



One of the workshop sessions



Meeting face-to-face is always beneficial

Do It Yourself Portability

WORDS BY GILLIAN

A New Zealand member, Alan, hasn't been issued a backpack with his portable Bodyguard Pump (which means it isn't portable!), so he uses this travel bag when he needs to move around. Also, he found that his dripstand was too big to move around the house, so has a detachable version which is small enough to carry inside and outside, and when visiting.

Good thinking, Alan!



PNDU is now a registered charity!

WORDS BY MIRANDA

We are very pleased to announce that as of 6th July, 2016, PNDU Inc is a registered charity with the Australian Charity and Not-for-profit Commission (ACNC). This marks an important recognition of our group and the charitable purposes for which it is set up. PNDU has also received endorsement from the Australian Taxation Office as a Deductible Gift Recipient (DGR). Any donations made to PNDU in Australia are now tax deductible for the donor, which makes it even easier to support PNDU!

Christmas is fast approaching! Time to buy your 2016 Christmas Cards!

WORDS BY KAREN

PNDU has 2 Christmas card designs for sale (see right). They come in packs of 10 for \$10 (AUD and NZD) plus postage from/within Australia. Both designs have gold or silver foil on the front design with PNDU's details on the inside.

We also have 2 designs of blank cards available. \$10 per pack of 10 cards (each pack contains 5 of each design) plus postage from/within Australia. PNDU's details appear on the back.

By buying Christmas cards and/or blank cards from PNDU, you are helping us to continue to support people living with Intestinal Failure in Australia and New Zealand. Put in your order TODAY by emailing us at contactpndu@gmail.com



HPNers Owning Pets

COMPILED BY GILLIAN

Editor's Note: One of our email chat forum members mentioned how much having her kitten helps her to cope with life and illness; this resulted in another member telling how she had been told by her hospital team to not have pets. I asked my nurse, who responded that she hadn't thought about it until now. This article in no way presumes to give advice to individuals about this issue – it needs to be discussed with your own medical team. However, the topic certainly gained many responses from eager HPN pet owners!

Renee says:

I have a wonderful dog, Alex – see right. He is a wonderful companion and also a health aid, as he keeps me walking every morning on the beach. When I started on HPN I was told that dogs were fine but cats a real problem, something that a friend of mine who is a biochemist agrees with. She does not want me near her cat. I keep him out of the room where I connect to HPN but I think dog hairs travel anyway and as long as I am strict with my technique, it is fine. I have had no problems associated with having a dog.



Susan says:

This is my fur baby "Willow". She is the best thing to have around and I have never been told I cannot have pets. She means the world to me and sleeps on my bed every night. She knows she isn't allowed to be around when I hook up and it doesn't seem to worry her at all. She keeps me company and is beautiful when I'm feeling low or sick.

Amanda says:

My son Sam shares his life with two special furry companions, Zoe, our 17 year old pet cat and Abby, who is Sam's Disability Assistance Dog. Both animals were a part of our lives well before Sam ended up on HPN (Home Parenteral Nutrition) and Abby in particular, has played a vital role in Sam's life since she first joined our family nearly four years ago. Aside from Sam's many medical issues, he has a dual diagnosis of Down Syndrome and Autism, is non verbal and also an only child. The special bond he shares with both of his furry friends has enriched his life and it would be hard to imagine them not being a part of it. I keep the animals out of the room I use to prepare Sam's HPN and always away from us during hook up. Abby has full public access so is often present at the hospital for clinics or during Sam's long hospital admissions. Thankfully, no one on Sam's medical team have ever mentioned having animals as being a problem and in actual fact seem disappointed if we turn up to clinic and don't have Abby with us! Unfortunately, when you lead a medically fragile existence, animal ownership (particularly having a dog) can add to the stress of day to day life. Particularly when Sam has been in hospital for long periods, like nine and a half months out of the last twelve, having animals at home that still need feeding, company and exercise has certainly been an added pressure I've often thought I could do without. Despite that, animals seem to sense when you're having a rough day and are very good at finding ways to cheer you up, so I wouldn't be without our two. **Editor's Note: Sadly, Sam passed away last month, since Amanda wrote this response.**



Karen:

I was instructed to have strictly no pets. And no plants anywhere near the set-up area. There was no discussion to be entered into – that was a condition I was to accept if I was serious about being able to manage my HPN. It was to minimise any possible infection risk. It did mean a bit of re-organising of plants, but I live in a unit, so apart from goldfish, see below, which were allowed by my nurse – (phew!) I can't have pets anyway. So no big deal. Actually the photo isn't of my current fish – I've had a number over the years.

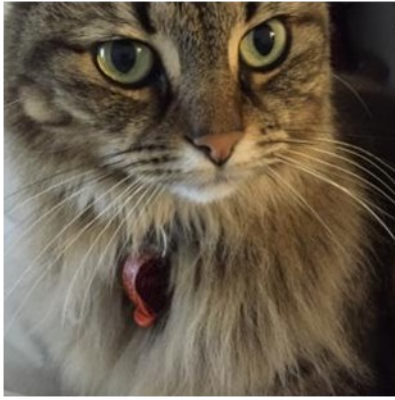
As we know here, all our hospitals teach us differently. We naturally develop a trust in their instructions, which is a good thing, but should also feel comfortable to ask questions. I'm very grateful to have not had any line infections in my 10 years of HPN. Whether no pets or indoor plants has had anything to do with that, I'll never know. But I'm comfortable with it. I do understand however, that having pets is a quality of life matter for many and I respect that.

Having lived that way for the past 10 years, I freak out a bit at the thought of having pets around. One unnerving experience was when I stayed at my dad's place. Because of the tap/space/toilet situation in the house, I ended up connecting up in the external laundry which was in a shed. I shut the laundry door, but not the outer shed door. All was going well on the first evening until the inquisitive cat decided to come and have a look at what I was doing! The more I shoo-ed him away, the more interested he became!! He was walking along the wall above where I had laid the sterile field and I had visions of cat fur floating down onto my sterile field. The outside shed door got locked behind me after that!



Jodie says:

We have an indoor cat. I just make sure I set up where she doesn't go and make sure she's not around when I set up. I've never been told to avoid having pets and having a cat has never caused me any health problems.



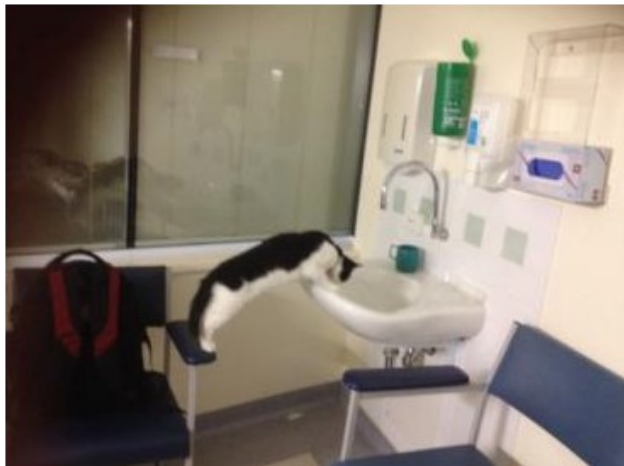
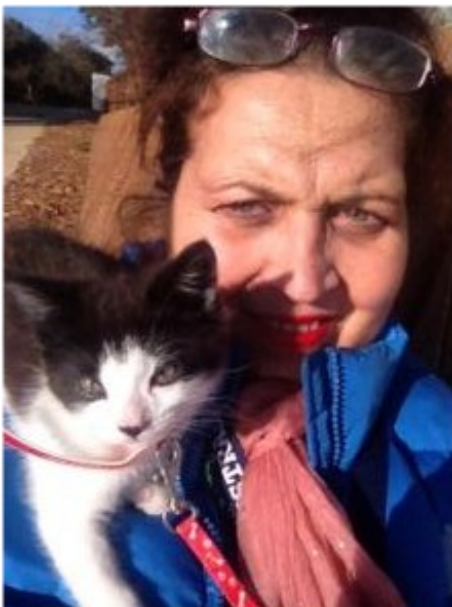
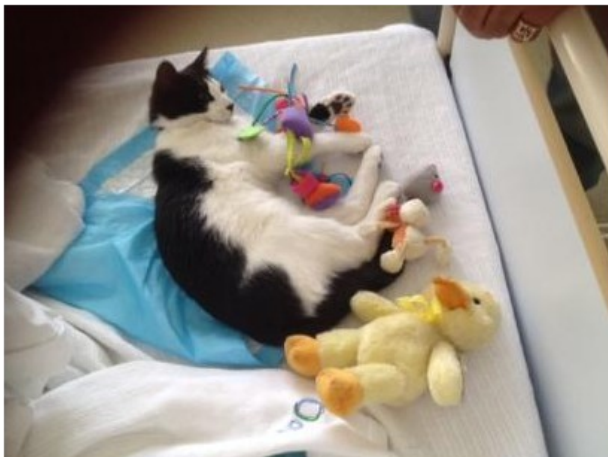
Teresa says:

I call my Pole my boyfriend because he goes everywhere with me and sleeps with me. My baby kitten, Victory, loves him. When I get off the bed he jumps and comes with me, standing on the base of the pole and he goes to the bathroom with me. When he goes to his toilet in the laundry, he then drinks some milk and then I wipe his paws and nose and he runs after me to climb on the bed again.

I brought Victory up since he was one week old, using a small bottle with a special formula.

I couldn't live without him, because he is great company. He is very clean, but I always cover my Hickman's (central venous line) with scarves. I couldn't manage a dog although I love them, but cats are very independent and clean.

When I am in hospital and have my own room, I am allowed to have Victory come in for visits.





Sal says:

These are my 2 snuggle pups, Pip and Jazz. Love them to bits. They always know when I am unwell and lie down next to me. One even seems to know when I need to rest and comes to me as though she is telling me it's time to lie down. My hospital team said no birds, but dogs were okay provided they stay away when we do procedures. The one line infection I've had came from hospital.

Chris says:

We were told strictly no pets at all inside the house when Jordan (Chris' HPNer grandson) was first discharged, so a neighbour adopted Brooke's (Jordan's mum's) cat.

Our 2 house cats, Misha and Simba, became outside cats when the boys came to visit. OCD cleaning mode also kicked in before the boys visit us.

The boys' bedroom and HPN set up area was permanently closed off to ensure the cats never entered that area of our house.

Simba left us 3 years ago and Misha this year after 13 years of companionship.

Shortly after discharge, Jordan developed a central line infection. We were told it was an E.coli bacteria more than likely to have come from bird and bat droppings, carried inside from our yard.

We cleared over 200 palm trees from Brooke's block. (We know better these days and if the central line infection is less than 48 hours after discharge from hospital, it more than likely didn't come from home)

We believe children should interact with animals and take the boys to petting zoos etc. to encourage this interaction. We put an extra layer of outer clothes or a coat on the boys and change the outer layer immediately after their interaction, carrying plenty of hand sanitiser also.



Misha



Simba



Brooke and Jordan (HPNer)



Mick clearing trees

Lara says:

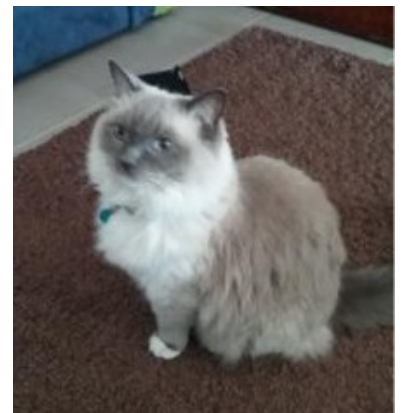
When I was first trained for HPN, the nurse at my hospital was very anti pets and plants; I even had to get rid of certain flowers people had brought me in hospital. She never said I COULDN'T have pets at home though, only that she advised against it.

Anyway, I have a Maltese shitzu named Fred, and I would be lost without her. We cuddle, close to the line, and she sleeps in the bed with me. I always wash and/or sanitize my hands before I touch anything HPN related, but I don't change clothes or anything. I've never had a line infection, so I figure what I'm doing is working (plus I'm somehow lucky enough not to be prone to them). She also knows not to come near me when I've got the metal trolley out that I set up my sterile field on.

The nurse who trained me has since retired, and the excellent ladies who replaced her are all about holistic care, and not letting HPN restrict our lifestyles, so they're fine with pets. Which is good, because we're looking for a second dog to adopt at the moment.

Monika says:

I have an indoor cat, and she never has bothered me. I think having a pet makes you feel better, especially when you have a bad day. They know, so they come and give you a hug in their special way.



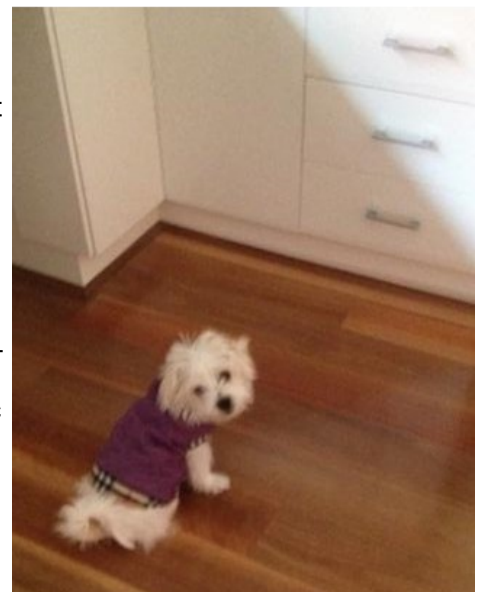
Carmel says:

I could not live without my mate. I have always had a family dog. 18 years ago, I was really ill. My son arranged a puppy for me for Mother's Day. A dog of my own — and what a buddy he proved to be. He knew all my moods: kept me company when I was bed bound; protected and amused. When I lost my mate just before Christmas, he was nearly 18 years old. I swore I could never have another dog.

I only lasted 3 months! It was awful without that company. For the first time, my new mate has been allowed on my bed! He is a Maltese Shi-tsu cross & believes everyone comes here to visit him. He already has the Couriers trained. I sign for my HPN or supplies — they cuddle "Gibbs".

No greater company and pleasure is there than seeing my "getting close to 3-years" grandson tearing around the backyard with Gibbs, who is now 7 months old. The delighted laughter of a little one racing with a pup - it's music to my ears.

I have never been told not to have pets or plants and depending on the circumstances may develop selective hearing if I were to be told that!!! I am practically OCD about hand washing though.



My mate keeps me company; makes me laugh; goes with me practically everywhere and gives me purpose. My buddy would manage just fine with another loving family. Me without my mate Gibbs — not so much. Like other PNDU members, with very long stays in hospital, when I am well enough, I am allowed out on the grass in a wheelchair and one of my friends is allowed to bring my mate to visit.



Jacqueline says:

We have always adopted unwanted dogs...to a max of 4. Our license, room, finances and energy doesn't stretch any further. Our old Airedale 14, adopted when he was 10 has just died and so 3 young golden retrievers complete our family now. They give unconditional love, joy and purpose. I couldn't cope with all my health stuff without them. It bonds David and I too. As for our bed....I just stopped them visiting us at night but they come up at 7 a.m. Basically because of dog fur...what an amount falls out...I Hoover daily and as I'm not well at present I am not able to do that. We have installed an outside hot shower for bathing them which is fabulous as I wash them every two weeks. The work involved is worth it and the benefits are enormous.



PNDU's latest member survey – HPN pumps!

WORDS BY KAREN

Being part of an incredibly small patient group, sometimes it can seem that the problems and challenges I face must be mine and mine alone. From time to time, there is discussion on our private forums about various HPN pump problems, so PNDU wanted to see how widespread these were within our membership and to make this information available to hospitals and HPN homecare companies here. Introducing the **PNDU Survey of infusion pump usage for Home Parenteral Nutrition in Australia and New Zealand!**



ABSTRACT

Members of the Parenteral Nutrition Down Under (PNDU) online forums were invited to complete a questionnaire about use of parenteral nutrition (PN) infusion pumps. Twenty-nine home parenteral nutrition (HPN) users or their carers (representing 19 adult and 10 child HPN users) participated. Twenty-seven (93.1%) respondents used Bodyguard 323 pumps of which 25 were provided by Baxter Healthcare. Ten (34.5%) respondents experienced problems with their pump either over or under infusing and eight (27.6%) reported the pump not alarming when there was significant air in the line. Sixteen (55.2%) respondents reported their pump battery did not last for the duration of the infusion when off the charger. Respondents did not always notify the pump provider of problems and more than half did not have their pump recalled annually for servicing. Only 4 (13.8%) respondents did not use an IV pole during set up or infusion but 23 (79.3%) used a pump backpack for at least some of the time. Fifteen of these thought a backpack with detachable wheels would be beneficial mainly because of the weight of the PN. This survey highlighted some of the issues faced by HPN users and should be considered when transitioning from hospital to HPN.

PNDU's Management Committee is very grateful to all members who took part in the survey and to Sharyn who collated the results into a very polished analysis. The Survey Analysis is [available on our website](#); we have made it and PNDU comments and suggestions available to our members for sharing with their hospitals; and shared these with Baxter Healthcare and Biomed. Some of PNDU's comments and suggestions are below. If anyone would like a copy of PNDU's letter and survey analysis for members, or has any feedback, please email us at contactpndu@gmail.com.

Reporting of problems and faults

While we continue to encourage our members to report any and all problems and faults to their hospital/homecare

company, including infusion pump problems, we are alarmed by the number of this survey cohort reporting problems with over/under infusing, no pump alarming for air in line, and limited battery life. We therefore wonder how much reporting is actually occurring firstly to hospitals, and then back to the homecare company? In light of this possible under-reporting, PNDU would like to suggest the exploring of ideas to make the reporting easier and more streamlined? Are there ways in which reporting of problems and faults could be made easier and also essential for both HPN patients/carers as well as HPN clinicians? PNDU is happy to explore ideas with hospitals and homecare companies at any time eg an on-line reporting form on hospital or homecare company website.

Annual pump servicing and calibration

Our findings are that over half of respondents did not have their pump recalled annually for calibration and servicing, and it was not clear how many of the remainder had it organised by the homecare company, their hospital or themselves. It would seem this is a matter that could easily be rectified by an electronic system of record-keeping which provided reminders to technical staff to contact appropriate HPN patients/carers to organise pump servicing and calibration. This together with regular battery replacement and the provision of a second battery for all users would potentially alleviate the battery life problems being experienced and which in themselves significantly limit mobility.

Backpack sizes and detachable wheels

And lastly, as our survey shows, many HPN patients experience difficulty carrying a backpack with PN and pump due to the weight and for some, particularly children, also the size. As a result, many continue to use the dripstand for at least some of the infusion time. This hampers mobility considerably and can create its own dangers in the home environment where floor coverings and home layouts are not necessarily suitable. As more products are now available to assist HPN patients with mobility, including detachable backpack wheels and different size backpacks, we strongly support the availability of these items to HPN patients and believe that they can have a significant impact on the quality of life, safety and independence through mobility of many HPN patients.

As said at the start, our aim in sharing these survey results is to be able to share a snapshot of HPN patient experiences and we hope this information will be of benefit to hospitals and homecare companies. If there are any questions or suggestions on how we can collaborate on this matter or any other matter for the benefit of HPN patients and carers, please don't hesitate to let us know.

PICC Line Extensions

Editor's Note: There are times when HPNers need to have a PICC line inserted, usually as a temporary measure, in order to administer HPN (Home Parenteral Nutrition). As these are inserted into an arm vein, it makes it impossible to hook up to PN by ourselves, as the PICC line isn't long enough to hold in a hand whilst attaching our giving set line. One of our members informed us that extension lines exist for PICC lines, which means HPNers are able to hook up independently, especially important for those who live alone. Please discuss this with your hospital team if you are in this situation.



These are the extension lines for the PICC. The bungs are added to the end. When I have primed the line, I can attach myself to the extension line.

PNDU Annual Awards – Winners to be announced!

WORDS BY KAREN

This is PNDU's third year of bestowing awards on dedicated people nominated by our members. PNDU's annual awards began in 2014 with great success and we are enjoying once again the opportunity to congratulate those whom our Aussie and Kiwi members recognise as doing a great job deserving recognition in the field of HPN – favourite HPN clinician, a helpful soul at the homecare company, someone involved with PNDU – there are a variety of categories.

Thank you to all those who nominated worthy candidates. An announcement of the winners is imminent.



Out of the Mouths of Babes

WORDS BY KAREN

I was remembering this evening a comment by my cousin's little when I stayed with them in London recently. She's just turned 3 and was fascinated by my PN, every morning wanting to see in the backpack multiple times, see my port needle, see how the giving set went from the bag, through the pump and to the needle. We talked about it quite a bit and what it did.

I think it was the day before I left, she didn't want to eat her dinner. So there was encouraging conversation about how she needed the energy from the food to play and to grow. She responded by saying she didn't want her food and she would have what Auntie Karen was having!!

How's that for understanding!! I was stunned that a 3 year old could understand the concept so easily while some adults just don't get it. Not helpful for her parents trying to get her to eat her dinner, but amazing nonetheless 😊



Thank You and Welcome Anne-Marie!

WORDS BY KAREN

A big shout out to Anne-Marie who has offered PNDU a couple of hours of her time each month for whatever we need. Anne-Marie is a busy mum dealing with medical matters, but has wanted to help in this way. This is a wonderful blessing to the Management Committee, whose members are also volunteers, as projects and ideas far outweigh our capacity. We were able to make good use of Anne-Marie's help in locating a suitable venue for our PNDU social gathering in Melbourne on 16th November. A time-consuming exercise.

Thanks to Anne-Marie's searching, we have booked the Rose Pavilion in the Melbourne Botanic Gardens. A great little venue suitable for our needs!

We really appreciate your help and time Anne-Marie and look forward to getting to know you better in the coming months.

PNDU is a volunteer charity, with all members of the Management Committee living with HPN (either as HPNers or carers). PNDU's Management Committee are therefore very grateful for the help of Anne-Marie, Sally who formats our newsletter each quarter, Sal who is our wonderful PNDU Birthday fairy, and Renee who monitors our private Facebook group. If there are others who have skills and time to assist the work of PNDU, please don't hesitate to contact us at contactpndu@gmail.com.

Thank
You

HPNer event in Melbourne this November

WORDS BY KAREN

We hope everyone has it in their diaries.

PNDU Social Gathering for HPNers and their families

Come rain, hail or shine, this will be a wonderful opportunity to get together, meet PNDU friends in person as well as new friends, and mix with others who totally 'get' living with HPN.

When: Wednesday 16th November 12 noon—3pm

Venue: Rose Pavilion, Royal Botanic Gardens

What to bring: BYO everything

RSVP: contactpndu@gmail.com or 0413 715 187 by Sunday 13th November



Congratulations to our travel sponsorship winners!

Congratulations to Clare and Jodie on great winning entries for PNDU travel sponsorship, worth \$500 each, to get them to the Melbourne HPN event. We look forward to meeting you both in Melbourne and know that the opportunity will be of great benefit to you. Happy packing!!



PNDU exhibiting at AuSPEN's Annual Scientific Meeting for clinicians

Thursday 17th - Saturday 19th November

PNDU will once again be operating an exhibit at AuSPEN's ASM and greatly appreciates the opportunity to touch base with Aussie and Kiwi HPN clinicians, raising awareness of PNDU's existence and our work to those who haven't heard of PNDU, and to touch base with our industry friends. We are also grateful for the opportunity to meet with AuSPEN Council on the sidelines of the ASM.



PNDU's new website launch

The date is drawing ever closer to when we will be launching our new website – 16th November 2016

Thank you to our friends at [Orange Line](#) for all your help!



Fair for Rare Campaign - Australia

WORDS BY GILLIAN AND CHRIS

PNDU is pleased to be participating in the [Rare Voices Australia](#), "Fair for Rare" Campaign Working Group. PNDU members all have a rare condition ('disease'), Intestinal Failure, although the cause of this is varied and often as a result of another underlying rare disease. PNDU has been invited to join in this campaign, and Management Committee member and Treasurer Chris is our representative in the Working Group.

This campaign is specifically for our Australian PNDU HPNers and carers where the disparity in HPN care, treatment and support between states/territories and even hospitals can be significant. On the other side of the ditch', we are very supportive of the work of [NZORD](#) (New Zealand Organisation of Rare Disorders) as well as the new [New Zealand National Intestinal Failure Service](#) (NZNIFS) – possibly a world first (see [Dripline Issue 16](#)). While still in its early development, the NZNIFS gives great hope for equity of care, treatment and support for all Kiwis living with HPN for Intestinal Failure.

Meanwhile, Rare Voices Australia advocates for Australians living with a rare disease to have equal access to safe, effective treatments and healthcare management in a coordinated and adequately resourced approach accessible to all throughout the country. The Fair for Rare campaign enables these people to share their story of living with their particular rare disease and highlight the opportunities for Australia to do better, and give them a 'fair go' ie Fair For Rare.

Objectives of Fair for Rare:

1. Generate greater awareness for rare diseases in Australia.
2. Strengthen the common voice of people living with rare diseases.
3. Address rare diseases as a national challenge.
4. Promote rare diseases as a national public health priority.
5. Demonstrate that rare disease communities extend beyond that of the rare disease patient.

6. Promote the need for people living with a rare disease to be given a 'fair go' with equitable access to health services at a national and state/territorial level.

How can our Aussie members get involved?

The Fair for Rare campaign is asking our Aussie members to write their story of Intestinal Failure, including any or all of the 4 different aspects:

- **Pathway to Diagnosis.**
- **Access to Coordinated Care.**
- **Access to services.**
- **Access to Treatments.**

These four campaign 'themes' have been developed to highlight the inequities that exist within the Aussie healthcare system and promote the need for a National Plan for Rare Diseases.

Chris will also be encouraging our Aussie HPNers and carers to participate in the 'Fair for Rare' campaign in a range of ways eg social media, Fair for Rare events, lobbying politicians. But most importantly, start writing your story, which Chris will be following up on our private forums.

The Fair for Rare campaign will deliver the campaign message at a Parliamentary event in Canberra planned for March 2017. Join the campaign today by sharing your story and help make Australian healthcare "Fair for Rare"

AuSPEN's HPN Vitamin Guidelines

WORDS BY KAREN

PNDU is very supportive of AuSPEN (*Australasian Society for Parenteral and Enteral Nutrition*) and all they do to support and educate clinicians working with parenteral and enteral nutrition as well as research and write guidelines as a reference for clinicians and promote best practice in this area.

Updated HPN Trace Element Guidelines were released by AuSPEN in early 2015 (see article in [Dripline issue 11](#)) and this year AuSPEN's updated HPN Vitamin Guidelines were published in *Asia Pac J Clin Nutr* 2016;25(3):636-650. PNDU was invited to sit on the review committee for these guidelines and was able to give input on behalf of the Aussie and Kiwi HPN patient population. We were very grateful for this opportunity and look forward to similar opportunities to work with AuSPEN in the future.

Below are the highlights of the updated Vitamin Guidelines and a copy of the full document is on our website ([Pharmacy Scripts page](#)). PNDU is keen for all HPN clinicians 'down under' to be aware of and follow these important guidelines.



Australasian society for parenteral and enteral nutrition (AuSPEN) adult vitamin guidelines for parenteral nutrition

Emma J Osland AdvAPD MPhil, Azmat Ali AdvAPD, Truc Nguyen MPharm, Melvyn Davis PhC FSHP, Lyn Gillanders NZRD

Background and Objectives: This work represents the second part of a progressive review of AuSPEN's 1999 Guidelines for Provision of Micronutrient Supplementation in adult patients receiving parenteral nutrition.

Methods and Study Design: A systematic literature review was undertaken and recommendations made based on the available evidence and with consideration to specific elements of the Australian and New Zealand (NZ) practice environment. The strength of evidence underpinning each recommendation was assessed. A multidisciplinary steering committee and external reviewers provided feedback on the guidelines.



Results: On review of the available literature it appears that the parenteral multivitamin preparations presently available in Australia and NZ are to sufficient avoid deficiency without causing toxicity in most clinical situations for adults receiving PN when provided regularly as part of the PN prescription. Vitamin D is the most vulnerable vitamin for the Australian and NZ PN population.

Conclusions: Vitamins are an essential component of PN and should be provided from commencement for all patients receiving PN. With the exception of vitamin D, which is recommended to be monitored annually, routine monitoring of vitamin levels is unlikely to be necessary in patients receiving regular parenteral multivitamin preparations. Clinical judgement is an important element when assessing, prescribing and monitoring patients receiving PN. Areas requiring further research have been identified.

Alarming pumps

Editor's Note: Two of our members shared their embarrassing pump stories on our email chat forum

- I thought I'd share what happened last night whilst out shopping, kind of funny for us HPNers. I went to Big W and set the security alarms off as I left, but, as no-one pursued me, I thought 'oh well, they must be faulty'. Then late, as I was leaving Woolies, the security alarms went off again. How embarrassing! And I was asked to show them my bag. So I explained it was a medical pump and fortunately opening the front pocket was enough and they let me go. Was it the pump setting the alarms off? Anyway, I had to laugh about it, always love seeing people's reactions to seeing the pump and realising it's all connected to me!
- I have never had my pumps set alarms off like that, but I have experienced shock as to what is in my backpack. In America I had to show my backpack and what is in it (they look in everyone's) and I, too, got a kick out of their reactions. Years ago I was with a friend in a shop when security approached me telling me I couldn't make phone calls in the store. He thought my tube was headphones. What! The IV line was going up my shirt, certainly not in my ears!!

A Day in the Life of an HPNer - Expect the Unexpected

WORDS BY GILLIAN

My gastroenterologist certainly got my attention with the words, 'I'm not thinking of a liver transplant yet.' Liver transplant! Who? Me? You're kidding, I'm not that sick! Am I?

This was in January 2016. Only a few months prior, my health had been fine. I had been on HPN (home parenteral nutrition) for nine and half years with only occasional blips with kidney and liver blood results. I was still working as an ESL (English as a second language) teacher at a local primary school, although I'd reduced to only one day a week in a lead up for retirement, walked for half an hour 5 days per week and had a session of Pilates to keep muscles fit. All in all, for a 62 year old on HPN, I was very healthy.

Last September and October 2015, my husband Ray and I were away from our home in Sydney in our caravan for 7 weeks, getting as far as Cooktown in far north Queensland. (Dripline Issue #13 was written/edited during that holiday). When we returned, my daughter saw me for the first time after that long break and her first words to me were, 'You're yellow!' Normally I have monthly blood tests to monitor my liver, but didn't for the 2 months I was away. I had just assumed my skin colour was due to tanning and hadn't noticed my eyes yellowing and as it was probably gradual anyway, neither Ray, nor our friends who travelled with us and saw me every day, had noticed these changes.

I immediately had a blood test, and my bilirubin levels were very high, so my GP sent me to the gastroenterologist who has monitored my liver at times in the past. Much to my surprise, he wanted to put me straight into hospital and run a battery of tests to find out what was happening, and why. I spent a week having a variety of tests, including an MRI, a liver biopsy and a fibroscan to detect my liver fibrosis, or stiffness. The upshot was that I had cholestasis of the liver, which was quite severe. I began taking 6 ursodeoxycholic acid capsules per day as a first option, capsules which had helped in the past.

My gastroenterologist and the hospital team who monitors my HPN then discussed what steps should be taken. One possibility was to change my PN lipids to SMOFlipid® (made up of a mix of soybean oil, medium-chain triglycerides, olive oil and fish oil), but they decided to try some other changes first. Immediately my calories were reduced to half to see if that made a difference. It certainly did! (But not to my liver). I lost weight and became very tired and lacking

in energy. When the change in calories hadn't fixed the problem, in fact all liver functions worsened, ALL lipids were removed from my PN to see if that made a difference.

The stairs at home that I could usually spring up and down became my Mt Everest to scale and I needed a sleep for couple of hours every day, as well as my usual night's sleep. Luckily, by this time it was school holidays, at the end of which I retired, so I was able to cope with this change relatively easily.

Meanwhile, my bilirubin levels kept climbing. My gastro rang up the head of the liver transplant unit in Sydney and the head of the intestine transplant unit in Melbourne, to discuss what he was doing for me and to ascertain if there was something else he should be doing. They agreed he was trying the correct treatments.

It was at this point that he said the attention grabbing words about a liver transplant. He wanted me to see the doctor in charge of the liver transplant unit at another Sydney hospital so that he had met me and knew my medical background, in case a transplant became necessary.

Shortly after this visit, the intensivist in charge of my HPN management, having realised that there was slight improvement after the removal of the lipids from my PN, organised to have SMOFlipid® 3 nights per week added to my PN with the other 4 nights being lipid free.

This began an instant and amazing improvement over the next few months. By July this year, after a few months of this regime, all my liver levels were nearly back to normal with no evidence of cholestasis.

Luckily, for me, SMOFlipid® made the difference, although there is no explanation for why my body, after coping for 9 and a half years with one lipid, then reacted against it. I am not meaning to promote SMOFlipid® as a cure for all HPNers' liver problems, as we are all individuals and react differently to treatments. However, it is worth discussing with your medical team if you are having such problems. (For further information on the topic, read **Omega-3–Enriched Lipid Emulsion for Liver Salvage in Parenteral Nutrition–Induced Cholestasis in the Adult Patient** in [issue 15 of Dripline](#), accessible on our website, a medical paper summarised by Prof Gil Hardy).

As the title of this article says, HPNers need to expect the unexpected, so although life has settled down into a routine again with my liver back to normal, I realise that this, or other problems, could arise again in the future. But then, isn't coping with the unexpected what life is like for everyone?



Gillian, yellow

Reduce Holiday Stress by Educating Others

Toni Bernhard, JD

Editor's note: Originally printed in Oley's 'Lifeline Letter', Nov/Dec 1915. Reprinted with Permission.

Chronic health problems can take a toll on relationships any time of the year. Most people have to experience unrelenting pain or illness themselves before they understand how debilitating it is, physically and mentally. Loved-ones (by whom I mean family and close friends) may be in some form of denial about what's happened to you, or they may be scared and worried about the future. Bottom line, suffering from a chronic condition can be an ongoing crisis—for you and for those you're close to.

That crisis can come to a head during the holidays when people's expectations of one another are high and when stress levels for everyone are likely to be off the charts for any number of reasons—health, financial, relationship issues. If you're



The holidays can bring the stress load.

like me, during the rest of the year, you carefully limit interactions with others in order to manage your symptoms; on a typical day, your most complex decision may be to choose between showering and shopping! But when the holidays arrive, you're suddenly thrust into the middle of a lively and chaotic social scene where you're expected to participate in a range of activities, often for days in a row. A bit of advance warning to loved ones can go a long way toward minimizing stress levels over unrealistic expectations.

I know that this piece won't apply to everyone. One of the heartbreaking consequences of living with chronic pain and illness is that some people are unable to be with loved ones at all during the holidays, either because people are too disabled by their pain or illness to be able to gather with others, or because family and close friends have drifted out of their lives. I know the pain of that isolation; I've written about it.

For those of you who are able to gather with others, the holidays can be a recipe for double disaster - the increase in activity exacerbates your physical symptoms, while coping with sadness, frustration, and maybe even guilt about your physical limitations gives rise to emotional pain. No wonder many people with health problems dread the approaching holidays.

If you're one of the many people with chronic health problems who don't look sick, the initiative is with you to make your condition visible. Here are some suggestions for helping loved-ones understand what your life is like and for giving them a heads-up on what to expect from you during the holidays. (This piece focuses on the winter holidays but applies equally to other times of the year when loved-ones gather together.)

Share Information with Loved-Ones

Often the best way to educate loved-ones about chronic pain and illness is to use a neutral source because it takes the emotional impact out of the communication. A quick web search will yield a host of organizations devoted to every conceivable medical problem. Print out select pages or forward a few links to family and close friends. Alternatively, if you have a book about your condition, photocopy the pages that cover what you'd like them to know about you. In your accompanying note, keep it 'light'—you could joke that “there won't be a test.” But also make it clear that this favor you're asking is important to you.

Find an Ally and Enlist His or Her Help

If you have just one close friend or family member who understands what you're going through, enlist his or her help in explaining your condition and your limitations. Before the holidays start, you could ask your ally to talk to loved-ones on your behalf or to be present when you talk to them. Ask your ally to be supportive if you have to excuse yourself in the middle of a gathering, or even to let you know if you're wilting (as we call it in my household). It's so helpful for me to be “prompted” by my ally because, when I start to overdo things, adrenaline kicks in which fools me into thinking I'm doing fine. But using adrenaline to get by just sets me up for a bad crash later on.

Your ally may be a close friend or family member who's just waiting for you to enlist his or her help. Think long and hard before you decide there's no such person in your life.

Others May Not Accept Your Limitations

Some family and close friends may refuse to accept that you're disabled by pain or illness. I know this from personal experience and it hurts. Try to recognize that this inability is about them, not you. Don't let their doubt make you doubt yourself. Your medical condition may trigger their own fears about illness and mortality, or they may be so caught up in problems in their own lives that they're not able to see their way clear to empathize with you.

Just as you can't force people to love you, you can't force people to accept you. But getting angry at them just exacerbates your own symptoms. That's why it's important to protect yourself from allowing their lack of understanding to continually upset you. Think of it as protecting yourself from another chronic condition: chronic anger.

The physical suffering that accompanies chronic pain and illness is hard enough to endure without adding emotional suffering to it. When I feel let down by family or close friends, the first thing I do is acknowledge how much it hurts. Then I reflect on the many possible reasons for their behavior. Finally, I work on genuinely wishing them well. These three steps immediately lessen my emotional suffering.

As you experiment with these suggestions, treat yourself kindly. Don't blame yourself if one of them doesn't work out. Instead, give yourself credit for having had the courage to try! My heartfelt wish is that your loved-ones come to understand and accept your limitations, but that if they don't, you'll be able to accept them as they are without bitterness.

Toni Bernhard is the author of the award-winning 'How to Be Sick: A Buddhist-Inspired Guide for the Chronically Ill and Their Caregivers' and 'How to Wake Up: A Buddhist-Inspired Guide to Navigating Joy and Sorrow'. Her newest book is called 'How to Live Well with Chronic Pain and Illness: A Mindful Guide'. Before becoming ill, she was a law professor at the University of California—Davis. Her blog, “Turning Straw Into Gold” is hosted by Psychology Today online. Visit her website at www.tonibernhard.com.

Lost Luggage

Editor's Note: *Most of us have heard stories of people having lost luggage on flights and having to buy or do without their belongings for anything from a day or two till never seen again! Travelling as an HPNer means that we need to be as vigilant as possible in travelling with our supplies. Here are stories from two of our members.*

Karen says:

I've had an eventful trip this time! Last week one of my medical suitcases didn't arrive at my destination with me. You know that sinking feeling watching all the suitcases go around the carousel, everyone gets theirs,.. and then the carousel stops : no more luggage.

My suitcase (with 'fragile' and 'medical supplies' tags on it) arrived a little over 24 hours after arrival, but it was a great reminder of why we encourage a couple of travelling tips (see our travel information booklet) - I had split all my medical supplies equally between two suitcases; I had the local contact details for the pump company, and hospitals, plus nearby contact details of the PN provider and stoma supplier. I also always carry my pump, charger, PN bag and extra saline as well as emergency supplies of ancillaries in my hand luggage (with a letter from my doctor, of course).

For all of us on HPN, but especially those of us who can't go a night without it, it's essential to be prepared for something like lost luggage, whether it's domestic or international travel. A lady I spoke to at the airport told me she didn't get her luggage until three days later!

This is the first time it's ever happened to me, but it was a good reminder that it does happen!

Lara says:

I arrived on my Barrier Reef island on Tuesday, and 9 bags of PN were supposed to come the same day. Unfortunately the shipment got delayed, and didn't get here until Wednesday morning. Then Baxter advised that they couldn't guarantee it had been stored correctly, so I should discard the whole lot and wait for another shipment. Thankfully, that came the next day.

I had a bag and two salines with me in my checked baggage, so luckily that didn't go astray, but I still ended up with only one bag for 3 days. I have two nights off a week, but I never have them that close together and I've had the feeling all day like my batteries are running out. It reminds me why I'm always so hesitant to travel.

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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 or PNDU, 128 Rainbow Street, Randwick NSW 2031, Australia to find out more.



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

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