

DRIPLINE

PARENTERAL NUTRITION DOWN UNDER



Parenteral Nutrition - Down Under™

Welcome to our second edition of Dripline, PN-DU's new quarterly e- newsletter.

Hopefully, you'll find something that interests, informs and inspires you. Find out what some of our PN-DU members have been involved in over the last three months, and what they are planning to be doing in the next three. Learn some travel tips, and some diet tips. View some photos of our members, and of the pharmacy at Baxter Healthcare in Sydney's Toongabbie, where HPN for consumers all over Australia is prepared, and carefully checked, for our unique formulae.

If you'd like to share something about life on HPN in a future newsletter, or ask a question that one of our member clinicians might be able to assist with, please email these to contactpndu@gmail.com.

I'd like to thank Carla, who is the aunt of a four year old HPN child, for designing the newsletter.

Gillian,
Dripline Editor

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IN THIS ISSUE

- SYDNEY BAXTER TOUR AND PILOT PATIENT FORUM
- AUSTRALIAN DIETS FOUND LACKING
- LISA HAS A BALL
- LET'S TAKE TO THE SKIES, INFUSING ALL THE WAY
- TRAVELLING ON HPN
- AWARENESS WEEK 2012
- ARIEL TAKES THE SPOTLIGHT
- WHAT IS IT ABOUT ENGLAND AT THE MOMENT?
- LIVING WITH A DRIP
- WHO ARE OUR OTHER COMMITTEE MEMBERS?

WHAT'S UP?

PN-DU – APPEARING AT A CONFERENCE NEAR YOU

PN-DU will be involved in three conferences in three different Australian cities over two months:

ADELAIDE 16-19 OCTOBER: Gillian and Karen will be operating a community stand for PN-DU at *Australian Gastroenterology Week*.

SYDNEY 22-23 NOVEMBER: Karen and Suzie will be presenting "Parenteral Nutrition – the consumer engagement experience" at the 2nd *Australasian Clinical Networks Conference "Network to Network 2012"*.

MELBOURNE 29-30 NOVEMBER: Rachel and Gil will be presenting "Maintaining PN Standards from Hospital to Home" at the *3rd Annual National Nutrition & Hydration Summit*.

These are fantastic opportunities to raise awareness of PN-DU, of the great work that is being done in several areas and of the ongoing issues facing all HPNers 'down under'. If members live in these cities and would like to use these conference opportunities to meet up with the PN-DU members presenting, please let us know at contactpndu@gmail.com and we'll see what we can arrange.

SYDNEY BAXTER TOUR AND PILOT PATIENT FORUM

WORDS BY MIRANDA

Early in June, PD-NU was contacted by Baxter and invited to attend a pilot patient forum at their premises in Toongabbie. This welcome invitation was well received by PN-DU as an opportunity to give some feedback to the supplier of nutritional supplies for all Australian HPNers, and equipment for many of us, also. Four members of PN-DU were able to attend the forum - Karen, Jane, Gillian and myself.

In the Hill's district of north western Sydney, the Baxter premises is a mix of sprawling 80's concrete buildings and newer ultra-modern structures of glass and steel. We were greeted warmly by Sue, Pharmacy Operations Manager and Ewan, Customer Service Manager, then given a guided tour of the Baxter pharmacy. On the first floor of the pharmacy is the open plan offices of the administrative pharmacy staff, who all don headsets as they attend to work on their computers. We met the lovely Bev and many others, who most of us talk to regularly, and who assist in taking our orders and sending the supplies to us.

Downstairs, the environment changes dramatically as the offices give way to two large glass walled rooms within the building. In each of the rooms, the workers wear protective suits, head covers, masks and gloves. The majority of them are in their late 20s and 30s, working in pairs and each with a very specific task of measuring one compound or another. Their deft, trained hands are careful and they pause to smile from behind their masks and wave to us outside.

In the first room, which has several workstations, we observe intravenous chemo-drugs in preparation. The room is fitted out with pressure pumps to ensure positive pressure in the space and a radiation monitor sits silently at ground level monitoring the conditions constantly.

But it is the second, and larger, glass walled room that is the focus of our visit- the PN preparation room. This was only half filled with glass hooded stations. We are told that the room has been built with space to expand to further workstations, an anticipated need, judging by the growth in PN users over the past decade. Inside we can see those familiar PN bags in various states of undress, some with several tubes attached, being filled with different coloured fluids, and others looking oddly empty. It is a strange realization for me to see actual workers with their clipboards and gloves putting the bags together, being so used to seeing the PN bags as they arrive each week at our house, all sealed and labeled in neat little silver pockets. Tracey, the Pharmacy Manager and our tour guide, explains the process of preparing the PN bags, which can be prepared in entirety in 1.5hrs each by a pair of workers, but which are in practice stepped in process and prepared in batches for efficiency. In the course of the bags



Clockwise from L-R: the new Pharmacy Building; taking orders from HPNers; Working in pairs to check every step.

preparation, the formula is crossed checked many times, as the work is done in pairs.

We move onto the packing area, just adjacent to the preparation rooms, piled high with insulating foil (great as a dashboard sunshield in summer!) and those familiar blue and white boxes (great size for storing and moving books!). A conveyer belt runs along one side of the room and into the dispatch area, where we meet Dimi and some of the Baxter couriers -some of them, no doubt, wondering why anyone would linger to see a room of shelves and boxes.

After lunch in the Baxter cafeteria, with Mark, the Group Marketing Manager, Sue and Ewan, we move to the meeting room to commence the formal part of the day- the pilot patient forum. PD-NU members brought a number of issues to the discussion, amongst others, the recent issue of spiking leakages, the changes to delivery arrangements and the afterhours helpline*. The Baxter staff were attentive to the comments made but could not make commitments as to actions that Baxter would take, citing challenges in chain of authority and control over some aspects of the issues that were being discussed. However, the Baxter staff in attendance did seem genuinely receptive to the discussion. The forum ended with an undertaking by Baxter to further investigate the issues raised and to continue convening joint patient and clinician forums on a regular basis.

**Detailed notes of the points of discussion in the pilot patient forum on 22nd June were prepared by Karen and circulated soon after to PN-DU members and Baxter via email. **

AUSTRALIAN DIETS FOUND LACKING

WORDS BY *SUZIE DANIELLS, ACCREDITED
PRACTICING DIETITIAN FROM SYDNEY,
AUSTRALIA*

The Australian Institute of Health and Welfare recently released its report 'Australia's Food and Nutrition 2012' which outlines the key components of the food and nutrition system, from 'paddock to plate'. The report found that 9 out of 10 adults are not eating enough vegetables, and only half are eating enough fruit.

Based on current levels of consumption, vegetable intakes need to increase by 30-50% and fruit intakes need to double to meet the recommended 5 serves of vegetables and 2 serves of fruit each day.

Fruit and vegetables are what nutritionists call nutrient dense foods. They are good sources of vitamins and minerals (such as magnesium, vitamin C and folate), dietary fibre, and a range of phytochemicals including carotenoids. They are also relatively low in energy, fats and sodium and high in water content.

Increased consumption of fruit and vegetables, particularly non-starchy vegetables has been shown to have a protective effect against cardiovascular disease, stroke and some forms of cancers such as lung, prostate, colorectal, oral and nasopharyngeal. High intakes are also associated with a reduced risk of weight gain and obesity,

ADD SOME EXTRA FRUIT AND VEGIES TO YOUR DAY

Start by adding an extra serve of fruit and vegies each day, slowly working towards the recommended 2 pieces of fruit and 5 serves of vegies (about 2.5 cups) a day for adults.

Vegetables and fruit should be eaten in their whole-food forms, rather than juices, to maximize the health benefits. Choose a variety of fruit and vegetables of different colours for a range of nutrients and antioxidants. Frozen and canned fruit and vegetables make a convenient, affordable and nutritious alternative to fresh produce. Choose canned varieties without added salt, sugar or fats where possible.

- Slice fresh fruit or berries over breakfast cereals
- Blend soft fruit such as banana, mango or berries into low-fat milk and yoghurt for a delicious smoothie to start your day
- Swap a slice of bacon or that second egg with grilled tomatoes, mushrooms or baked beans or try an omelette with mushrooms, onion and capsicum for a hearty cooked breakfast with more fibre and less calories
- Serve homemade soups loaded with vegies for a warm winter lunch
- Add extra salad vegetables to sandwiches
- Keep a bowl of fruit at home and work for handy afternoon snacks
- Substitute raw vegies for crackers and serve with salsa, hummus or low fat dips for a tasty snack. Try carrot, capsicum and cucumber sticks
- Serve salad with a simple vinaigrette dressing as an entrée or a side to your meal. Replace fries with salad when eating out
- Add extra vegies or legumes to casseroles, soups, pasta sauces and stir-fries.
- Grated vegies are great added to pasta sauces
- Pre-cut or frozen stir-fry vegetables make for a quick stir fry
- Opt for fruit-based desserts such as fresh or canned fruit with yoghurt or custard. *

LISA HAS A BALL

WORDS BY LISA



From L-R: Lisa; Jessica Birkin, Professor Gil Hardy and Lisa

On the 25th August I had the pleasure of representing all the HPNers in PN-DU at the University of Auckland's Pharmacy Ball 2012. It was held in the Auckland Museum Events Centre, a truly stunning venue. Professor Gil Hardy and I were honoured to receive a donation of \$1100 for PN-DU. This was the profit raised by a Revue put on by APSA, the Auckland Pharmacy Students Association. Jessica Birkin was the producer for the Students' Revue, and responsible for the decision to support our charity this year. I cannot thank Jessica and the Pharmacy students enough for this extremely generous donation.

What struck me the most about the whole event was how friendly and welcoming everyone was. My Mum and I were warmly greeted and included in the events of the evening. The atmosphere was buoyant. I felt support for our group from the moment I walked in. I was connected to my HPN and made to feel right at home, even though I could not eat or drink. When I talked about life on HPN and the positive impact of PN-DU on my life, I really felt people listening and absorbing what I was saying.

The event was a lot of fun and a fabulous way to raise awareness for HPN and PN-DU. Being able to show the human element of HPN was extremely powerful. Many thanks to Professor Gil Hardy, who enabled this to happen. Gil did a fabulous job of organising everything, and looked after my Mum and me on the night, in a very caring way. The Pharmacy Students are a lovely group of people. Their donation will be of huge benefit to us. I feel privileged to have been given the opportunity to attend this special event and represent PN-DU. *



From L-R: Lisa and her mum; Professor Gil Hardy and Lisa

LET'S TAKE TO THE SKIES ... INFUSING ALL THE WAY!

Thanks to the efforts of PN-DU, both Air New Zealand and now Qantas have approved the BodyGuard 323 ambulatory pump for use throughout flight. This includes during taxiing, take-offs and landings. This allows HPNers the freedom to travel without the risks associated with having to switch off the pump during take-offs and landings. For those on very long hours of PN or travelling long haul flights, this is a very exciting development.

In Australia, the approval process took considerable time (6½ months) and testing, in order to meet all of Qantas' requirements, and involved significant expenditure by the suppliers, REM Systems. We are very appreciative

of REM Systems' work, time and expenditure on our behalf.

Travellers will still need to contact the airlines' special handling departments to arrange the details and will still need to request specific approval to wear the ambulatory backpack strapped to their chest during take-offs and landings. (It is advisable to carry a copy of the written approval to show cabin crew.)

If you have any questions relating to travelling with HPN, please don't hesitate to contact us at contactpndu@gmail.com and check out our website's travel page at <http://parenteral-nutrition-down-under.webs.com/WEBPROTECT-travel.htm>. *



Karen, winging her way to England, with her BodyGuard 323 in its backpack, infusing throughout flight.

TRAVELLING ON HPN

WORDS BY GRAEME

After living in Cairns for most of the 'naughties' we had returned to Victoria for a while when Carol ended up on TPN due to deterioration in her small intestine. After suffering with idiopathic pseudo-obstruction for around 50 years, she was fighting a losing battle.

Our 'retirement plan' was to spend the summers in Victoria (away from the North Qld heat) and the winters in Cairns (away from the Victorian cold weather). However, a four-month stay in hospital early in 2011 put a big hold on things for a while. After a few months' post-hospital settling down at home, in Victoria, we started preparing for travelling and making a six-month move to Qld, by car, for the winter in 2012.

Our preparation began by staying a night away in the motel in Melbourne, 160 km from our home in Traralgon, that I had stayed in whilst Carol was in hospital. We knew what the surroundings would be like, we were only a couple of hours' drive away from home, and not far from our support hospital, Monash Medical Centre. I made a compact, dismountable pole that we can use to travel (Happy to pass on the details to anyone who is interested). The night went without a hitch – so first base passed!

We would frequently travel to friends' places, also a couple of hours' drive from home, and hook up into the back-pack. I made a different, small 'pole' to hang over a cupboard door, that makes it easy to set up before putting the pump and bag into the back-pack (Also happy to provide the details). We set up an old Baxter box with a corner cut out for the pink stuff, and a 4 litre ice-cream container to hold the 'loose bits' – syringes, needles, NaCl, swabs etc. This was also useful if we needed a container to bleed the line into during the set-up. Anytime we travelled, we could just pick up the box and basically have everything we needed. The next step was a couple of nights away at a church camp at Philip Island, also a couple of hours from home, but this time we needed enough supplies for a few days, plus spares, and also manage the refrigeration etc. Things went really well, except that Carol had a fall and broke her arm (not TPN related). Second base passed!

The final test before heading for Far North Qld was to travel for about a week in multiple motels. We made a trip around the Great Ocean Road to Mt Gambier for five days. Again, we were only a day's drive from home if anything went wrong. We needed to take a week's supply of TPN, and so we bought a large 60 litre icebox that would hold the week's supply – PLUS leave enough room for the usual food and drink that we need to put in an icebox. [TIP: Buy a high-efficiency icebox. The one we have will keep things cold for 5 days, so we don't have to re-freeze all of the cold packs every night. Sometimes the motel freezer was only big enough for two



*Carol and Graeme and his compact,
dismountable IV pole*

or three of them.] This also gave us a good idea of how we could pack everything in the car, and how much room we would have left. Setting up in the motel rooms was really no problem, and the fall-back position was to set-up on the top of the icebox if needed, but it stayed in the car for the duration. Third base passed!

At Easter, we went to a church camp near Mansfield, about 4 hour's drive from home. The first night we went to hook up to TPN and found that we had forgotten to bring any normal saline. Oops! One option was to drive home again and get it. However, I made a call to the local hospital and they were able to help us out. [Tip: Always know where the nearest hospital is. They will almost always help you out if you need it.]

The big day came for the trip north, with the car carefully packed. We packed a Baxter box and another larger box with some supplies, and forward posted them to Qld. We also packed a 60 litre plastic storage box with enough supplies for the trip AND enough to last for a week after we arrived in Qld, in case the posted boxes got lost in the mail. We also had the 'Travelling Baxter Box' with enough supplies for four or five days whilst travelling. [Tip: Keep an inventory of what's in each box, so you know what's where, and what you've lost if it doesn't arrive in the post!]

We arranged to pick up our week's supply of TPN from Baxter in Sydney, as we would be within an hour of the plant on the day that they normally dispatch it. We had a great reception, a tour of the pharmacy, and gave a talk to the staff about life on TPN. In southern Qld we stayed with Carol's sister for a few days, and the best place that we could use to set up the TPN was the top of the washing machine!

All up, our trip to Cairns took us 11 days, and this time we were no longer just a few hour's (or even day's) drive from home. As anticipated, everything went really well. Our experiences with 'short trips' gave us high confidence for the longer trip, and enabled us to 'bed down' any problems. We arrived in Cairns three days before our next Baxter delivery, and the supplies that we had posted up were awaiting collection at the local Post Office. Home Base!

We began talking to Baxter about a month beforehand about our delivery changes, and then followed that up about a week before the last delivery to Victoria. Baxter and TOLL have both been fabulous, and we have had no problems at all with our deliveries. Thank you to those who helped us, if you are reading this. Our next move will be back to Victoria in October for the summer. *

AWARENESS WEEK 2012 A GREAT SUCCESS!

WORDS BY KAREN

August 5th – 11th 2012 was designated as the 2nd international HPN Awareness Week and with our big sister organisation in the US, Oley, PN-DU celebrated the week with gusto.

Once again, we had a YouTube slideshow, this year showing the nitty-gritty of life on HPN – <http://www.youtube.com/watch?v=tPxmFi1u3TA>. There was also a media release telling the personal story of one of our member families, posters, Facebook profile picture, Awareness Week badges (thanks to Oley and Baxter Healthcare USA) and a member visit to Baxter Healthcare's pharmacy department in Sydney. And to top it off, Auckland University Pharmacy students held their annual Revue during Awareness Week, highlighting the Week to their audiences and donating all profits from the Revue to PN-DU. Thanks Auckland Uni Pharmacy students! (See 'Lisa has a Ball' above)

We had a number of new members join our website, articles published and money raised. More importantly however, lots of questions were asked and ensuing conversations about HPN took place.

The purpose of the week is obviously to raise awareness and understanding of HPN and for many members the opportunity the week brings for family and friends to ask questions is exciting. To be able to tell your own story, to explain and to help those around you understand what it means to be on HPN, is invaluable. Here are some of the responses received from members after Awareness Week 2012:

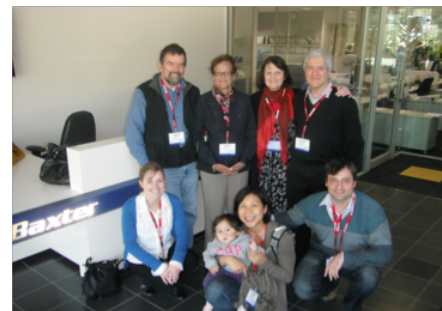
- "Have been able to use this to help friends and family to understand and appreciate what 'food' XX has. Thank you."
- "Thanks so much for sending the badges! They are great, and one is staying on my work lanyard throughout the year."
- "My friends have commented on the courage and strength of all on HPN and the parents/carers."
- "Some friends and family have commented that they weren't aware children were on HPN."
- "I also found the slideshow helped to explain things to friends. People really liked seeing how the "hook up" process worked and some of what was involved with life on TPN. I got a lot of questions regarding how long a person can live on TPN and what the complications are and whether people feel sick/well."
- "I also found that the slideshow a good springboard- I had a few conversations with friends and colleagues which were sparked by the slideshow who were too embarrassed to brace the subject or didn't want to pry previously."
- "Found that changing my Facebook pic to the logo was definitely a conversation starter!"
- "XX hasn't taken her TPN badge off since you gave it to her! She even told all the kids about it at kids' church!"

We look forward to more good things in Awareness Week 2013! ✨

ARIEL TAKES THE SPOTLIGHT

In addition to the Patient Forum visit in June, Baxter, in Sydney, also kindly hosted a visit by a group during HPN Awareness Week in early August. Eight people, including HPNers, spouses and parents, were able to visit the Pharmacy Department, as well as meet staff from other departments. Andrew, Pharmacy Manager, and Jane, Head of Pharmacy, guided the group around for the same tour of the facilities, omitting the first floor. (see Sydney Baxter Tour and Pilot Patient Forum article above).

After the tour, David and Miranda introduced their little, Ariel, to the nutrition staff, and spoke about her very early arrival and their life with Ariel on HPN. Renee writes that the best parts of the day were meeting other HPNers; seeing the impressive facilities and being able to put a face to names of the staff members; and meeting little Ariel and her



*PN-DU members visiting Baxter Healthcare during HPN Awareness Week
Standing: Lindsay, Fay, Renee and Mervyn.
In front: Karen, Miranda with Ariel, and David*

parents, Miranda and David, who have unique issues as parents of a child on HPN. Thank you to Kensi, Andrew, Jane and all the Baxter Sydney staff for their warm hospitality. ✨



Watching our Awareness Week YouTube slide show after David's talk.

WHAT IS IT ABOUT ENGLAND AT THE MOMENT?

WORDS BY KAREN



From L - R: Karen (infusing PN) and her mum heading off; beautiful Paris; Karen and Executive Officer and Chair of PINNT, Carolyn Wheatley.

It seems all eyes have been on England this year with the Queen's Diamond Jubilee celebrations, the Olympics and then the Para-Olympics, not to mention my cousin's wedding!

Not that I made it to any of these events, but I did make it to England! With HPN! When I think back on it now, I'm truly amazed that it happened. The idea began as a wee small seed when I was issued with my ambulatory pump a couple of years ago. This new pump definitely opened up the travel horizons. Slowly the seed grew until I decided to give it a go. With the Aussie dollar soaring, my health being good and all the rellies to visit, what was there to stop me?! So the planning began.

Now I'm a planner, but I don't think I've ever undertaken anything quite so challenging before. I had no idea where to start and no-one to say: do this, next do this, next organise this. Thankfully I was put in contact with another Aussie who had done the trip the previous year with her child on HPN – a wonderful sounding board. Our big sister support group in the UK, PINNT, was brilliant too and Baxter was able to organise all that I needed. Despite all this, I still found the whole planning process quite overwhelming and I started planning over 6 months beforehand! On top of that, there were things that I only found out in the last 10-14 days before I flew out, which either meant more work, or I had already prepared things unnecessarily. To save any future HPN travellers from down under having the same stresses, I have since written up feedback which is available to anyone. Just email us at contactpndu@gmail.com to go to our website <http://parenteral-nutrition-down-under.webs.com/WEBPROTECT-travel.htm> or <http://parenteral-nutrition-down-under.webs.com/apps/documents/>

Part of the planning was organising for in-flight infusion of PN: getting approvals to use the pump throughout flights, carry fluids and medical equipment including syringes and scissors! I must admit, I was quite nervous about how it would pan out, but by God's grace, it all went relatively smoothly and I wouldn't hesitate now to let others know that, with a bit of preparation, infusing in-flight, travelling from down under with medical luggage AND enjoying an overseas holiday on HPN is all very do-able, even if the numbers of us who take to the skies for long haul travel are few and far between.

It was fascinating to experience HPN in another country – to see firsthand the standards and regulations in England. But it was more than fascinating - it was a load of fun to meet with the head of PINNT – Carolyn Wheatley. In between lots of good belly-aching laughs, I learnt so much about how HPN is done in the UK and the integral part PINNT has played in keeping the standards high.

Aside from the HPN side of things, I had an absolute ball travelling around the stunning English countryside with my Mum (couldn't have done it without my Mum!), catching up with rellies galore. Being a bit older than when I had my last trip, I had a much greater appreciation for the incredible heritage and delicate beauty of springtime in this tiny country, as well as the warmth shown by extended family – something I miss, living so far away. And believe it or not, we had great weather! Some of it was rather cold, being English springtime, but there was not a drop of rain for 3½ weeks!

The icing on the cake was 3 days in Paris at the end of our holiday. Je t'aime Paris – always have, always will! Travelling to the UK is something I never dreamed possible only a few years ago. HPN has offered a level of health that I never thought possible and PN-DU has given the encouragement and support to dream and live life to the fullest on HPN. I give all thanks to God for both HPN and PN-DU and for this trip of a lifetime! *

LIVING WITH A DRIP

WORDS BY GILLIAN

No, the drip that I live with isn't my ileostomy – that's more a 'run', and it isn't my husband - he's wonderful! The drip is actually lifesaving Parenteral Nutrition, and if you haven't heard of it before, it's because there are only about 200 of us in Australia and New Zealand who depend on this form of nutrition, and many of us are also Ostomates.

My story begins in early 2006. The school year had just begun, and I was busy getting my ESL (English as a Second Language) program and timetable up and running. At this time, I was a very healthy 51 year old, who had built up immunity after 30 years of regular exposure to young children's germs so that I rarely caught a cold, let alone anything more serious! My illness, even now, without a definite diagnosis, began with a headache every day. After two weeks of this, I went to a physiotherapist, thinking it might be due to a back problem. One session of physio transferred the pain from my head to my neck and shoulder! This pain intensified over the next two weeks, despite regular physiotherapy. After this time I decided to visit my GP, but before my appointment, I vomited and developed diarrhoea. Magically, my neck pain vanished...and moved to my abdomen. In too much pain to work, I spent the next three weeks having various tests and trying different drugs to see what the problem was. Blood tests showed there was infection present, but CT scans didn't show anything wrong. At this point my GP sent me to see a gastroenterologist, who luckily saw me within a few days. He also couldn't diagnose the problem, but because of my great pain, admitted me to St George Private Hospital, which was to be my home for the next two months. Here I was introduced to my colorectal surgeon, who planned to do an exploratory operation after the inflammation had settled with the use of strong antibiotics. I don't remember much about this time because I had my morphine pain button, which I can assure you was used frequently! After about 5 days with no change, the resident doctor, feeling my abdomen, realised that my situation had become critical, so on Good Friday morning I was whisked off to theatre and the beginning of my life as an Ostomate.

My surgeon was shocked to discover that almost all of my intestines were necrotic. I had lost all of my large intestine, and most of my small intestine, so I am left with a high output ileostomy. The most likely diagnosis was that it was a form of Vasculitis, where the blood can't get to parts of the body due to a narrowing of the veins, but I had no symptoms of any known form of this disease. Also, the presence of blood clots seemed to point to something else. It doesn't really matter what caused it to happen, I'm just glad that it was my bowel that was affected because it could have been any organ, including my heart or brain or kidneys. I've been lucky that I haven't had any problems associated with my ileostomy, and with the wonderful support of our government in providing all necessary equipment, as well as the marvellous network of volunteers that fill my order each month, and our great Ostomy magazine with so much support and advice and encouragement, I feel that if I have to have a medical problem, this is a good one to have.

As the weeks passed after my operation, unfortunately my small intestine wasn't doing its job of absorbing nutrition from the food that I was eating. My weight had fallen from 62kg to about 45kg, and the output from my ileostomy was often larger than the input of fluids and food. The dietician tried various changes of diet, but nothing worked. They then tried enteral feeds (through a nasal tube) directly into the stomach, but this also didn't work. My remaining 1.2m of intestines were still refusing to adapt, and nearly six years later, they're still sulking. During the latter part of my stay in this hospital, one of the specialists who visited regularly kept saying to another specialist, each visit, that he felt I'd need 'TPN' (Total Parenteral Nutrition, or often referred to as simply PN).

It was explained to me that PN was a form of liquid nutrition delivered directly to my heart via a central line in a major vein (the distal third of my superior vena cava, for those with a medical bent). This central line can be a Hickman's, a Porta-Cath or a PICC line. I would still be able to eat for pleasure (although not all people on PN are able to eat), but all required proteins, carbohydrates, fats, vitamins and minerals would be delivered via tube, with the help of a pump, into this vein. The training and monitoring for this could only be done for a long term home TPN patient at the public hospital, so I transferred to St George Public Hospital for the next month.

Although this sounds a relatively simple fix for a major problem, it needs to be monitored very closely, especially in the beginning. PN can affect the liver and cause osteoporosis in the bones. It can set off diabetes because of the sugar content. Kidneys can be affected, and levels of minerals and vitamins need to be regularly checked with blood tests. Potentially life threatening line infections can occur relatively easily, so scrupulous care needs to be taken when setting up each night. In the beginning, my weight dramatically increased by several kilograms a week, because most of my 'weight' was the weight of the 2kg of daily TPN fluid. Over the 5 ½ years that I've been on HPN, the prescription has changed at times in response to blood test information, and the frequency of feeds has varied. At first I had 5 per week, then it changed to 3, then due to weight loss, back to 6, then, for the past 2 years, it's been every night.

My TPN runs over 9-12 hours at night. This means that every night when I set up, I decide what time I want the pump alarm, which signals that it's finished, to go off and I adjust the time accordingly. For example, on a work day, if I want to get up at 6:30am and set up at 8:30pm the previous night, I would set it to go for 10 hours. 'Setting up' begins with mixing 2 chambers of fluids together in a bag which holds about 2.2 litres. My husband, Ray, usually does this for me, while the bag hangs from a hospital IV pole. For 5 years, once I was set up, I had to walk around the house before bed pushing the pole, or disconnect from the pump and carry the TPN bag with me. However, during last year, I received a new, tiny pump which goes with the TPN bag into a backpack, and when I need to walk around I carry this with me. The most important thing about setting up is sterility – the biggest threat is infection in the line; so the kitchen bench has to be wiped with surface alcohol, dressing packs, syringe, saline, and pump tubing packs have to be opened carefully without touching the contents. I have to do a sterile hand wash (like doctors before operations) and then be careful not to touch anything else while attaching to my Hickman's line. In my case, this hangs from my chest. Initially, setting up took almost half an hour, but now, with experience and confidence, it only takes about 10 minutes.

Luckily, I haven't had major problems with my TPN, apart from annual infections, but others aren't so lucky, especially babies and young children, who are on TPN as well as having serious health issues. Because TPNers are few and far between, it's difficult, if not impossible, to meet someone in the same boat to discuss issues. However, 3 years ago, a couple of TPN consumers began a support group called PN-DU (Parenteral Nutrition Down Under) for those in Australia and New Zealand. Anyone who is interested can visit our website, and if there are any Ostomates out there on PN, feel free to e-mail us at contactpndu@gmail.com for further information.

After awakening from surgery that Easter Friday with an ileostomy, I decided that my life would change as little as possible; that this change would be accepted and life got on with. Going on TPN didn't change this decision. One of the best things about the articles in Ostomy is that almost everyone has a positive outlook and doesn't let their medical problems overwhelm them. One of my friends suggested that I try to get medical retirement, but I wanted to continue teaching; I didn't feel 'sick'. As Ray is retired, I compromised by reducing to working 4 days per week.

Ray and I enjoy caravanning holidays, so we worked out that we could continue this if we put my hospital pole in a water-filled outdoor umbrella stand beside the caravan bed. In this way, we have not only enjoyed many short breaks in NSW, Vic and SA, but we travelled 'up the centre' from Port Augusta to Darwin, and back through outback Queensland, taking us and our friends 6 weeks. My TPN, which has to be refrigerated, was delivered weekly along the way, while I had a careful of the necessary peripherals, such as dressing packs, as well as my ileostomy supplies. I had built up these supplies over the months before the trip and had enough to last; however, I was informed that the supplies could be delivered to a town along the way if I'd preferred. Before the trip, I googled the towns we were to travel through with the word 'hospital', and so had many addresses handy, just in case, but luckily not necessary. Because a high output ileostomy is very unpredictable, and there are relatively few toilets throughout the outback, I had to make do with low shrubs or sand dunes quite often. Changing ileostomy bags could be a bit tricky sometimes, with a lack of spreading out room in showers at caravan parks, but it was more of a nuisance than a problem.

We also had a wonderful 4 weeks touring around New Zealand last year. I didn't take a base for my pole, just propped it against a wall, but still needed a separate suitcase for all the paraphernalia associated with setting up each night. Nowadays, I don't need a pole, just my backpack and new pump.

From the first, I let everyone I knew that I have an ileostomy, including all of my work colleagues. If I were young and single, I might have a different attitude, but I'm happy to let people be aware of ostomies, and that having one needn't limit what you do, unless it is accompanied by illness. I think the more that people in the community are aware of ostomies, the better the understanding and tolerance.

Different appliances suit different people. I began with a 2 piece appliance which mostly worked well, and being a creature of habit, I continued using this for a few years. I had a few accidents, though, when the clip didn't hold and the bag, with its quite liquid contents, fell off, creating a mess to clean each time. So I changed to a one piece appliance, 'Dansac Nova', which is working well for me. I've had an occasional leak around the flange, but a boomerang- shaped 'Hydroframe', by Welland, can be put on top to help stick the flange down, if it lifts, as well as using 'Eakin Seals'. Welland's 'Barrier Wipes' are also great to clean the skin when changing the bag. Using a dry chux wipes the faeces off the stoma quickly and easily.

I know that people cope with difficult situations in different ways, but my strength and resilience is from my faith in Jesus, who promises to be my strength in all situations.

I would encourage everyone with an ostomy to make the most of this wonderful medical answer to bowel problems, and enjoy life in whatever way you are able. *

This article was published in the August 2012 issue of Ostomy Magazine



L-R: Dinner under the stars, Uluru; Mataranka Thermal Pools, NT.

WHO ARE OUR COMMITTEE MEMBERS?

PART TWO

MELANIE

I have 2 teenage step children, as well as Emily, who is 3, and Matthew, who is 15 months younger. Emily suffered a 'catastrophic mid gut volvulus in June 2011. She has had several bowel resections and is left with 8 cm of duodenum and 50 cm of large intestine. She does not have enough intestine to absorb nutrients to sustain life and so is TPN dependent. Emily spent 5 months in the Children's Hospital at Westmead and is still regularly hospitalised as her TPN is changed, for line sepsis and normal childhood illnesses such as ear infections which require IV antibiotics.

Being such a rare occurrence for a child to suffer this sudden twisted bowel, and to survive, we feel she is so very blessed. However it is a lonely journey for Emily and for her family. PN-DU was first brought to my attention by Emily's clinical nurse consultant and I have welcomed the informal advice and support. It has been such a wonderful support to meet a few precious individuals from the group who have become family friends for us all.

DONATIONS

If you feel able to contribute to our support group, you may wish to make a donation. Donations are currently only tax deductible in New Zealand. We are grateful to our sister charity IPANEMA (Charities Commission Registration CC21178) which receives donations on our behalf.

Cash, NZ cheques or International Money Orders made payable to:

"IPANEMA TRUST" and sent to:

PN-DU Treasurer, c/o G Hardy, Massey University, Private Bag 102 904, Auckland 0745 New Zealand

On-line donations:

directly to IPANEMA's bank account with the notation "PN-DU":

NBNZ 22 06 0273 0308 799

COMMITTEE MEMBERS

Convenor: Karen

Minute Secretary: Gillian

Treasurer: Gil

Information and International Liaison Officer: Brenda

Regional Reps; QLD: Rachel, NSW: Gillian/Karen, TAS:

Jacqueline, NZ: Gil/Brenda, US affiliate: Jodee

Paediatric Coordinator/Advocate: Rachel, Vanessa, Kelly

Adult Coordinator/Advocate: Brenda, Karen, Gillian

More about our other committee members in future newsletters.

CONTACT US

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. Visit the website at <http://parenteral-nutrition-down-under.webs.com/>