



This issue celebrates the third anniversary of Dripline, so I thought it would be an appropriate occasion to look behind the scenes and reveal how Dripline evolved and who makes it happen each quarter. Also, some of our members share their joys, pains and hobbies with us, and our regular 'A Day in the Life' is written by a 14year old HPNer. One of our youngest members is the face of Sydney Children's Hospital's fundraising appeal, whilst another young member sparks panic at her school. It will soon be HPN Awareness Week '15 and it is also time to nominate worthy people for our annual PNDU Awards.

Gillian - Editor

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Behind Dripline

WORDS BY GILLIAN

This twelfth issue marks Dripline's 3rd anniversary, which amazes me because when I took on the role of editor, I didn't know how I'd have enough articles to make it to a second issue! I thought this would be an appropriate occasion to reminisce about how Dripline came about.

In our Management Committee (Skype) meeting in October 2011, we decided that I would investigate how to send an e-newsletter to interested people. I'm a primary teacher, and my school sends its newsletter this way. I also agreed, somewhat apprehensively, that I'd take on the editor's role. A local high school has a motto 'Don't limit your challenges, challenge your limits', and I definitely felt that I was doing this, as I'd never taken on such a job before. I was assured by Karen and Gil that I would have their support.

The first issue was finding a way of mass emailing large documents to our readers. The first company, which my school uses, agreed to do it for us but didn't follow through. We then decided to use Mailchimp, recommended to us by one of our then MC members in NZ, Jodee.

The next problem was how to make a long Word document look like a newsletter and not a boring business letter. Again, one of our then MC members had a sister, Carla, who designed our eye-catching layout and kindly did the laborious work of putting my final Word document into her program for the first two years (8 issues).

Meanwhile, our MC had to decide on a name for our new 'baby'. Several possibilities were suggested by our MC members and then put to a vote and Drip Line was the winner, a name suggested by our founding member, Brenda. This was simplified to one word Dripline by the second issue.

The articles are sourced in several ways. Some come through discussions which members have had on our Google Groups chat forum that I feel are of interest to others; some are written by members because I have asked them to write about themselves or a recent experience that I know that they have had; some have been written voluntarily; some I write myself; some have been written by Karen and some by Gil; and some have been sourced from other journals. Karen tends to write about events related to PNDU's involvement in various activities and Gil writes/adapts/ sources medical articles from his plethora of experience.

Putting together Dripline for its 3 monthly cycle means that after an issues is sent, I have a month to be slack, maybe putting some ideas in a folder for the next issue, or asking people for a contribution, or filing articles sent to me from Karen or Gil. The next month is busy, editing the articles that I have, writing more, reminding people to send me their work by the deadline, which is approximately the end of that second month. The third month sees the articles put in order, which is tricky because they can't all be first. There needs to be a mix of personal stories, medical articles, information about upcoming events and reports of PNDU events so that the light-hearted is mixed with the more serious. I then send this on to Karen, who proof-reads it for me and ALWAYS finds some small errors, and then she sends it to Gil, who also usually finds something to add or change. It then comes back to me to accept or reject their suggestions (usually accept) and then I send it to our designer, who is now my daughter, Sally, to put into our final format in Publisher.

After many hours of work, Sally sends it back to Karen and me, when there are still sometimes small errors that were missed before to be fixed. When these changes are made, the document is then sent to Karen or me to upload into Mailchimp and send out to our subscribers, hopefully to be read and enjoyed by them.

The team:

Gillian: I have been on Home Parenteral Nutrition (HPN) for 9 years due to a 'mystery' virus which triggered an auto immune response which killed all my large intestine and most of my small intestine. I'm a primary school teacher who works part time and plan to retire this year. In my spare time I help to run a Bible study at my house once a week, as well as being on various rosters at church, including singing. I walk 5 mornings a week for half an hour and attend one Pilates class a week, which helps to keep me fit. I write up the minutes for PNDU's Management Committee (MC) meetings as well as this editor's job. Ray and I have as many holidays as possible, both short breaks and long, often in our caravan.

Karen: I've been on HPN for 8.5yrs due to multiple resections for Crohn's disease which caused Short Bowel Syndrome and eventually Intestinal Failure – that seemingly endless intestine does in fact have an 'end' if you keep needing bits cut out. I 'retired' from my legal secretarial job just before I started HPN. A good deal of my time now is spent as Convenor for PNDU. I also co-lead a ladies' Bible Study group (but unlike Gillian, I can't sing to save myself!) and help out with a monthly seniors group at my church, visiting various members throughout the month too. My neighbour calls me a 'social butterfly' and I guess I am, very much enjoying catching up with friends, old and new. That said, I also enjoy solitary time as well as a bit of gardening (when I can find the time and energy). I



absolutely love travelling, but finances and energy levels keep that fairly well to short visits to family and friends or representing PNDU.

Gil Hardy PhD FRSC FASPEN, trained as a Biochemist in UK and worked with Nobel Prize Winner, the late Professor Sir Hans Krebs at the University of Oxford, where he developed the 3 litre PN bag and pioneered work with combinations of amino acids, lipids and micro-nutrients, for improving formulations and methods of administration of Home Parenteral Nutrition (HPN) regimens for patients with intestinal failure (IF).

Since 2008 he has been Professor of Clinical Nutrition at Massey University in New Zealand, where he has expanded his international research collaborations and helped establish a new Masters in Nutrition & Dietetics. He is also Micronutrients Editor for 'Current Opinion in Clinical Nutrition and Metabolic Care' and edits the Nutraceuticals column for the journal "Nutrition". Gil has published over 200 papers, textbook chapters and scientific abstracts in a variety of scientific journals. These have established an international reputation in the field of clinical nutrition with several awards, culminating with his Lifetime Membership Award from *Parenteral Nutrition Down Under* (PNDU), receipt of the ASPEN Distinguished International Nutrition Support Service Award at Clinical Nutrition Week 2014 in USA and election, as a Fellow of ASPEN (FASPEN) in 2015.

Gil sits on various committees for several international nutrition societies and was involved with the group responsible for establishing the AuSPEN HPN patient register and publishing the 2008 Guidelines for HPN management. In 2009, Gil helped form PNDU and has served as treasurer on the group's management committee, providing assistance with Dripline, since its formation. He has hosted a few Kiwi social gatherings of PNDU members at his home in Auckland.

Sally: I am Gillian's younger child. I became aware of HPN after mum's mystery virus and subsequent ileostomy, and slowly came to know more about just how recent and relatively rare the process is over the 9 years since. A misspent youth reading books and surfing the 'net developed workable skills I now use in Marketing and Communications at a not-for-profit in Sydney and more importantly - for Dripline and PNDU! I struggle occasionally to access the keyboard of my laptop to do the layout because of the friend in my picture, who loves to sit on it.



Proof Reader: Karen



Proof Reader: Gil (with his PNDU Lifetime Membership Award)



Layout: Sally

Distraction: Belmont

Thank you to PNDU Management Committee members Jacqueline, Jodee and Kelly

WORDS BY KAREN

PNDU has a Management Committee (MC) which meets via Skype every 4-8 weeks to discuss various matters and plan activities and projects.

Since the MC was created in late 2011, Jacqueline, Jodee and Kelly have been involved, as much as time and health allowed. Jacqueline and Jodee are founding PNDU members and were involved in getting PNDU off the ground. Kelly was involved soon afterwards. Jacqueline was awarded last year with our inaugural PNDU Lifetime Membership Award and in late January 2015, presented with the perpetual trophy. The last few issues of Dripline have included articles about this award.

PNDU wouldn't be where it is today without the involvement of these 3 women as well as other MC members past and present, including past members Brenda, Rachel, Vanessa and Melanie.

As their situations have changed, Jacqueline, Jodee and Kelly have all recently bowed out of the MC, and as they do, we would like to publically thank them for their involvement and contributions – we have really appreciated their work and support. Thankfully, although they have stepped down from the MC, they will continue to be involved in PNDU, including our private forums.

Our MC currently consists of Chris, Gil, Gillian, Miranda and Karen.

Many thanks again Jacqueline, Jodee and Kelly for all you've done for PNDU!

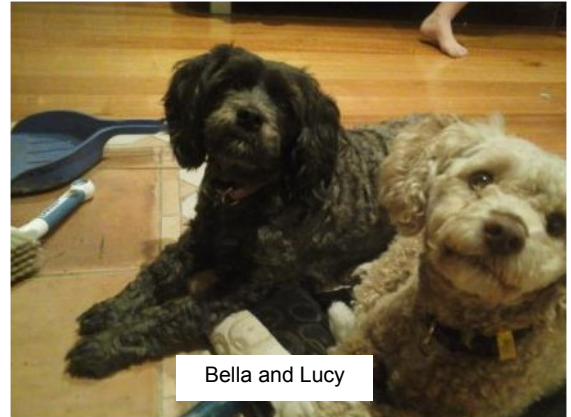
A Day in the Life of a HPNer

BY BRYLEY AGE 14

I have always loved animals but when I was little I was terrified of dogs. I would scream or cry if one came near me. I guess I just thought that they would jump on me and push me to the ground. Well that all changed in 2010 when I was in hospital with a line infection. I was well enough for my Mum, Dad and my brother Matt to take me out of the hospital on day leave. We decided we would go down to the Victoria Market which was a short tram ride from the hospital. We bumped into a nurse I know from the hospital and she knew how much I loved animals. She told us where there was a pet shop within the market that always had lots of pets for sale.

The puppies were soooooo cute. There was a little one that caught my eye. A Poodle X Shitzu. She was a jet black bundle of fluff. Mum asked if I wanted to nurse her. I wanted to so badly but I was really scared and started to cry. While Dad was having a cuddle, Mum took me outside and said "we will buy the puppy, but you have to cuddle her first". I badly wanted to, but I was scared, but in the end I said I would. We went back in to the shop and Dad handed me the gorgeous little fluff ball. I was still really scared but I did it! So we bought her.

We took her back up on the tram, back to the hospital because I had to still be there for another week. We called her Bella. I did Italian at school and Bella meant "beautiful". So that's her name.



Mum brought her in to visit me one day during the week. We took her out to the playground and I cuddled her and let her run around. It was amazing!!!! When I came home from hospital I didn't want her in my room, on my bed or even sitting next to me on the couch. After about a month I finally got used to her and we have been best friends since.

If I am unlucky to be in hospital on weekends, volunteers from the Lort Smith Animal Rescue bring in their dogs and rabbits to make ward visits. They even have their own ID card issued by the hospital! They come into your room and even sit on your bed if you want them to. I have been visited by a white poodle whose owner has dyed her in rainbow colours. It takes her 4 hours to do it. But my favourite dog is Ralph. He is a Giant Schnauzer and I just love seeing him. He even has a book written about him, which I am reading at the moment.

I now have my own dog. She is a poodle and I named her Lucy. I love it when I'm in hospital and Mum and Dad bring the dogs and even my Mini Lop rabbit Leroy in to visit me. It makes being in hospital so much more bearable!!



Lucy with my rainbow Teddy



Right: Me with Leroy



Lucy was so small that she couldn't control her little feet so we had to put carpet everywhere. She was so small that she could fit into a bowl and a beanie. We had to watch our feet because we could stand on her. She was very clumsy and would run in to doors, and fall off the couch. When she was little she drank through a bottle and drank warm milk.

When Lucy got sick, Mum had to feed her water through a syringe and we had to feed her chicken tenderloins. Her hobbies are eating, drinking, playing, licking and sleeping. She now sleeps in my bed and gives me lots of cuddles. She can do lots of tricks like talk, rollover, crawl, dance, jump, shake and much more.

Lucy loves to be around people, but when strangers come to my house, she and Bella start barking, which is really annoying. Another thing she loves is getting a wash; every 2 weeks we wash Lucy and Bella in the shower.

After they have a shower they go crazy, then they sleep for about 2 hours. One of her many values is caring. Whenever you are crying, she comes and gives you lots of kisses.

The one thing Lucy really loves is getting dressed up. You can put her in anything you want. Every now and then I put her in a nappy and stick her in a pram. She even drinks from a bottle and if you push her around long enough, she might go to sleep.

When Lucy was 8 weeks old she went to puppy school. She did a 3 week course and she was the smallest in her class. Her first lesson she slept through. The second class she did a little bit more. By the third class she was playing with the other dogs. In the last lesson she graduated.

Every year we have to take Lucy to the Casey Cranbourne Hospital for her yearly vaccinations against heartworm and Paro virus. Every month we have to give Lucy her flea treatment. Going on holidays can be quite a problem. We are only allowed in dog friendly parks, but they are still not allowed off the lead. She loves going on holiday.

I picked Lucy as my subject of my school 'passion project' because she is very friendly and would do anything to make you feel better.

She is my little baby.

A comparison of the efficacy of 70% v/v isopropyl alcohol with either 0.5% w/v or 2% w/v chlorhexidine gluconate for skin preparation

WORDS ADAPTED BY G/L

Chlorhexidine gluconate ([CHG](#)) is often recommended for skin antiseptics; however, the most efficacious concentration is currently unclear. In a recent comparative study by Casey et al published in the American Journal of Infection Control. May 13th. [epub ahead of print] the objective was to compare the efficacy of 70% isopropyl alcohol (IPA) containing either 0.5% or 2% CHG for antiseptic skin preparation in patients undergoing coronary artery bypass grafting.

One hundred patients were randomised to 1 of the 2 CHG concentrations. The designated antiseptic was applied to the skin of the operative site of patients before long saphenous vein harvest. Bacterial counts on the skin incision site were determined at various time points to assess any immediate and persistent antimicrobial activity. The number of patients developing surgical site infection was also determined.

Results: The total numbers of microorganisms on the skin two minutes after skin antiseptics and after wound closure was lower with 2% CHG/70% IPA compared with 0.5% CHG/70% IPA.

Six of 41 patients in the 0.5% CHG/70%IPA group developed a superficial surgical site infection compared with 2 of 44 patients in the 2% CHG/70% IPA group.

Conclusions: Isopropyl alcohol (70%) containing 2% CHG compared with 0.5% CHG reduces the number of microorganisms detectable on a surgical patient's skin perioperatively.

Gold Telethon: Ariel Einstein one of Sydney Children's Hospital's success stories

Adapted from 'The Southern Courier', from an article by James Taylor 19 May 2015

Miranda and David Einstein's daughter Ariel spent the first year of her life in hospital after being born three months premature. DRESSED in a Little Miss Sunshine T-shirt and carrying a blue backpack, a bright-eyed Ariel Einstein cannot wipe the smile off her face. She looks like any other little girl, full of the wonder of life, but Ariel was born with the disease, necrotizing enterocolitis, which kills intestinal tissue.

In Ariel's case, it resulted in 93 per cent of her intestines being removed. The condition is primarily seen in premature infants and is the second most common cause of mortality in premature babies. To live, Ariel must wear a backpack containing nutrient rich fluids, which are fed through tubes directly into her body.

But for dad, David, his "little miracle" is a living embodiment of the Little Miss Sunshine character from Roger Hargreave's children's book series.

David said the character summed up his daughter perfectly. "She is such a happy girl," he said. "She really is a ray of sunshine."

Ariel was born 15-weeks premature on her parent's honeymoon in Israel. She spent the first five months of her life in a Tel Aviv hospital. "It didn't even occur that a baby could survive that early," David said.

She survived her lifesaving surgery to remove most of her intestine but weighed just 740 grams. The family returned to their home in Randwick on an emergency flight, where Ariel was put in care at the Sydney Children's Hospital when she was five months old. For the next six months, a care team worked to keep the little fighter alive.

"Our team was fantastic ... they trained us in how to administer her daily intravenous nutrition so we could go home," David said. The Einstein family is encouraging everyone to get behind the Gold Telethon Appeal, the Sydney Children's Hospital's biggest annual fundraiser.



Ariel's poster pictures

In early June, Miranda told our Google Groups forum: "Our hospital asked Ariel to be part of their Goldweek fundraising campaign a few weeks ago. We are so chuffed! We didn't realise the poster would be so big!"

We are told she is also featured at bus shelters and buses throughout the city, so keep an eye out! Feeling very proud!"

A pint-sized battler Ariel supported by her parents Miranda and David Einstein. Picture: Daniel Aarons Source: News Limited



Ariel, with her sister Eadie and parents Miranda and David. Picture: Daniel Aarons. Source: News Limited



Ariel on the right at Wynyard Station



David with Ariel; Miranda with Eadie

Jodie's Story

WORDS BY JODIE

Life Lines - A short history

The timing couldn't have been more perfect. I'd already spent seven years of my fourteen devastatingly ill, and nobody expected a turn-around in my health of such magnitude as was shortly to occur; not even the doctors. I'd spent more time in Princess Margaret Hospital than out of it.

I have a condition called Chronic Intestinal Pseudo Obstruction (CIPO). It was not curable then, and even now there is no hope of finding a cure in my lifetime. When I was fourteen, the condition was considered so rare that there weren't any resources to use for research into finding a cure. Nor did I have the option to be a guinea pig for study (an option I would have taken). My body was quite simply an anomaly, and most appropriate treatments didn't work on it.

In late 1997, I heard talk about God and someone named Jesus. Before I knew it, mum had given her life to God. I quickly followed in her footsteps – guided by the same Christian nurse who had befriended my mother. I didn't understand this 'born again' business, but one thing was crystal clear, *hope* had suddenly rocked up in my hospital room and it was getting comfortable in my visitor's chair.

On the back of finding God came the second big event that changed my teenage life.

Hello nutrition!

Repeatedly, my illness became terminal. Specialists had exhausted all the possibilities of treatment by the time I hit fourteen years old. They argued among themselves as to whether Home Parenteral Nutrition (HPN) -intravenous nutrition- was a good idea for me or not. (Remember, this was eighteen years ago, when PN was considered unsuitable for long-term use.) I was young, naive and spending most of my energy on managing horrid symptoms as privately as possible. But I did sense God was working. Something big was on the horizon.

Eventually, the specialists gave the go-ahead and I started HPN. It changed everything. The quality of life it's given me cannot be overstated. Later, for example, I was able to marry, travel a little and have a baby (an absolute miracle for someone with CIPO).

Young and in love

Ryan and I started dating at age twenty. We married two years later. 2005 was a hard year for me as depression and anxiety took a firm hold. I self-harmed while trying to find a medical professional who would take my emotions seriously. I overdosed twice, landing myself in hospital for very different reasons to those of my past.

Then, 2012 brought us an amazing miracle; the birth of my son, Daniel. Growing a baby in a body with CIPO was almost unheard of, so getting pregnant took extensive planning and a huge investment of faith, in both God and doctors.

A new identity

On PN, Daniel grew perfectly in my womb. Obviously, my body was unable to give him the nutrition he needed to develop well, but on increased PN we both flourished. In fact, my body had never functioned so well and nor has it since. The pregnancy hormones helped my gut to work much better.

At thirty weeks gestation, bowel evacuation issues began. I was in a lot of pain by the end of week thirty-one; unable to defecate despite a desperate need to. I started bleeding from my vagina. Ryan took me to the local hospital, where we were told in a matter of minutes that I was already 5cm dilated. Daniel would be arriving prematurely. (To this day, the reason as to why remains unanswered.)

I was flown to King Edward Hospital, Perth, in a splendid rush. Fifteen or so hours and many drugs later, Daniel was stressed and turned into an unhelpful birthing position. He was wrenched out with forceps and I tore. I have never known such pain (and trust me, I've been through some excruciating pain) nor such relief, in my thirty-two years! Today, Daniel is in great health; a vibrant and sweet little boy.

For the last three years, I've been pretty much mothering my difficult, but beautiful, boy full time. Around the time Daniel was born, new PN arrived with a three-month shelf life. Baxter also gave me a replacement compact pump and backpack. Have bag, can travel? Not yet. I was kept busy by motherhood. My dream of seeing the world would have to wait a little longer.

Flying solo and ready for adventure

But this year, I took my first solo international trip. I could finally spread my wings and fly! It was a most amazing experience. I wrote about it on my blog, Motionandmusings.com. Look for the post called 'We are Winged' if you want to have a quick read.

I stayed at Bliss Women's Retreat, just outside of Seminyak in Bali. It was beautifully serviced and each hostess was personable and helpful. I took extreme precautions by not eating any food from outside of the retreat and took packed lunches from the Bliss kitchen if I was going to be out an entire day. I drank only bottled water, kept my port covered when it wasn't needed and I washed my hands often. I used a sterile technique for all PN procedures.

The only real problem I encountered was at Denpasar airport. The security guards pulled me aside and inspected the suitcase that carried my PN and supplies. They were very suspicious. I was nervous – I'd never done this before. I handed them my medical letter, which explained everything. They had trouble understanding it. They called their boss. He arrived, approved my luggage and I was free to go on my way. I was held up for approximately twenty tense minutes, which felt more like an hour.

In retrospect, I would have had my hubby package my PN more 'professionally' by labelling an esky with medical stickers. I would also have had my medical letter translated into the language of the country I was visiting.

Since getting back from my trip, I have been needling and de-needling my own port. This newly gained independence has breathed more freedom into my life.

Thank you

I can't thank PNDU enough for helping my husband and I to prepare for my Bali trip. You have all given us so much confidence for a future of travel and adventure! I'm grateful for the much needed support you gave Ryan, and I have been inspired by the stories of other HPNers. In a very real sense, you have changed my life for the better. Thank you.





Editor's Note: Jodie is a writer who loves poetry and loves to read. She struggles with depression and anxiety and has written the poem which starts on the next page to reflect her feelings, which she has offered to share with us.

Trapped

Confines made
of brittle bone,
curtained
with membrane,
filled with viscera.

A vibrant soul,
forced
into
a small space.

I expand and stretch,
finger the boundaries
with delicate tendrils.
It is familiar,
I hope.

There's no door -
nowhere to slip out of,
no thin place
to pass through.
Completely sealed.

I'm trapped.

Hope dies fast.
I panic.
Pressure all round.
I'm suffocating.
The prison decays
about me...
on me...
within me...

I'm crushed.

My confines
cannot be fixed
or replaced.

This body is inadequate.

I must inhabit
the dysfunctional matter
within which
I've been placed.

Freedom means sacrifice
but
sacrifice cannot be made.

Somehow,
I must survive.

Medical play puppets

WORDS BY KAREN

One thing that any parent of a little on HPN knows is the importance of medical play. Some parents have been very creative in adapting soft toys and dolls to reflect all the extra bits and pieces these little ones live with. PNDU has a special page on our website – [Kiddies Korner](#) – dedicated to great ideas and tips for parents and carers.

Recently PNDU has also begun to make available free of charge to all our PNDU under 10yrs Aussie and Kiwi HPN littlies, a customised puppet to suit them. These 'Gastronaut' puppets are produced in the UK and many will have seen them, and maybe received one, through their local stoma association. The standard Gastronaut puppets have a stoma, but they can also be customised to include Hickman lines, Mic-key, naso-gastric tubes, etc. All these bits appear on the outside of the puppet's clothing.

PNDU is really excited about this new project to provide such a wonderful medical play resource for PNDU's youngest members and thank the QLD Stoma Association for assisting us with the logistics.

Iron Deficiency in Long-term Parenteral Nutrition

WORDS ADAPTED BY GIL

Iron is not routinely added to parenteral nutrition (PN) formulations in the United States because of the risk of anaphylaxis and concerns about incompatibilities. Studies have shown that iron dextran in non-lipid-containing PN solutions is safe. Data are limited on iron status, prevalence of iron deficiency anemia (IDA), and efficacy of intravenous iron infusion in long-term home PN (HPN). A study recently published by Hwa, Y.L et al in JPEN 2015 aimed to determine the incidence of IDA and to examine the effectiveness of parenteral iron replacement in patients receiving HPN.

Medical records of patients receiving HPN at the Mayo Clinic from 1977 to 2010 were reviewed. Diagnoses, time to IDA development, and hemoglobin, ferritin, and mean corpuscular volume (MCV) values were extracted. Response of iron indices to intravenous iron replacement was investigated.

Of 185 patients (122 women), 60 (32.4%) were iron deficient. Five patients were iron deficient before HPN?, and 18 had unknown iron status before HPN. Of 93 patients who had sufficient iron storage, 37 had IDA development after a mean of 27.2 months (range, 2–149 months) of therapy. Iron was replaced by adding maintenance iron dextran to PN or by therapeutic iron infusion.

Patients with both replacement methods had significant improvement in iron status. With intravenous iron replacement, mean ferritin increased from 10.9 to 107.6 mcg/L, mean hemoglobin increased from 11.0 to 12.5 g/dL and mean MCV increased from 84.5 to 89.0 fL.

Conclusions: Patients receiving HPN are susceptible to IDA. Iron supplementation should be addressed for patients who rely on PN.

NOTE: The most recent (2014) AuSPEN guidelines for Australasian HPNers (> 15years old) recommend a maintenance dose of 1.1mg /day iron. Higher doses may be appropriate for some individuals.

Time to celebrate! HPN Awareness Week 2015

WORDS BY KAREN

This is PNDU's 5th year of celebrating this very special week in the calendar of all HPNers – HPN Awareness Week. Do you continue to encounter blank looks or assumptions when you mention HPN? Does 'parenteral nutrition' continue to be confused with 'parental nutrition'? Well this is a great opportunity for you to help raise awareness and understanding amongst friends, family, work colleagues, clinicians and the wider community of what HPN is, how it keeps you or your loved one alive and the vital role PNDU plays in supporting those living 'down under' with HPN.

We'd love everyone to get involved and celebrate this week with us and alongside various sister organisations overseas, including Oley (USA), PINNT (UK), Poland, Czech Republic and Italy. We will be making various resources available to everyone – a YouTube clip for you to pass on to others with your own story, a media release to send to your local newspaper, stickers for you to wear during the week, a poster to put up in your workplace, local library, chemist, doctor's surgery, and a flyer about PNDU for you to share with your medical teams.

And HPN Awareness Week isn't just for HPNers! We want all of you who know the difference HPN makes to people's lives, but also how complex it is, to join in celebrating with us!

We look forward to our most successful HPN Awareness Week yet and especially thank Fresenius Kabi for their support and sponsorship of this event.



Doctor, do you have a moment?

National Hand Hygiene Initiative compliance in Australian hospitals

WORDS ADAPTED BY GIL

Dr S Azim and colleagues published in the May 2014 issue of Med J of Australia their assessment of hand hygiene compliance rates for medical and nursing staff by analysing data from three different cross-sectional datasets: Hand Hygiene Australia data for 246,665 hand hygiene opportunities from 82 public hospitals representing eight Australian states and territories, and hand hygiene rates and Staphylococcus aureus bloodstream infections (SABSI) rates from the MyHospitals website.

Medical staff consistently performed below the national threshold for hand hygiene compliance regardless of hospital size. Nurses' compliance was consistently above the threshold. One-third of the patient interaction hand hygiene opportunities were before touching a patient, for which compliance was below the national threshold in 68% of hospitals. Hand hygiene had little impact on the rate of SABSI.

This paper was summarised in the newsletter: Infection Prevention and Control Research Review 2015 with comment below by Dr Richard Everts, an Infectious Diseases Physician and Microbiologist working in New Zealand: Australia and New Zealand both have developed national hand-hygiene initiatives, based on the WHO's '5 moments' and involving education and audit. This report presents recent audit results from Australia, including poor hand hygiene by doctors compared with nurses, poor compliance with 'moment 1' (the moment before touching a patient) and a wide range of hand hygiene compliance (e.g. 49% to 78% in 301- to 400-bed hospitals). Similar results are reported in New Zealand. The authors suggest that the high cost of ongoing audit may be better spent on interventions to improve practice, focusing on doctors and 'moment 1'. I like the idea of making hand hygiene education mandatory for doctors, interrupting and reminding doctors about hand hygiene at the bedside and senior medical staff modelling and promoting good hand hygiene.

International Patient Experience Week 26th April – 2nd May 2015

WORDS BY KAREN

As part of International Patient Experience Week, which celebrates 'healthcare staff impacting patient experience every day', the 2015 Patient Experience Symposium was held in Sydney on 30th April 2015. The Symposium was sponsored by NSW Agency for Clinical Innovation, Clinical Excellence Commission, NSW Government Health, NSW Kids & Families, Bureau of Health Information and Cancer Institute NSW and invitations were offered to healthcare staff as well as patient representatives.

Right from when I walked in I was encouraged – the number of healthcare staff in attendance showing their passion for this topic was exciting. Obviously a symposium with this title attracts the 'converted', but with over 450 registrants (patient representatives being a very small minority), it was wonderful to see and be a part of. Although it was a NSW symposium, I would hope it was indicative of the attitudes of the increasing number within our healthcare systems in Australia and New Zealand.

The keynote speakers were Patrick Charmel, CEO Griffin Hospital and Planetree Inc, Connecticut USA; Dan Wellings, Head of Insight and Feedback, NHS, England; and Laila Hallam, Consumer Advocate. All 3 gave insightful and motivational presentations on how our medical system can be more patient-focused, providing benefits for everyone.

There was the successful example of Griffin Hospital which has broken all moulds and achieved a standard of patient-centred compassionate care which is second to none (what a hospital – I want to go there!!). It has been in the top 100 of US organisations where employees wish to work for the past 9 years! Dan Wellings' presentations on the NHS' specific use of data collection and measures to improve patient experiences gave the practical example of how to use data to change a system as big as the healthcare sector. And Laila's personal and tragic experience with her father's ill health and death gave the reasons why our healthcare system needs to change. To her absolute credit, this personal tragedy has not crushed Laila, but motivated her to assist in making sure other families don't suffer the same way, by using her skills to identify ways to improve patient participation that contributes to more effective personal healthcare decisions.

Other topics during the 2 jam-packed break-out sessions included compassionate care; engaging young people with chronic conditions in transition from paediatric to adult services; visiting hours – patient experience driving change;

and engaging clinical staff organisation-wide to improve patient experience.

A few take-home points for the healthcare profession from the day:

- Get patient experience/feedback in various formats
- Feed this information back to patients
- The strong role of compassionate care
- Families/carers need to be involved
- The important role of leadership
- The powerful nature of patient stories
- Engaged staff are an important enabler for good patient experience

And for consumers:

- Be informed
- Speak up
- Give the health system time to adapt
- Patients aren't islands
- Enough voices can lead to change

This is a brief overview of what was a great day of presentations by healthcare folk and patient representatives passionate about and striving to achieve more patient-focused care. Understandably, trying to change organisations the size of our healthcare systems doesn't happen overnight. But even if the steps are small, change is starting.

A really encouraging day.

Sal's Amazing Cakes

Editor's Note:

In our 3rd issue, we had an article about our first Sydney get-together, for which Sal made an amazing cake in the shape of our then logo. We also read about 'Sal's Story', including some pictures of the wonderful cakes that she makes for family and friends. After sharing a picture of her daughter's beautiful 16th birthday cake on our Google Chat Forum, I asked Sal if she'd send photos of more cakes so that we can inspired by what she does, despite her illness and busy life with 4 teenagers, a husband and a job.

Sal's words: I made my first cake when my eldest turned 1 in 1999, and went from making them from the Women's Weekly cake books to my own creations. I am self taught and never had a lesson. I have made over 120 cakes over the years - I have lost track of the actual number. I make them for family and friends mostly, but occasionally for others who have got to hear about them. For me, it's fun and my art and creative outlet. I have a facebook page called 'Sarah's sensational cakes' with more photos on them. I make sure they taste yummy too and never use cake mixes. I personalise them as best I can.



Star Wars



Frozen



*Top left: Sal's daughter's 16th birthday cake
Top right: A wedding cake
Left: Car theme
Bottom left: Harry Potter series theme
Bottom right: Gardening theme*



Baxter Healthcare's new HPN Patient Guide

WORDS BY KAREN

Did you know Baxter have a new booklet "Parenteral Nutrition at Home – Patient Guide" which you can obtain from your HPN hospital team? The Australian version is available now. The New Zealand version will be available soon.

Birthday Corner

Jordan (6 years old)

POP/CHRIS

Thank you for the birthday wishes for Jordan (HPNer). He had a big morning before school, opening presents with Mum, Dad and Auntie Katie.

At school, Jordan had a small celebration and shared cupcakes with his teachers and friends. Just before bedtime Jordan had a big surprise; Nana returned home after 3 months caring for her parents in QLD. All 3 boys were overwhelmed with excitement at Nana's return.

We had a small party with family on Saturday, and a George the pirate pig birthday cake, thanks to Auntie Katie. Pirate toys and games were the main theme this year.

6 years seem to have passed so quickly, another great milestone.



Dylan, Jordan (HPN) and Logan (HPN)

Sam (6 years old)

MUM SHIRLEY

On June 6th, Sam turned 6. He really wanted a Jungle Junction cake even though he doesn't eat. We had fun making it and he loved it.



Sam

PNDU's Annual Awards – let's celebrate great work!

WORDS BY KAREN

We've received a few nominations already! You have until 31st August to nominate those you believe deserve recognition for their work in the field of HPN – your favourite HPN clinician, a helpful soul at your homecare company, someone involved with PNDU – there are a variety of categories.

PNDU's annual awards began in 2014 with great success and we look forward to once again being able to congratulate those whom our Aussie and Kiwi members recognise as doing a great job.

Email your completed nomination form(s) to contactpndu@gmail.com . Nominate as many times as you wish. More details and the nomination forms can be found on the [PNDU Annual Awards page](#) (under the 'Get Involved' tab on our website).

PNDU Award categories:

- **HPN Professional Awards** recognise positive efforts by health professionals and industry to provide good quality service to consumers. There are 4 categories of HPN Professional Awards:
 - **Adult Parenteral Nutrition Professional of the Year**
 - **Paediatric Parenteral Nutrition Professional of the Year**
 - **Commitment to Patient Care - Company Employee of the Year**
 - **Outstanding Achievement Award:** a prestigious award to an individual/group/body who has made an outstanding contribution to IF/HPN throughout their time working within the field.
- **Lifetime Membership Roll of Honour Award** is a special award for any member who, as an HPN consumer, parent or carer, has given their time "over and above" for PNDU.

Get your nomination(s) in now!

Calling all Brisbane HPNers to 2 great events in September!

WORDS BY *KAREN*

PNDU HPN Social Gathering in Brisbane

When: Sunday 27th September 11am-3pm

Where: Venue to be confirmed, but somewhere in or close to Brisbane's centre

Who? For HPNers and families

Come and meet other PNDU members in person and enjoy a great time of chatting with others who totally understand life with HPN. If you aren't a PNDU member but are living with HPN, you are most welcome to join us. And HPN clinicians – please let your patients know about this event.

Please contact us at contactpndu@gmail.com or mobile 0413 715 187 for more details.

AuSPEN HPN consumer workshop in Brisbane

When: Monday 28th September 12.30-4pm

Where: Princess Alexandra Hospital

Who? For HPNers and families

This is AuSPEN's second HPN consumer workshop (see [Dripline issue 10](#) to read about AuSPEN's inaugural HPN consumer workshop in Auckland last November 2015). Come along and learn more from clinicians about this complex but life-saving treatment which we are all living with. PNDU applauds AuSPEN for this invaluable event and thank them for all the hard work they do.

PNDU's Charity Cards

WORDS BY KAREN

We've received delivery of our PNDU charity cards and they look great! Please go to our [website](#) to find out how to purchase or email us at contactpndu@gmail.com.

There are 1 x Christmas card design and 2 x blank card designs (shown here). Every pack of 10 cards you purchase will assist PNDU continue our work of supporting Aussie and Kiwi HPNers and their families.



Folding Cards

WORDS BY GILLIAN

Karen came to my house on Friday 3rd July with 2 boxes of cards and envelopes- 1000 in total. It was PNDU's charity card folding and packaging day. The cards, which we had chosen and ordered late last year, arrived 'flat'. They needed to be folded, counted into groups of 10 with envelopes, then put into cellophane bags. As with most jobs, the time passed quickly doing it with a friend, being able to chat and catch up on news as we went. Ray, my husband, also put some time into helping with this, as well as acting as barrista for us. Miranda had planned to help, too, but unfortunately, Ariel was in Club Med (our term for 'hospital', not a holiday resort) with a respiratory infection. See the previous article for details of how to buy these cards.



Karen, Gillian and Ray

What Would People Say?

Editor's Note: I asked members of our Google Chat Forum about how often, if at all, they went out and about whilst infusing PN in their backpacks; and if so, whether or not people who saw them had commented or asked about what was happening. Here are the responses.

I have been doing back stage crew and puppetry for my daughter's musical that she is in (Ruddigore by Gilbert and Sullivan) whilst wearing my backpack. Fortunately, it was just for the dress rehearsals and I have had my off PN nights for the performances. I must say that I am amazed at the fact no one has asked what it is and why, or anything like that. People are either very accepting, or too scared to ask I guess.—**Sal**

I remember going to a big fundraiser a couple of years ago with my backpack on and ended up sitting at the front and even won one of the games. I was there on my own with a very obvious backpack on for all to see (not what I'd wanted, but it happened). Only one person asked later (when I was getting a drink) what it was – she was an ambulance officer and figured it was something medical. I wonder whether people simply assume I like wearing a blue backpack that clashes with evening attire, and that's all! - **Karen**

I don't really go out with it. We've only taken Daniel, our son, to the hospital with it on and some night trips in the car. But other than that I haven't taken it out in public. It's the tube more than the backpack that I don't like. Just had my second night out on PN in 18yrs. Gaining a small measure of confidence.— **Jodie**

I wore mine to Pilates last week as we were to go out to dinner straight after and I work the next day, so I needed to set up early...no one queried the backpack with long line attached across the floor as I went through the hour long routine – I guess people don't like to embarrass you by asking personal questions (or aren't prepared to listen to possibly long-winded answers).—**Gillian**

Like many others, I do get tired so have to be careful with going out at night. A very good friend supported me early on to go out and ignore others - good advice. I have been invited on numerous occasions to put my backpack down. A little while ago, when visiting the Sydney Opera House to see the ballet, I was asked by the staff to check my backpack into the cloakroom. Profuse apologies followed when I explained that was not possible. I have also gone to meetings and driven my car while connected. Hooray for portability!! - **Renee**

I have a rule that any passenger in the front seat has to hold my backpack. At one stage I used to have a hook at the back of my driver seat and just hooked the backpack there as I got in. It is awkward though.—**Karen**

I struggle to push my dripstand around the house on the carpet. I have only ever been offered a large hospital Baxter pump so I hook up to that for 10-12hrs a night. I would never venture out or even try to drive a car with this pump, so I tend not to go out after 7pm after I've hooked up. I would love to get my hands on a smaller or portable pump that would fit in a backpack especially for travelling. I have only ever travelled once and had to cart the pump in hand luggage which took up all the small suitcase and was over the 7kg limit, but luckily they didn't weigh it. It's not going to stop me from travelling that's for sure.—**Susan**

When I have been asked to put away the backpack and I replied 'can't because it's attached to me', no one has asked why! So glad to have the backpack. I have just once gone to the supermarket, a gingerbread house night and church with my drip stand and big pump, pre backpack. We had to take the bus to transport it!!! Got a few looks, but no questions from strangers.—**Sal**

I've started driving the car while infusing. Two weeks ago, after nearly having a little panic attack for fear.....I went to a workshop at my workplace. It was an advanced paediatric life support class...I was also able to do the CPR with the pack on my back. I suspect I wouldn't have been able to do an adult mannequin. I had got myself all stressed, but after the tutor, a friend of mine, apologised when he realised that it was my liquid lunch and not the type he thought I had in there, we got on with the workshop and it was fine. It's awkward with the weight of the pack trying to lift it in and out of the car. I infuse often now for 30-odd hours continuously, so better get used to it. I'm gaining confidence and now go out a lot on my own while infusing. I've done the shopping, went to the movies, went to a night thing by the dock, and even to a doctor's appointment recently.—**Jacqueline**

I've just had a lovely chat with Rosie and having been on HPN for 20+ yrs, has loads of stories!! The dripstand and hospital pump never stopped her and her family going on holidays, with the pole attached to a suitcase. She and her husband even travelled on the Indian Pacific with her dripstand and pump. Now, with the backpack, and having being on long infusions for a while now (up to 20hrs/day), Rosie is often out and about with the backpack – shopping, hairdressers, movies. Clothes shopping is a bit challenging though! At home, she uses the adapted shopping trolley to move around. She's only ever been asked once to remove it and that was at a museum in Queensland. Once she explained, the guy was very apologetic. In a supermarket, she heard a boy tell his mum that that lady shouldn't have her backpack on in the store (school kids can't take backpacks in) and that she should take it off! But she has never been asked to! Of all the years that Rosie has been wearing the backpack out and about, she has had the occasional staring, but only remembers one person asking - a workman at her house asking if she was going trekking. Once she explained, he was very interested to know more about it.

Following on from the recent chat about where we go with backpacks, I went with friends to the Sydney Vivid Light Festival last night. A lot of fun and very family-oriented which was nice, even if it was challenging to be able to all stay together (bumper to bumper people – I reckon most of Sydney was there!) and I certainly doubt that I would have ever heard if my pump alarm went off! The best bit though was being able to crash almost straight into bed once home again – no connecting up once I got home. Nice! - **Karen**

A funny thing happened...

BY MEL

I have a story that only you [ie people on Home Parenteral Nutrition (HPN)] will find as amusing as us. Earlier in the week Emily's [6yr old on HPN] school called me saying "don't panic, the ambulance is on the way and we have cleared the room from all the other children. There is a bit of a situation with Emily, but we are following procedures and applying pressure. Can you please come straight away?"

Needless to say I gathered the other kids and bolted up there. A very stressed principal met me in the car park and I rushed to the classroom with sounds of a siren in the distance. Thoughts racing around my head of "not again, not other disaster".

I opened the door to the room to find several staff crowded around Emily and no other kids in there. Her support teacher had a large towel pressed against her chest wall. Em meanwhile is chatting away quite obviously loving all the attention, and looking perfectly fine.

I ask her what happened and she says "mum, my line just came out of my top!"

As most of you know, Emily wears a little top with a pocket on the inside that keeps the lumens up over her shoulder and away from her colostomy. She and I burst out laughing just as the ambulance staff rushed in. I explained that the lines have just come out of the little pocket in her top and NOT out of her chest wall! I also suggested that perhaps there would be a lot more blood and Em may look a bit unwell if that was the case!

After we all started breathing again, I am thrilled to announce that the action plan for Emily at school works perfectly!

What's in your PN bag?...Iodine

WORDS BY GIL

Editor's Note: As with all medical information, if you have questions or concerns, these need to be raised with your medical team.

Iodine (I) is an essential trace element that occurs in soil, plants and sea water. There are consequently traces of iodine in all foods, but ocean fish are the best natural source.

Unfortunately, in many parts of the world, such as Australia, New Zealand and UK, soils and crops are iodine deficient resulting in inadequate intakes. Since the only known function of iodine is for thyroid hormone synthesis, iodine deficiency (ID) will lead to inadequate thyroid function. Thyroid enlargement (goitre) is the classical sign of chronic ID, which was common in the early settlers 'Down Under' until table salt was fortified with iodine. Chronic intestinal failure (CIF) patients with a normal duodenum, who are able to eat, may absorb dietary iodine but this quantity may be reduced in short bowel syndrome (SBS) patients.

The recommended daily iodine intake for adults is 150 mcg, with extra needed during pregnancy for the lactating breast. In healthy adults about 90% of dietary iodine is absorbed in the stomach and duodenum and then about half is transferred to the thyroid (a process which is inhibited by cigarette smoking). A high dietary intake of iodine (up to

1mg/day) is well tolerated by most healthy adults, but some adverse reactions, such as headache, fever, metallic taste, gastrointestinal irritation and acne have been reported.

It is therefore important to assess iodine nutrition status using several complementary tests:

- Urinary iodine (UI) is a measure of recent iodine intake. Low UI indicates insufficient iodine intake and suggests a high risk of developing thyroid dysfunction
- Thyroid function tests for *Thyroxine (T4)*, *Triiodothyronine (T3)*, *Thyroid stimulating hormone (TSH)* and *Thyroxine binding globulin (TBG)* which is synthesised in the liver, provide an index of iodine intake over past weeks to months. *TSH* is a good marker of iodine intake in newborns but in older children and adults, *TSH* is relatively insensitive, so serum concentration alone is not a good marker of ID
- Thyroid size is related to long-term iodine intake.

It always used to be assumed that ID was unlikely to occur in CIF adults on HPN. Iodine absorption from iodine-containing antiseptics, radiographic contrast dyes and absorption of dietary iodine by patients with a functioning duodenum, were thought to be sufficient. However, there is no iodine absorption in CIF patients totally fed by PN, and some patients who are exclusively fed by Enteral Nutrition, may still have inadequate iodine intake, depending on the amount of iodine in the enteral formula. For these reasons, the European Society of Clinical Nutrition (ESPEN) advocates routine supply of 100mcg/day iodine in their home parenteral nutrition (HPN) guidelines for adults and AuSPEN (the Australasian Society for Parenteral and Enteral Nutrition) advocates 130mcg/day. ASPEN (the American Society for Parenteral and Enteral Nutrition) makes no recommendation. For children a daily PN dose of 1mcg/kg/day has been recommended. This supplementary iodine is included in the PN bag, usually as part of a multi-trace element additive, in the compounding unit.

A recent case report of hypothyroidism in an infant on PN from the USA and a publication by a leading European HPN expert questions some of these earlier assumptions and concludes that HPN patients may have an increased risk of ID. Italian researchers examined the amount of iodine supplied in the PN bag to CIF patients on long term PN. Only 26% of patients received iodine in the range recommended by ESPEN. 19% patients received less, while 55% received no iodine at all. Even those patients who received a PN iodine supply according to ESPEN guidelines had a low UI. SBS-patients had lower UI than non-SBS, but TSH was low only in 22% of patients. Interestingly, all subjects used chlorhexidine instead of povidone-iodine antiseptics for their lines, and this fact, coupled with low oral intake, seem to be the predisposing factors to low iodine levels.

Iodine requirements for CIF patients may therefore have been underestimated and more research needs to be conducted in large cohorts of patients to better define iodine requirements in long term HPN. In the meantime, these recent results would suggest a need for more frequent monitoring of HPNers' iodine status to prevent iodine deficiency occurring.

References: Clarridge KE et al JPEN 2014; 38;901, Guidetti M, et al Nutrition 2014; 30:1050

Like books?

WORDS BY KAREN

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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, telling us about yourself.

Benefits: Through membership you are invited to join one or both of our private forums: our Google Groups email 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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We are grateful to our sister charity IPANEMA (Charities Commission Registration CC21178) which receives donations on our behalf. (Donations are currently only tax deductible in New Zealand.)

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Contact us

www.pndu.org

contactpndu@gmail.com

128 Rainbow Street, Randwick NSW 2031, Australia

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