DRIPLINE

PNDU
Parenteral Nutrition Down Under

ISSUE #16
May-July
2016

Welcome to Issue 16 of Dripline. There are several member's stories for your enjoyment, including one from a member who 'drips with talent' – our 2016 Awareness Week slogan. Other member stories include a successful pregnancy; a child who has been able to come off HPN; a mother of 2 gorgeous children, both on HPN; a sibling's point of view about life on HPN; and one member's wonderful imagination. There is also information about an HPN Workshop and PNDU social gathering in Melbourne and how two members can receive sponsorship to visit; how PNDU has been involved in a few conferences; how carers have access to resources on government websites; a book review of a wonderful book, 'It Takes Guts'; and more. I hope you'll enjoy this issue.

Gillian - Editor

In this issue:

Growing a Baby with CIPO Malnutrition

WORDS BY *JODIE*

Around 2008 and 2009 my husband Ryan and I began to talk seriously about having a child. We'd been married for four years at this stage.

At one point, I decided not to put my body under the pressures of growing a baby. I didn't want to expose my would-be, innocent child to health risks because my body couldn't provide it adequate nourishment. Neither did I want to pass on to my child Chronic Intestinal Pseudo Obstruction (CIPO). Ryan supported my decision.

But we couldn't live with this choice for long. There was the possibility that I could successfully grow a child and bring it into the world – that everything would be fine. After all, we thought, I'd experienced many miraculous health improvements since I was fourteen years old. Could I, a woman, bear not trying for a baby in the face of possibility? No I couldn't.

Preparation

So, in early 2010, Ryan and I decided to take the leap of faith. My gastroenterologist got very excited about the challenge of my potential pregnancy with CIPO and promptly increased my parental nutrition (PN). My weight, usually sat around 48kg, increased rapidly to 53kg. I felt like a blimp! (I'm only 157cm tall you see, with a petite frame.) Meanwhile, my family looked at me with a glint of suspicion in their eyes. Ryan and I maintained secrecy about our plan. We told our family that I was doing exceptionally well and hoped they would believe me (they did).

I soon decided I wasn't ready for all the changes taking place, or those still to come, in my body and our married life, to have a baby. So we told my gastroenterologist, he decreased my PN, and Ryan and I went away to Thailand for a holiday and cultural experience. Soon after our trip we decided it was, finally, time. I now felt emotionally ready for a baby. I was quite a few kilograms lighter (back then, I didn't take PN with me on holidays, and my health suffered as a result). Ryan and I talked over the risks again with health professionals. Until 2011, not many women had been pregnant on PN. Most of what we were to face was unknown, but doctors assured us it was unlikely I'd pass on CIPO to my child.

There was a greater-than-average possibility I would deliver a baby prematurely. But equally, it was possible I'd deliver a baby at full term. There was a small risk my uterine muscles (which are very similar to intestinal muscle) might also be affected by CIPO and that this could cause problems. But it wasn't an anticipated difficulty. More than concern, we were given a lot of hope and encouragement to bring a baby into the world.

When I got to 49kg, my gastroenterologist said, 'Go ahead, start trying!' We were taken aback by his immediate permission after all the preparation we had to make last time. The surprise didn't last long. We walked out of the hospital with happy, hopeful hearts. My PN was increased again, but not as drastically as the first time we'd talked about pregnancy. I started to gain a steady amount of weight as my PN was increased gradually (no flash-fat this time!) I also started taking a high dose of oral folate (to account for the malabsorption).

Conception

Ryan and I were becoming discouraged when, in our eleventh month of trying to fall pregnant (and many pee tests later), we finally learnt of a little speck of baby life in my uterus. I can't explain just how ecstatic I felt. Ryan was over the moon too. That was August 2011. Ryan and I had purchased some land down south (WA) and locked in house plans with a building company. We'd been trying for several years to buy (or build) our first house. It seemed everything was falling into place.

What most amazed me was that I suffered no morning sickness during the pregnancy. I was beyond exhausted during the first trimester but otherwise felt very well. Tiredness and lethargy forced me to leave my casual job but I had no other cause for complaint.

At three months gestation, we told everyone about our healthy, growing baby. Most of our friends and family were excited. Some were concerned about whether the baby would survive and whether I would keep well throughout the pregnancy. I remember my mum's response to our news. She was alarmed! She thought this was the end for me – that I wouldn't survive having a baby. Poor mum. I wasn't expecting that response.

Around this time my GP discovered I had hypothyroidism. Whether this was caused by pregnancy or was an existing, undetected condition, we'll never know. Fortunately, starting on oral thyroxine was everything I needed to treat the deficiency. I maintained a strict, nutritional diet. I craved fruit and juice the entire time. I didn't dare take any risks with food. I ate much less than before we conceived but that was expected. Although my diet was very restricted, I felt fantastic! All the pregnancy hormones must have made my gut (and body) feel great. I can't ever remember

feeling so physically well.

I started seeing the medical team at the High Risk Clinic in (a nearby town), which was affiliated with (a hospital) in Perth. I frequently had ultrasounds, to check on our baby's development. I also went to regular doctors' appointments in order to monitor my weight gain and CIPO symptoms. I had regular, extensive blood work done to ensure maintenance of nutrients in my body. At sixteen weeks gestation an ultrasound showed that we were having a boy. He was positioned with his head down, feet up and stayed that way until birth.

Pregnancy was turning out to be the most amazing experience of my life. My body, so many times close to death in years past, was now bringing new life into the world. I felt my boy's fluttery movements and my heart soared. We decided on a name. Daniel John. He would be our one huge miracle.

I had one random vaginal bleed between 20-30 weeks but otherwise experienced no health difficulties whatsoever until Daniel was 31 weeks. My belly never got that big. In fact, I felt smaller and more comfortable than with other bodily changes in my past (for example, during episodes of severe gastric bloating).

Then I started struggling in the 32st week of Daniel's gestation. I became constipated and experienced terrible back pain, in spite of repeatedly trying to mechanically evacuate my bowels. We hardly had time to sort out this issue before I began to bleed again. Pain and the urge to push set in. Ryan took me to hospital after we enjoyed a lazy breakfast. I felt unconcerned and pretty relaxed!

Labour & Delivery

At the hospital a nurse determined I had pre-eclampsia. More importantly, I was 5cm dilated. Surprise; Daniel would arrive early!

The hospital staff seemed slightly panicked – everything around Ryan and I became frantic. One doctor believed my waters had already broken because he said he could feel the hair on Daniel's head. I was given nifedipine to postpone delivery and The Royal Flying Doctors flew us to Perth. Then an ambulance rushed us to the hospital as I inhaled nitrous oxide and absently chatted to the paramedic next to me. Ryan went home to pack bags and feed the pets then drove the three hours up to(the hospital).

I sat, aching, in my hospital bed in the labour ward with a heart monitor secured around my tummy. The contractions weren't as strong or frequent as they should have been by this stage and they weren't changing. I tried pushing a few times (at 8cm dilation), instructed by my very calm midwife. No result. Meanwhile, five anxious family members and a student midwife came in and out of my room. Ryan and I got no space.

The midwife then 'scooped' inside of me and my body's amniotic fluid broke all over her in a powerful gush. Well, that was quite embarrassing, but maybe he'll come out now, I thought. We both laughed. Our baby didn't budge. He sure was stubborn. The midwife injected me with oxytocin to induce labour. Daniel's birth then went quickly from super easy to traumatic. Whilst my contractions failed to strengthen or increase, Daniel became panicked and twisted into an awkward position. The situation was an emergency.

The room filled with staff (I had no idea who they were), my legs were stretched high into stirrups. My bladder was full and I complained about it. A catheter went into my urethra and my urine slapped hard onto the floor as the doctor at the end of my bed yelled for someone to get a bucket. All the while, my anxiety was increasing to a whole new level. Ryan held my hand at the head of my bed. This all happened with great speed. Ryan and I could barely keep up. The first registrar tried to determine Daniel's position. He couldn't. The second registrar tried, at length. He couldn't work it out either. The obstetric consultant yelled at them to hurry up and tell her how my baby was positioned. At the same time, Daniel's heart monitor continually alarmed.

There were so many people in my room. Everyone was under pressure. I started crying. It was all too much. I wanted all their hands away from me. I felt violated. I wanted Daniel safe in my arms NOW. I looked at Ryan. His face was drained of pink. He was growing faint, given a chair and sat. The student midwife held my hand now.

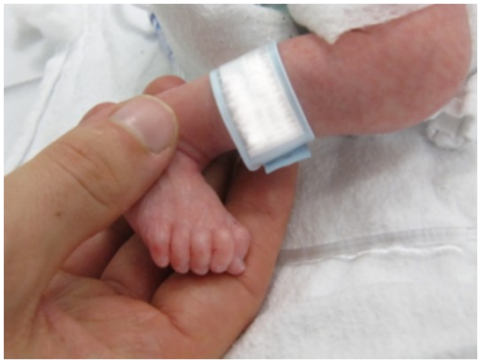
A vacuum machine stood nearby. I thought they were going to use it. I wasn't worried about any pain because I hadn't seen the disturbing medical instruments nearby. The obstetric consultant pushed everyone aside and pushed a forcep into my cervix. I thought I had experienced the worst pain imaginable at the cruel hands of CIPO. I was wrong. In that moment, I tore and went to somewhere black. I screamed, arching my back. My 'lights' came back on and I panted in shock. My midwife consoled me and I forced myself to breathe deep and slow. A second forcep was inserted. Next second, the obstetric consultant yanked Daniel out by his head. My stressed little baby was being delivered into the world. I curved my body forward to see Daniel's face as it emerged. He made a sound just like mewl. The forceps were removed. Stretched and exhausted, I pushed his tiny body out. A paediatrician took him from the foot of my bed directly to an examination table.

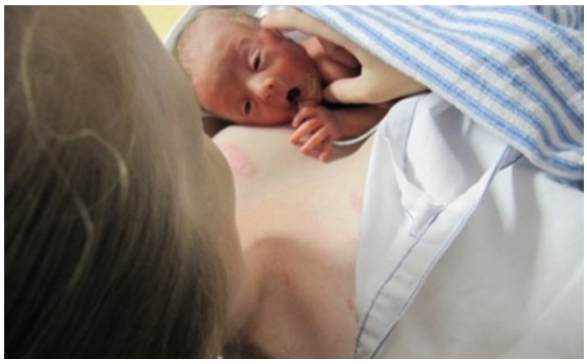
Our baby had just reached 32 weeks gestation at birth. He was given a precautionary shot of steroids to help his breathing. He weighed 1.5kg.

He was skinny, wrinkled and severely marked by the metal forceps. He was laid on my tummy, positioned like an upside down turtle and I held him close for a few mere minutes. He was perfect in our eyes, but I worried. His head was damaged. Daniel was taken to the special care nursery and I lay there with Ryan, my mum and aunty next to me. We cried.

A short while after the birth, I passed five large stools (with roughly half hour intervals) and felt so much better but I just wanted my little boy in my arms.

Daniel and I stayed in hospital for five weeks with daddy close by. Thanks to God, modern medicine and PN, at 37 weeks we were finally discharged and arrived home with a healthy, growing, beautiful baby boy.

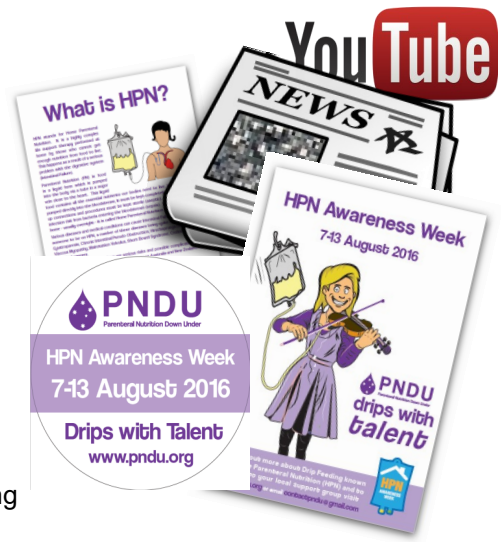




Why?

Ryan and I weren't given a clear reason for Daniel's premature birth. The doctors can only speculate about why my body (medically assisted) delivered him early. Maybe my uterine muscles were affected by CIPO and couldn't hold him inside to full term. Maybe his prematurity was caused by some other 'normal' female factor. Maybe, it was because my bowels had stopped functioning in their usual, albeit ineffective, manner. Nobody knows. The important thing is both Daniel, Ryan and I came out of the experience intact. Today, we are a close, happy family.

PNDU drips with talent for HPN Awareness Week!



WORDS BY *KAREN*

Editor's Note: Due to unforseen circumstances, Dripline was unable to be sent before Awareness Week, so the activities below have already occurred.

7-13 August 2016 is HPN Awareness Week – a wonderful opportunity for everyone whose lives are touched by HPN to help raise awareness and understanding amongst family, friends, schools, workplaces, the local community, and even the medical community.

This year we are celebrating with the theme 'PNDU drips with talent', showcasing

the marvellous hobbies, crafts and artistic talents of many of our HPNers who live with the day-to-day challenges of HPN.

Once again PNDU has been working hard to prepare and provide our members with lots of fresh resources to assist you in raising awareness right where you are, including:

- HPN Awareness Week video clip
- Media Release for members to use to share their own story in their local newspaper
- Stickers, posters, and HPN info flyers
- Social media profile for use during the week

An exciting addition to the celebrations this year – Baxter Healthcare is hosting HPNer and carer tours of their pharmacy departments in at least 4 cities in Australia and New Zealand (Biomed in New Zealand hope to join in next year).

We are thrilled too that a couple of hospitals are joining in the celebrations and holding their own HPN Awareness Week displays. If you are an HPN clinician and think your hospital would be interested, it's not too late, but contact us now at contactpndu@gmail.com!

While the primary aim of the week is to raise awareness and understanding of HPN 'down under', we are also encouraging donations to PNDU to assist us to continue our work of 'supporting, researching and informing consumers, carers and providers of Parenteral Nutrition for Intestinal Failure' in Australia and New Zealand.

We look forward to a wonderfully successful HPN Awareness Week 2016, and hope that this celebration of HPN will grow in the years to come.

To find out more about any of our resources, please contact us at contactpndu@gmail.com.

A Sibling's Perspective

WORDS BY *CANDACE - 13 YEARS OLD*

I can remember when I was six, walking into my brother's room in hospital. NICU was scary and smelled funny with monitors beeping and flashing. I thought, 'where is my little brother?' And then I saw him in a tiny glass case with little holes so that you could touch him. He was so little and chubby and for a moment I forgot that Sam was in a scary beeping place and I just wanted to pick him up and cuddle him. For seven years now Sam has been in our family.

Sam was born with a rare condition called MMIHS (mega-cystic micro-colon, intestinal hypoperistalis syndrome). He is one of two people in New Zealand with this disorder. It means his bladder and kidneys are damaged, and so are his stomach and intestines, so he can't eat food. He also has ongoing issues with his heart and lungs. He is constantly having UTI's (urine tract infections) and needs a drip with intravenous nutrition (Home Parenteral Nutrition, HPN) for 12 hours at night. He also has mobility issues (running, jumping, moving as fast as other kids). When he was born, he was covered in tubes, probes and so many other monitoring widgets he looked like a small robot. Thankfully as he's grown, he's been more able to do things. Now he only has a PICC line, a GJ tube, colostomy bag and drainage holes for his urine.

Sam has obviously always been different, but I've never seen him that way until recently. Recently I've noticed that he doesn't want to play on the swings like other kids. It's hard watching Sam grind his teeth and roll his cars around in his room with a drip hanging over him while the four of us sit at the table eating food. When I asked if he wants to do something with me, he'll be slower or won't want to do it. I've grown used to seeing someone never eat, and call that normal.

It's really hard when Sam goes into hospital and Dad is away for work. It means that I leave my house to go somewhere else for the night, or the week, or a fortnight. At first I thought going to my friend's house for a sleepover on a school night was awesome, but after a while, missing my family became a routine.

Of course I love my brother but I'm not going to say I wouldn't have it any other way because I would. Truthfully I

would much rather have a normal brother without tubes hanging out of his body. I would LOVE a brother who wants to come on the flying fox with me and splash around in the pool. I used to imagine that all his problems would wear off eventually, but reality always strikes back. I still have a brother who can't eat and who can't run fast and who is often in hospital having another surgery on another part of his broken body.

Sam's hospital stays seem endless. One year I counted how many notes I got from the school office telling me who I was to go home with as Sam had had another emergency trip to hospital. I had at least 5 pink slips in my bag in the first term. If Sam is coughing in the morning, I know that I will get a call or a note from the office in the afternoon.

I appreciate all the hospital does, but sometimes I wish they would care about the family of the patient they're letting down by mixing up appointment times and having to wait two hours. My birthday this year was put on pause because the doctor hadn't filled out the correct paperwork, which delayed the pharmacy giving out the medicine. Instead of having a fun afternoon with my sister and Mum, I had to go to a friend's house (again), waiting hours for them to return. People forget about the impact disabled kids' siblings have to deal with.

I love my little brother. Everyone loves him. As a big sister, I feel an impulse to protect him. Just like any other kid, when he comes home from school and tells me that no one wanted to play with him, I feel hurt for him. When he comes home and tells me he licked a biscuit, I see it as the next headliner on the front page of a newspaper. If I could change him, I would… but I can't. I hate seeing him in pain. When he misses out on school for a doctor's appointment, he feels it too. He's not a rock with no feelings. Sam is a little boy who loves cars and people and learning and dancing. Sam loves to read and draw (well, scribble) and play with friends. So when I feel as if he is just another patient on the list, I feel really hurt.

It's funny how you walk down the street and see someone sitting in a café and have no idea what could have ever have happened to them. Maybe they had cancer, been a refugee, fought wars or never eaten food! God chooses everyone's path in life and I've always wondered why He chose me to be the sister of this incredible person. Probably for something great.

What do you think?

WORDS BY *KAREN*

Being such a small patient group (just over 250 adults and children across both Australia and New Zealand), it can be difficult for stakeholders and decision-makers to lay their hands on any data about what works/doesn't work for HPNers 'down under'. Welcome the patient/carer survey!

Surveys allow an honest appraisal by HPNers and carers of various issues which affect us, and give stakeholders and decision-makers vital information needed when making decisions related to HPN in both countries. PNDU has already conducted 3 pilot surveys of our members, and abstracts and analyses of these are available on our website. Our surveys so far have been:

- 2012 Opinion on Compliance with AuSPEN HPN Guidelines
- 2013 Costs to Consumer of HPN
- 2014 HPN Set-up and Connection Procedures

These surveys, although not statistically valid in terms of the total Australian and New Zealand HPN patient group, nonetheless serve as useful snapshots, highlighting some issues and challenges affecting our members, as well as providing valuable information for further investigation.

After a bit of a hiatus, it looks like 2016 might be the year of the HPNer survey!

1. Following one-on-one interviews late last year, through an independent market research company, Baxter Healthcare continued to obtain feedback from HPNers and carers in May 2016 with a comprehensive survey of its HPN homecare provision.
2. PNDU recently conducted its own member survey regarding HPN pumps.
3. A market research company (CaPPRe) has offered the opportunity for adult Aussie members with Intestinal Failure/Short Bowel Syndrome to be involved in a patient preference survey.
4. And Surgical Outcomes Research Centre (SOuRCE) at Royal Prince Alfred Hospital (RPAH), RPAH and the University of Sydney, are making some final adjustments before launching a survey of HPN carers for adult patients, which PNDU will be sharing with our members.

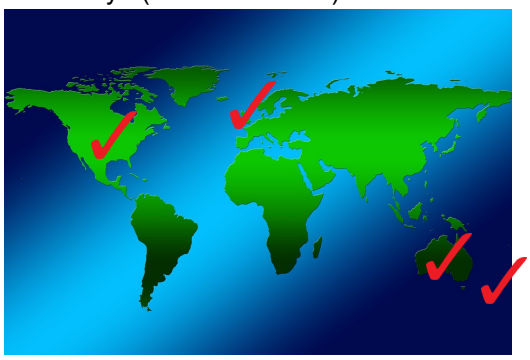
We applaud Baxter Healthcare, CaPPRe, SOuRCE and RPAH for their work and initiative to gain HPNer/carer feedback, and we welcome every opportunity to have our voice heard!

HPN homecare around the World

WORDS BY *KAREN*

Have you ever wondered how HPN homecare looks in other countries?

In late 2015 PNDU welcomed two international HPNers to Australia's shores – Carolyn (Chair of PINNT) from the UK and Emmy from the USA. Both Carolyn and Emmy joined us at our October Sydney gathering (see Dripline Issue #13). Anticipating the expected questions about HPN in our various countries, Carolyn, Emmy and I gave a presentation at the gathering of what HPN looks like in our respective countries – Australia/New Zealand, UK and USA. We firstly gave an overview of HPN provision (observations about living at home with HPN and the services received from the PN manufacturers), and then some more information on PN packaging and delivery.



As it was such an interesting presentation, we thought it was too good to leave there!

This fascinating look at what HPN looks like in four countries is now available on the Clinical Information page of our website. Whether you're simply interested to read how HPN is done elsewhere, or you're planning to travel to one of these countries, this document makes for very interesting reading.

Carolyn, Emmy and Karen following their presentation on 'HPN home-care around the world'

Our Wonderful Children

WORDS BY *CLARE* AND *MICHAEL*

Elsie and Bertie were both born with Total Colonic Anganglionosis due to Hirschsprung's Disease. Elsie has 52cm of functioning small intestine and Bertie has 64cm of functioning small intestine- both to the jejunum. They were both also born deaf.

Elsie is a typical 20 month girl. She loves the outdoors, reading and playing peek-a-boo. Despite all she has been through she is meeting all expected developmental mile stones and amazes everyone who meets her. Bertie is 10 weeks old and has been in [hospital] since birth. His smiles melt the heart of all those who see him and we can't wait to bring him home.

Living life on HPN has become our 'different'. We often joke that it would be nice if the machines slept as well as Elsie through the night. We can now prime a line, find an occlusion and change a stoma bag in the dark!

Elsie still doesn't eat and this time, with Bertie, we are keeping up with bottle and breast feeding in the hope he isn't as dependent on PEG feeding and HPN as Elsie. She is 20 hours PEG fed with Pepti-Jnr every day and has 12 hour PN five nights a week. Bertie is still on 20 hours PN which we hope to reduce to 16 hours before he comes home. Like her, he will probably live in the bouncer with the pole attached until he can crawl.

The downside to children on HPN is going out, as we are the only two who can do their cares in home. We still manage to socialise by supporting each other to have 'nights out' and we have a lot of dinner parties at our house.

Elsie and Bertie were both in hospital together a few weeks ago and we took the opportunity to go out for dinner and a movie. Before spending months living on fold out chairs and beds we would have felt guilty about this, but it's important to ensure you make time for yourself and partner too. We've also learnt to accept support and help. We spend a lot of time travelling to and from appointments, so the little time we do have, we want as quality time with the children being a 'normal' family. We are grateful to have amazing friends and family.

Elsie (HPNer)

Bertie (HPNer)

Clare, Michael and Elsie, when younger

New Zealand Education and Network Day for National Intestinal Failure Service (NIFS)

WORDS BY *PROF GIL HARDY*

The inaugural meeting of NZNIFS that took place at the Westpac Stadium in Wellington on 13th May 2016 was attended by approximately 90 health professionals from all disciplines.

Gil Hardy was an invited delegate and with the kind agreement of the organisers was able to organise a PNDU flyer in all delegate's bags and take along lots of PNDU literature for display by our industry friends, Biomed and Fresenius Kabi, who together with Baxter were supporting the meeting with their company exhibitions.

Dr Julian Hayes, colorectal surgeon, at Auckland Hospital and Dr Helen Evans, paediatric gastroenterologist at Starship Children's hospital, clinical directors of NIFS welcomed delegates and introduced Kerry McIlroy, who chaired the programme for the day. Everyone was very excited that NIFS had finally received all the necessary approvals to begin operation and that it appears to be the first national service for home parenteral nutrition (HPN) and intestinal failure (IF) anywhere in the world.

There were presentations outlining current PN services from different District Health Boards, the proposed national NIFS operational processes and various other aspects of PN with workshops on PN in the adults, paediatric and neonatal settings. Case studies and round table discussions on lipids, guidelines, nursing management and intestinal failure associated liver disease (IFALD), facilitated by Briar McLeod and Cate Fraser Irwin, Nurse Specialist/Co-ordinators, were very lively and productive. The day concluded with an interactive panel discussion with experts, including Sue Larsen of AuSPEN, on the principal questions/issues arising from the workshops.

Baxter stand, with Mary and Joe

A full report will no doubt be available from the NIFS team in due course, but it was very encouraging to hear that the Kiwi patient and their family will be at the centre of NIFS care and all delegates seemed very supportive of patient involvement and specifically the important role that a patient support group can play.

Biomed stand, with Jessica

Fresenius Kabi stand with Angela and Jane

Gil with pharmacist Karen Street

Venue for NIFS meeting, Wellington

Delegates at the conference

Christmas in June …Card Folding

WORDS BY *GILLIAN*

Early in June, Ray and I drove across Sydney to visit Karen for what is becoming our annual card folding day. (Last year she drove across Sydney to our place). As you probably are aware, PNDU sells cards via our website. These cards are selected early in the year in February, then delivered in May. They are packaged flat, so need to be a) folded, b) put in packs of 10, c) have 10 envelopes counted and included, and finally d) put into cellophane bags for sale. This year we selected 2 Christmas designs, 500 of each, so when you're in the Christmas mood, start ordering!

A work in progress – Gillian , Ray and Karen

The best part of this day is, of course, getting together with a friend, one who shares your lifestyle. It was lovely to catch up with Karen in person and share a delicious lunch – salmon quiche, salad, bread and apple cake slice for dessert. It was also good to catch up with what is happening in each other's lives and to get to know each other that little bit better.

What could be a very boring, repetitious job for one person became an enjoyable day out, proving the old adage 'Many hands make light work'.

Salmon Quiche

Ingredients:

- 1 pastry base
- 1 can of red or pink salmon
- 4 rashers of bacon (optional)

- 1.5 cups cream
- 3 eggs
- Salt & pepper
- 1/2 tsp paprika
- 2 tblsps chopped parsley
- 1 tblsp grated parmesan cheese

Method:

1. Dice bacon (if including) and fry gently until crisp. Remove from pan and drain well.
2. Drain salmon, reserving liquid. Flake salmon lightly (crushing bones) and arrange salmon evenly in base of par-baked pastry shell. Sprinkle bacon over.
3. Beat together cream, eggs, salt, pepper, paprika, parsley, parmesan cheese and reserved salmon liquid.
4. Carefully pour egg mixture into pastry shell to cover salmon and bacon.
5. Bake in a moderately hot oven (190oC) for 10mins. Reduce heat to 170oC and cook for a further 30-35 mins or until filling has set.

Apple Slice

Ingredients:

- 1 pkt vanilla cake mix
- 1 cup coconut
- 125g melted butter or marg
- 1 450g tin pie apples (or apricots)
- 1 sour lite cream
- 1 beaten egg
- Cinnamon

Method:

Mix the cake, coconut and melted marg together. Press into a greased slab tin. Cook in a moderate (180deg/160deg fan forced) oven for **10 minutes only**.

COOL, whilst mixing the topping.

Mix together the pie apples, lite sour cream and egg. Spread carefully over the base, sprinkle with cinnamon.

Bake for 20-25min at the same temperature as before.

Great Resources for Carers

Information from Chris shared on our private email forum for the benefit of members. Although the first tool is a NSW government initiative, the information can be used by all carers. The second tool is for Aussie carers.

1. Preparing a CV

SkillsLink2Work is a new interactive website to assist Carers to match their skills to employment, to assist in writing a resume and preparing for a job interview.

SkillsLink2Work: translating caring skills for job applications. Employers understand that carers bring valuable skills and experience to workplaces. And one of the highest priorities for carers in NSW is to be able to combine caring and work. But as a carer, it can be difficult to see how the tasks being performed each day are valuable to an employer, except maybe in a paid caring role, but even then it can be easy for carers to talk down their skills. Until now, that is.

A partnership between the NSW Government Department of Family and Community Services and the Australian Government Department of Social Services to give carers choices and opportunities to participate in paid work has led to the development of a new interactive website, SkillsLink2Work: A carer's toolkit to match skills to employment.

SkillsLink2Work translates daily caring activities into "employer language" that can be used when preparing a resume, writing job applications or seeking recognition for training. The NSW Community Services and Health

Industry Training Advisory Body partnered with government to develop this website, which uses nationally recognised core skills in the two personalised reports it produces for carers.

The website asks carers to simply select the caring tasks they perform on a regular basis. The website produces two personalised, printable reports. There is a short report that is great for attaching to a resume or referring to as you write your resume. There is also a longer report which is useful when applying for jobs or preparing for a job interview.

SkillsLink2Work is available at www.skillslink2work.com.au

Visit it today to see how caring skills can be translated into useful employment skills in many different industries, not just paid care work.

2. Gateway for support and services for (Australian) Carers

Caring for complex medical conditions can be difficult enough, but there are times when carers can feel they are doing it all alone, not knowing where to turn for assistance.

The Australian government has started a Carer Gateway, which is a great place to start for support and services.

Carer Gateway is a national online and phone service that provides practical information and resources to support carers. The interactive service finder helps carers connect to local support services.

1800 422 737 Mon – Fri 8am – 6pm

https://www.carergateway.gov.au/

Life without HPN

WORDS BY *ANN-MARIE*

Recently, Daniel, my three year old son who was on HPN since birth, received his Gastronaught Puppet, “Johnny”. I am starting to think that “Johnny” also brought some good luck with him.

To re-cap, Daniel was born at 27 weeks gestation and weighed 595grams. He developed NEC and lost 80% of his small intestines. Luckily, with time he was able to tolerate continuous feeds throughout the day and overnight.

Like many, we spent the first 15 months in hospital before we got to take our baby home for the first time. I always was very proactive in Daniel’s cares and daily routine so that when we arrived home, I felt confident and was ready to be at home with a child on HPN. Finally, after 15 months, I could be a mother, I could look after my baby and I was responsible for him. I was so proud.

Over the two years, that Daniel was at home on HPN, I would set goals for ourselves. I would try to avoid hospital admissions for at least one month, two months, six months and so on. It was my way of getting through to the next step. It took forever to get into a routine and stick to it, to re-evaluate what was a priority and to get all those medical supplies organised. But we got there and I was so proud.

At first, it was a very lonely path. I didn’t know anybody. My friends, I had realised, had moved on and they were leading a different lifestyle. But after a while, I met new friends, my HPN friends and it was so comforting to know we had so much in common. They understood. Along with another HPN Mum, we would meet with the new Mums and Dads about to take their little ones home from hospital and guide them, hoping they didn’t feel so isolated when they were discharged. I felt so proud being able to help another HPN family.

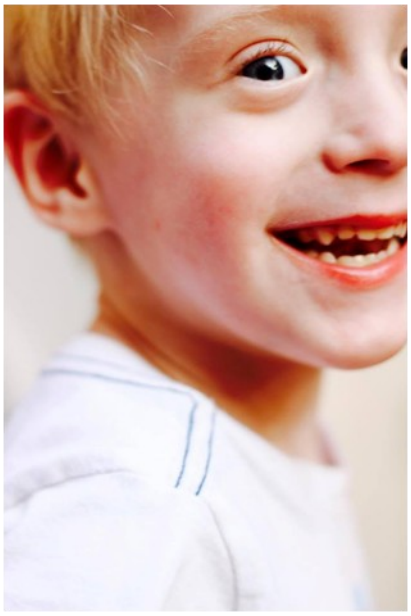
Then one day last September 2015, Daniel’s CVL had a fibrin sheath and his line would have to be replaced. While we were waiting a few days for surgery, our Gastro Team, said, “Let’s try to avoid putting in a canula and see if he can tolerate full feeds?”

Much to the delight of the team and I, he did. He was on full feed maintenance and had not lost weight. His bloods were stable and he was full of energy.

So from there we went home on a trial of no HPN. Those first three weeks I recall a feeling of grief. Yes, weird as it sounds, grief. I had lost the one thing that I felt I was responsible for. Connecting and disconnecting HPN was my way of being a mother after missing out on all that time being in hospital. I felt grief because I knew the people who had become such good friends were still on HPN and I felt a sense of guilt. What had we done to be so lucky?

The gastro team decided to keep the line in as a pre-caution for a while, so when his surgery day came up for his gastrostomy, the decision to take out his central line would be done under the same anaesthetic. I had had six months to prepare for this day and in those

six months I had realised the enormity of the achievement that Daniel and his bowels had achieved. The human body can really do amazing things, if you believe that it can be done. I always believed that one day he wouldn't need HPN and whether this was part naivety on my behalf or part positive thinking, Daniel's HPN days had finished.



So on March 23rd 2016 I was so proud to see Daniel go into surgery for potentially the last time. A day when my son finally had nothing stuck to his face from his NG, nothing dangling out of his chest from his CVL and only had one little button for feeding. I was proud, but I still felt such guilt. I didn't want to share my joy with others because I know that our friends still have their daily connection and disconnection, ED admissions, blood tests, doctor's appointments, the list is endless. I even messaged my HPN Mum friend and asked her, "Would she still talk to us, even though we weren't one of the cool kids with a CVL anymore?" Her reply made me wake up to myself: "Dan "is" the "cool" kid who makes AMAZING achievements!!"

Even though I was hesitant in sharing Daniel's story at first to my PNDU family, I decided to do so, to potentially heal the feeling of guilt but to celebrate his achievement, to thank the PNDU community for being my friend when I needed it the most and to say, rehabilitation off HPN can actually happen. Daniel doesn't realise nor remember the events of the past three years but as he grows older I will be teaching him an important skill, the ability to be proud of his achievements. I AM so proud.

PNDU at the inaugural Australian Vascular Access Society (AVAS) conference – Brisbane, April 2016

WORDS BY *KAREN*

In late April 2016, PNDU had opportunity to be involved in the very successful inaugural Australian Vascular Access Society (AVAS) conference in Brisbane. We are very grateful to AVAS and the conference organisers for allowing PNDU the opportunity to exhibit and also present on what it's like living with long-term vascular access, including the challenges.

There were over 250 delegates at the 2 day event with lots of great presentations and discussions, including local and overseas speakers. As an HPNer and on behalf of PNDU, I gave a presentation entitled "Living with a Drip: CVCs are close to my heart.. Literally!", which was very well received and attracted a lot of interest. From the May 2016 newsletter of Alliance for Vascular Access Teaching and Research Group (AVATAR): "Hearing about the patient perspective was an invaluable addition to the conference, and we would like to thank Karen for taking the time to come and speak about her experiences with chronic vascular access needs."

PNDU had a fantastic exhibit location and really couldn't be missed, just outside the exhibition hall. Not all the nurses attending have HPN patients at the moment, but if/when they do, they will remember that there is a patient support group for these patients – PNDU!

For PNDU, it was a very successful conference, particularly in terms of being seen and achieving recognition amongst vascular access clinicians caring for those on HPN, but also in being able to highlight challenges for those of us living with long term vascular access for HPN. The conference has also already led to more opportunities for PNDU and our members to give the patient perspective in vascular access, which is a great thing. So many thanks again to AVAS and to Anagram Events for this wonderful opportunity for PNDU, and for all your support.

We're looking forward to the 2nd annual AVAS conference in Perth next May!

Above: *Karen at AVAS conference 2016*
Right: *Karen with Dr Evan Alexandrou, AVAS Conference Chair, in front of our PNDU exhibit. Note our new banners – we can't be missed!!*

Left: *Karen with Steven and Debra of Anagram Events, the conference organisers*
Above: *The exhibition hall where 24 companies exhibited all things vascular access.*

Our friends from Fresenius Kabi and Baxter Healthcare exhibited at the event

Imagine….

WORDS BY *KAREN*, AS TOLD BY *ANNE*

Anne's story appeared in Dripline #11 April 2015. Even though Anne came off HPN nearly 18mths ago, and against all odds is still alive, her health continues to be very poorly. Daily living is a constant struggle. Even for her husband to drive her to the beach (not far) which she loves, and watch the ocean from the car, can be too difficult, let alone being able to get out, walk across some sand and touch the water.

We all know what a wonderful thing imagination is in the life of a child. But do we have to leave it there as we grow older?

Today Anne told me that she'd recently been on a 'la-de-da' holiday to Europe… in her imagination! Some retired friends recently went on a lavish European holiday, so she asked for their itinerary and followed along with them.

In days gone by, Anne felt a sense of guilt and believed that day-dreaming was a time-waster, and not something sensible people should engage in, especially if they were unreachable dreams. However, this idea was challenged by an elderly woman, who although physically not able to do much, talked about her 'big' plans. When challenged that she shouldn't be even contemplating such ideas in her state of health and at her age, this elderly woman replied 'don't take away my joy'. There is joy in imagining!

So, encouraged also by a Bible verse from Isaiah 40 ("He's Creator of all you can see or imagine"), and using knowledge from books and the internet, Anne imagined what it was like to be with her friends on their 'la-de-da' holiday … and had a most wonderful time! She even wrote a bit of a travel diary. Anne told me about this wonderful apartment when in Venice for 4 days, sitting by the door, watching and imagining daily life on the canals.

Anne is now planning a 4WD holiday to Central Australia! Her brother will be travelling there soon, but unlike her brother, Anne's imagination doesn't have any financial restrictions, so she is enjoying designing in her mind the perfect 4WD campervan to travel in!

I just think this is such a wonderful use of imagination, and am so encouraged by these great experiences Anne is having, despite her probably never being able to physically go.

PNDU Annual Awards 2016

WORDS BY *KAREN*

Is there someone you think does a marvellous job when it comes to HPN care or PNDU? Here's your opportunity to let them know! This is PNDU's third year of bestowing awards on dedicated people nominated by our members:

- Professional Awards: your favourite HPN clinician, a helpful soul at your homecare company, an individual/ organisation who has contributed big time to the field of HPN; and
- Lifetime Membership Award: someone involved with PNDU.

Let's celebrate the great work being done for those of us living 'down under' with HPN!

There are a few different categories and you can nominate as many times as you like. You can even nominate winners from previous years:

- **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.
- **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.

The nomination forms for both categories are on the PNDU Annual Awards page on our website. Simply complete the form(s) and email them to contactpndu@gmail.com by 15th October 2016.

A reminder of our 2015 PNDU Award winners:

Jodee Reid (left)

Prof Ross Smith

Suzie Daniells (on right)

Merran Spargo (middle)

Dimi Chrisafis (right)

Birthday corner

WORDS BY *CHRIS (POP)*

Seven years ago our little miracle was born. Jordan had the doctors saying that it would be far better to place him in a box in the corner and let him perish. Thankfully we didn't. What an amazing little man he has grown to be.

Sixteen of Jordan's friends, mostly from school, attended his 7th birthday today. What a wonderful day for everyone!

Lots of games in the backyard and then the carport, when we had a few sprinkles of rain.

The biggest hit for the day was a giant inflatable slide. I was kept busy for hours helping over-excited children up the ramp, made slippery by the intermittent showers. As quickly as the kids made it to the top, they came screaming down with excitement and lined up again. The wonderful aunty Katie had a multitude of games to play- 'Stick the treasure chest on the pirates' map', 'What's the time mister wolf' and 'Musical statues' were the biggest hits.

Time for lunch and a well earned break for Pop. Nana's fairy bread disappeared at an astounding rate, followed closely by party pies and sausage rolls, little frankfurts and tomato sauce. All consumed by the cheekiest smiling faces you have ever seen.

Fed and watered, then came the cry 'Pop, pump the slide back up PLEASE!'. Another hour of fun before the rain chased us back in doors, then time for presents. Paw Patrol vehicles and several remote control cars kept everyone busy until it was time for cake. I forgot to tell the kids to pick the toys up before the cake, so the new play room looked like a bomb went off in Toys r Us!

A Batman Cake today - super heroes are back (sorry, no Aunty Katie Cake this year because ClubMed, i.e. hospital, took all our time this week). Then it was time to say good bye as the parents arrived. Jordan handed out bags of treats to his friends. Big hugs all around and far too many tears from his friends, tugged at the heart strings of everyone.

Jordan is a well loved little boy, and it is amazing to see how far we have come in the past 7 years.

Happy Birthday J-Man!

Logan (HPNer and Jordan's brother, right)

Jordan (HPNer and the birthday boy)

HPN Workshop and PNDU Social Gathering plus Travel Sponsorship to get there! – Melbourne – November 2016

WORDS BY *KAREN*

PNDU Social Gathering – Brisbane, September

PNDU Melbourne gathering

A great time to meet with other HPNers and families and talk about living 'life with a drip'. Open to all families living with HPN.

When: Wednesday 16th November 12-3pm

Venue: Yet to be confirmed

Bring: anything and everything you need for the afternoon

RSVP: contactpndu@gmail.com

AuSPEN HPN consumer workshop

AuSPEN will once again be holding this workshop specifically for adult HPNers and carers. It's a great opportunity to learn more about our life-saving treatment. PNDU very much supports this great initiative and we hope to see many HPNers and carers there too.

When: Thursday afternoon 17th November 2016

Venue: Yet to be confirmed.

More information will be provided as it comes to hand.

AuSPEN HPN workshop – Brisbane September 2015

Travel Sponsorship to get there!

In order to assist PNDU members from New Zealand and other parts of Australia to travel to both these great events, PNDU is offering **two $500 travel sponsorships for Aussie or Kiwi HPN consumers/carers who will be attending the AuSPEN consumer workshop and PNDU social gathering for the first time**. Applicants should not be receiving any other financial assistance for travel and/or accommodation expenses related to attending the workshop/social gathering. Travel sponsorships are limited to one per family.

Qualified workshop/social gathering attendees should write two paragraphs describing how they believe attending the workshop and social gathering will affect their life and submit them to contactpndu@gmail.com. Travel must be completed and receipts received by PNDU before reimbursement can be made.

Cut-off date for applications: Wednesday 31st August 2016

Announcement of successful applications: Wednesday 7th September 2016, giving sufficient time to plan your trip.

Medical Play Puppets

The second delivery of medical play puppets arrived recently! These puppets are provided by PNDU to our little under-10 years PNDUers free of charge and with all the same extra 'bits' our youngest members have.

Here's a gorgeous shot of little Cataleya with her Princess Savannah puppet (*next page*). And one of her sleeping with her puppet. She loves that they have the same 'toys'.

Cataleya with her Princess Savannah

Little cutie Mayana with her puppet.

“Our newest family member has arrived!! Milla has a new best friend, Tamara. Milla was overjoyed to welcome Tamara and recognised immediately by saying "mummy, buttons same". They're loving hanging out together! Thank you PNDU ☺ ”

“Thank you so much for my puppet, Princess Savannah. I think she is brilliant. Love Elsie x”

Book Review – 'It Takes Guts'

WORDS BY *GIL*

Editor's Note: If you wish to purchase this book, it would assist PNDU if you bought it from The Book Depository, through our website – just click on the link on our home page (www.pndu.org) to take you to their website and we receive 5% commission of all books purchased.

IT TAKES GUTS is a true 'story of love, hope and a missing bowel' written by Evelyne Brinke, mother of little Tuffel, who with the help of Parenteral Nutrition is a survivor of 'ultra short bowel syndrome'

This paperback, costing GB£13.99, consists of 22 chapters in approximately 200 pages that vividly describe the sequence of events following Tuffel's birth in January 2012. Evelyne describes the battles with medical and nursing staff, who thought that death was inevitable, and the way in which she and her partner Thomas, together with an inspired surgeon, overcame the many hurdles for Tuffel to continue to survive, against all the odds.

Evelyne, who is a writer, personal coach and Madonna impersonator, pulls no punches in her story: "Life is shit. We all know that sometimes shit hits the fan. It's messy, sure. But you know what, we would love that right now. Because, in our case there is no shit. And that is a much bigger problem!"

Tuffel was born in St Thomas's hospital London, and his condition shocked even experienced paediatric gastroenterologists. Within the first weeks he was fed with, what Evelyne describes as, "white space food called TPN (Total Parenteral Nutrition) – doesn't it read like parental? It's not. It's para enteral, *going past the digestive tract.* A bit like paranormal but less woo-woo!"

Chapter 5 describes the battles with an experienced nurse who had worked in the hospital so long her name tag had faded, but failed to ensure that Tuffel stayed connected to a saline drip when being moved. In chapter 12 called Coping and Helping, Evelyne diligently expresses over 40 litres of breast milk to repay the kindness of the Neonatal Unit, whilst learning more about HPN, pump training and supporting Tuffel through follow up operations. In time, they were transferred to the local children's hospital, and 8 months later, were allowed home. The hilarious chapter 14 recounts the hospital discharge process, the 'dis-organised' procurement of HPN supplies, refrigerator and creative use of limited storage space in their small apartment. Amazingly, the family was initially told there were no support groups for intestinal failure/PN, but eventually they made contact with PINNT, who helped the family organise a short holiday to France.

The various discussions and disappointments surrounding possible transplantation, are emotionally but eloquently described. Finally, the explorative surgery that culminated in connection of Tuffel's duodenum to his colon, "Bottom management is now our mission. I'll print it on my business cards: Evelyne Brinke, Author, Coach and Bottom Management Specialist".

The book concludes with Tuffel at home, enjoying Christmas with cousins and other family members. The constant line infection scares and the challenge of combining parenthood and care giving whilst juggling their careers are philosophically addressed, with a touching but hopeful epilogue: "Taking each day at a time for the gift that it is. *That* is the teaching of Tuffel"

Consider the patient's voice

Gillian Ray-Barruel, Research Fellow, AVATAR Group, Menzies Health Institute Queensland, Griffith University, Australia

Editor's note: We thank the 'British Journal of Nursing', Vol 25 No.8 2016, for allowing Dripline to reproduce this article.

Too often in the past, patient preference has not been considered a high priority when selecting a vascular access device (VAD). However, as patient populations become increasingly unwell, with complex health requirements necessitating reliable intravenous (IV) therapy amid rising healthcare costs, the concept of choosing the device that can best meet the physical and psychological needs of the individual patient is becoming more important.

No patient wants to undergo repeated catheter insertions. Unfortunately, too many catheters become blocked, dislodged and unusable before therapy is completed, resulting in patient discomfort, delays in treatment, extended length of hospital stay, and the need for insertion of replacement devices. Appropriate device selection, aseptic insertion technique, avoiding insertion in areas of high flexion, and proper catheter securement would go a long way to preventing device failure and improving the patient experience (Wallis et al, 2014).

Technological advances have created many new VADs. The use of peripherally inserted central catheters (PICC) in particular has greatly expanded in recent years, but these devices carry a risk of thrombosis and bloodstream infection (Chopra et al, 2013), and should not be regarded as the 'benign cousin' of centrally inserted devices. No device inserted into the body is ever risk-free. Therefore, it can prove challenging to select a VAD for optimal patient care, particularly for sicker and more compromised patients, such as the neonatal and elderly populations, patients undergoing chemotherapy, who are immunocompromised, obese, or with skin disorders, and those with chronic vascular access needs, such as haemodialysis and long-term parenteral nutrition. The Michigan Appropriateness Guide for Intravenous Catheters (MAGIC) is a structured clinical decision framework for choosing the most appropriate VAD for the desired type and duration of therapy (Chopra et al, 2015). You can read an overview of the guide in this supplement (page S15–S24).

Patient experience surveys can provide a valuable adjunct to clinical audits. Not enough is known about the patient experience of having a VAD, and more studies in this area would provide clinicians with a greater understanding. Seeking the patient's opinion will become increasingly relevant as patients are encouraged to take a more active role in their own healthcare journey. Many organisations now encourage patient and caregiver involvement in infection prevention, for instance, giving people the right to speak up if they observe a health professional has not washed their hands (Longtin et al, 2010). With the availability of online healthcare information at their fingertips, we should not be surprised when patients request an expert inserter or express a preference for a certain type of VAD.

In the belief that much can be learned from hearing about patients' experience, the Alliance for Vascular Access Teaching and Research (AVATAR) group at Griffith University is currently undertaking a survey on the consumer experience of having a peripheral IV catheter (PIVC). We would like anyone who has had a PIVC in the past 5 years to complete a short, anonymous survey online (http://tinyurl.com/avatargroup). Parents of paediatric patients are also encouraged to complete the survey. If you know of someone who fits the criteria, I encourage you to pass on the opportunity for them to have their say.

The best VAD is not always the easiest to insert, but is the one that will be comfortable for the patient and stay in place for the duration of treatment. Let's make it our goal to choose the best every time. **bjn**

Chopra V, Anand S, Hickner A et al (2013) Risk of venous thromboembolism associated with peripherally inserted central catheters: a systematic review and meta-analysis. *Lancet* **382**: 311-25
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Wallis MC, McGrail M, Webster J et al (2014). Risk factors for peripheral intravenous catheter failure: a multivariate analysis of data from a randomized controlled trial. *Infect Control Hosp Epidemiol* **35**(1):63-8

PACIFHAN is growing!

WORDS BY KAREN

PACIFHAN is the 'International Alliance of Patient Organisations for Chronic Intestinal Failure and Home Artificial Nutrition', and it's growing!! There are now 9 member organisations representing 10 countries: Australia, New Zealand, Czech Republic, Denmark, France, Italy, Poland, Sweden, United Kingdom and USA. I am privileged to be the PNDU representative in PACIFHAN, and PACIFHAN's Interim Convenor.

In late July 2016 PACIFHAN representatives from all 9 member organisations will be meeting in London for 2 days of workshops. As Interim Convenor, I will be travelling to join everyone there.

The first day is a dedicated workshop for PACIFHAN business, with agenda topics including progressing PACIFHAN's legal set-up; how to function well as an international organisation; World HAN Awareness Day promotion; and future project ideas. We will also be taping footage for inclusion in a PACIFHAN promotional video. The second day is a Shire workshop on Short Bowel Syndrome.

Then from 17-20 September, PACIFHAN will be exhibiting at ESPEN Congress 2016 in Copenhagen – the big conference of The European Society for Clinical Nutrition and Metabolism. Three or four PACIFHAN representatives from Europe will operate a stand, and will be raising PACIFHAN's profile and the benefits of PACIFHAN for clinicians and patients alike, as well as showcasing our HAN Dictionary (see Dripline issue #15).

Unfortunately the Dictionary wasn't uploaded onto www.pacifhan.org in time for our previous Dripline, but it should be now. It's a list of HPN and HEN medical words translated by PACIFHAN members into 6 languages - English (UK & Australasia), English (USA), Czech, Italian, Polish, Swedish. Danish and French translations will also be included soon. It is for use by HPN and HEN travellers when communicating with medical staff, should they find

themselves needing medical assistance in any countries using these languages.

PNDU is pleased to be an inaugural member of PACIFHAN and we look forward to all that can be achieved as we work together.

Amusing comments/thoughts about being Connected To HPN

Editor: here are a few thoughts/stories from our members

- I had my ancillary delivery nice and early this morning – 7.30am. I was still connected, in my pyjamas with an apron on while I got a slow cooker meal ready and on the go. The young delivery guy was very pleasant and asked if I was heading out. I thought that was very odd considering I had slippers, dressing gown, pjs and apron on. I simply replied 'no, I'm doing some cooking'. It wasn't until after he left that I realised – he saw me with a backpack on and assumed I must have been going somewhere! I'm so used to it that I ☺ didn't even realise I had it on. Poor guy must have been very confused. Anyway, I had a bit of a chuckle to myself!
- I am having to wear my pack more and more throughout the day and have gained confidence to go out socially. I've just had to resign from work after 8 months' sick leave and so went to my farewell "lunch" with my pack. I'm beginning to feel more comfortable wearing it, except my back and neck are not comfortable. I've now figured out how to wear it in the car. I used to place it on the passenger seat but now continue to wear it on my back and put ☺ the seat back a little. I've got out the car too many times and forgot to pick it up and so wearing it is better for me.
- I have this thought that if I was to ever get pulled over by the police and asked to step out of the car, how they might react if I had to reach over and grab my bag and step out with this line connected to me and the bag.... I was very wary of that at the ☺ airport when collecting my daughter a couple of years ago...might they think I am some terrorist with explosives?!

PNDU's new website

WORDS BY KAREN

Progress is continuing on PNDU's new website and the Management Committee is excited with how it is looking. We are very thankful to our friends at Orange Line for all their help.

We're looking to launch the new site in November 2016.

Travellers' Top Tips to Pack Smart

Editor's note: This advice is not HPN related, however there are some good travelling tips for the rest of your packing.

Trip Advisor reached out to Top Contributors in their traveller community and asked for their best-ever packing tips.

Here's what they had to say.

- **Pack light to travel light.** If you can manage with a carry-on, do it. Try taking half of the things you need and twice the money. You can make buying a few new items a fun part of the adventure.
- **Pack a sleep mask and ear plugs.** These can come in handy on a plane, train or in your hotel room.
- **Capitalise on empty suitcase space.** Roll your clothes, instead of folding them. Stuff socks, underwear, and accessories inside of shoes. Leave no space unused.
- **Keep a sarong or pashmina in your carry-on.** They can be used as a blanket on the plane, a scarf if it's cold or a shawl on an evening out.
- **Bag it.** Kitchen sandwich bags can be used to hold your accessories, vacuum pack bags can be space savers, and bin bags have multiple uses (laundry bag, shoe covers).

- **Skip airport snacks and bring your own.** You can save yourself a bit of money and keep your hunger at bay in case you have a delayed flight.
- **Create compartments.** Two words: packing cube. If you are visiting more than one city during your trip, packing cubes will keep your suitcase organised and save you from having to pack and unpack.
- **Share your packing space.** Travelling as a couple? Split your clothes between two suitcases on the off chance one of them gets lost during the flight.
- **Bring a multi-socket extension cord.** Although newer hotels have USB ports in rooms, it's best to have an extra outlet to charge all of your electronics at once.
- **Make photocopies before leaving home.** If you're travelling out of the country, make two photocopies of your passport. Use your smartphone to take pictures of your car in the airport's car park and do the same for your luggage and its contents in case it gets lost.

Upcoming PNDU Activities

- July 27th-28th. PACIFHAN and Shire workshops in London. Karen to attend and participate.
- August 7th-13th. HPN Awareness Week 2016.
- August 31st. Entries close for PNDU travel sponsorships to AuSPEN HPN Workshop and PNDU social gathering in Melbourne. Winners announced 7th September 2016.
- October 15th. Nominations close for PNDU Annual Awards 2016.
- November 16th. PNDU social gathering for HPNers and families – Melbourne.
- November 17th. AuSPEN HPN workshop for HPNers and carers – Melbourne.

Thank You

We wish to thank the following for their generous donations which totalled $2500:

Baxter Healthcare

PNDU Membership for Aussie and Kiwi HPNers and carers:

We welcome all Aussie and Kiwi HPNers and carers to become PNDU members. If you are interested in joining PNDU, please email us at contactpndu@gmail.com, 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 bene-fit 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

Donations

If you would like to support the work of PNDU, we would welcome your donation, no matter how big or small. Now that incorporation has been achieved(!), PNDU has its own account! When making direct deposits, please provide your name as a reference. If you require an acknowledgement/receipt of your donation, please email us at contactpndu@gmail.com.

AUSTRALIA:
Direct deposit (Australian dollars only) to PNDU Inc.'s bank account:
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Account name: PNDU Inc.
BSB: 032056
A/c No: 482738

NEW ZEALAND:
For our Kiwi members, our sister charity IPANEMA (Charities Commission Registration CC21178) kindly continues to receive donations on our behalf:
Online donations: PayPal via our website www.pndu.org
Or **direct deposit** (New Zealand dollars only):
Bank: ANZ
Account name: IPANEMA
A/c No: 0602730308799-00
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Parenteral Nutrition Down Under Inc. ABN 49742201085

If you have an experience with Parenteral Nutrition that you would like to share, or if you have questions please email these to contactpndu@gmail.com.

PNDU Inc.'s privacy policy is available on our website www.pndu.org

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