Issue 1: June 2012

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Parenteral Nutrition - Down Under™

Welcome to the inaugural PN-DU Newsletter, hopefully you will find some interesting information in this issue that might help you in some way. With only about 200 people on Home PN in New Zealand and Australia, and many of those unaware of PN-DU's existence, we are only a small, albeit growing, group. Some of you will be PN consumers, some parents or friends of users, and some health professionals. All will have individual experiences of life on PN. If you have an experience with Parenteral Nutrition that you would like to share with others, or if you have questions that you hope can be answered in a future newsletter, please email these to contactpndu@gmail.com

In This Issue

What's Up

April 2012 - We've reached 100!
During April this year, we reached and surpassed the milestone of our 100th PN-DU website member!! Considering the rarity of HPN 'down-under', it's great to know we are gradually reaching other HPNers and that there are many people interested and supporting our work.

June 2012
Oley Foundation Annual Conference
June 25-29
Redondo Beach, CA, USA

August 2012
HPN Awareness Week

Who Are Our Committee Members?

Karen: I found myself in the world of Home PN at the end of 2006, when after 16 years of Crohn's disease and 5 re-sections, I was left with insufficient small intestines to live. I have had a 'dream-run' with HPN and I give thanks to God for the huge blessing it has been to my quality of life. I stopped work in 2006 and am now able to put what energy I do have into the things I value highly and enjoy. Through my hospital, I was introduced to PN-DU in 2009 and have found it to be a wonderful source of information, support, friendship with people who "get it", and encouragement to see and grab hold of the possibilities in a life with HPN, even so far as travelling to the UK and Paris last March!! (More about my holiday in our next newsletter.) Considering HPN is so complex and our numbers are so small in this part of the world, there is a great need for PN-DU. And knowing how much support, information, friendships and more I've gained from my involvement, I'm very proud to be a part of PN-DU and look forward to what great things the future holds for us.
Brenda: After three years of frequent upper GI and hepatobiliary surgery, including PEG feeds, the ability to maintain nutritional needs failed and I started on Home PN in 1999. I am one of the few (outside of the Netherlands) that has received my nutrition via an Arterial-Venous graft. It was also the experience at my local hospital for another patient on long term (28yrs) HPN. I am now using a port for access, which is ideal for my lifestyle, but can come with some curly moments of its own.
Jodee: Mum to 11 year old Matisse, PN dependent since birth due to chronic idiopathic intestinal pseudo obstruction. Matisse received a small bowel and large bowel transplant 07/12/2010. Visit us at http://www.caringbridge.org/visit/matissereid .
Rachel: Rachel has a young daughter who has been HPN dependent for over three years. Her daughter has had numerous complications associated with PN (gallstones, nausea, thrombosis, bacteraemia). Rachel is passionate about working with health care providers to achieve consumer driven, coordinated care of children and adults on PN and improved supports to help people cope at home.
Gillian: My body had an auto-immune reaction to an unknown virus, which killed all my large, and most of my small, intestines. My body wouldn't absorb nutrition, so my weight kept dropping dangerously low, so I was put on HPN. This was 6 years ago, and my health has been fine since, with fine- tuning of PN when needed. As with Karen, I thank God for this blessing, and have been able to continue with working as a primary ESL teacher, although over the years I've cut back to 4, and this year, 3, days per week. I was introduced to PN-DU by my Baxter courier. Although I don't have a lot of health issues myself, apart from living with a high output ileostomy and being on PN, I am myself interested in being in contact with people who, like myself are PN dependent. Belonging to PN-DU helps me find out interesting and sometimes helpful information about a variety of aspects of PN.
Gil: Gil Hardy is Professor of Clinical Nutrition at the Institute of Food, Nutrition and Human Health, Massey University and Chief Scientific Officer of AnQual Laboratories at the University of Auckland. He is a founder member and treasurer of PN-DU, through his registered charitable trust, IPaNEMA (International Parenteral Nutrition Education and Methodology Advancement) that has supported the group since its formation. Gil has long been associated with our sister organisations; PINNT (in UK) and Oley Foundation (in USA) and regularly speaks at their annual meetings. Together with other health professionals he was responsible for establishing the AuSPEN HPN register and publishing the Australasian Guidelines for HPN Management.

Birth of PN-DU

(The big mouthful of Parenteral Nutrition Down Under for Australian and New Zealand consumers)
The support group came about after years of personal isolation within New Zealand. I knew of, and had belonged to, Oley, (the USA support group, for Enteral and Parenteral users) since 2001, as well as another patient support group, the Gastroparesis Yahoo Group. Initially I felt that it would be best that the health provider caring for the HPNer should play a part in the support group, but after four years of broken promises, and getting to hear of other HPNers in the same situation, the desire to get something off the ground and onto the internet exploded, or imploded, and took off.

PN-DU Founder - Brenda

I had met Gil Hardy, (Professor of Clinical Nutrition at the Institute of Food, Nutrition and Human Health, Massey University and Chief Scientific Officer of AnQual Laboratories at the University of Auckland) in 2008, and with his encouragement and inside knowledge of PINNT, the UK support group, I had the green light (or bomb) needed to get underway. First was the name, which dawned on me at 1:30am whilst driving home after a long day at work. I wanted to have the 'down under' theme, as that belongs to both Australia and NZ. After a few kilometres spent thinking, PNDU seemed good so I stopped and scribbled it on a piece of note paper. The next day, the name still seemed good and there were no more thoughts in the bucket. I then made up the Google groups forum and wrote my first introduction, what our aims were and what it was meant to do. I decided that none but the nicest of rules would apply, and I've never had to send out a please apologise note yet… Later that day I sent the name and email address to Gil and said we were ready to go. Those that I knew who were on HPN were notified, and I asked them to notify anyone else they knew. Jodee had her list from her own blog site and by the end of the month we had 5 new members.

James

We then discussed the need for an emblem; an identity for a small group. So on a trip back home to England, and with the artistic skills of his grandsons, Gil came up with the simple sketch of the PENDOO (a unique cross-breed between a NZ yellow-eyed penguin and an Australian kangaroo).

Pendoo: A rare, exotic animal, native only to Australia and New Zealand

That then led to meeting a soft toy manufacturer and the making of a very exclusive and rare animal.



We were in existence! Our colours were simply the gold and green of Australia mixed with the black and silver of New Zealand. And so it was that the website was formed. Due to poor knowledge on my behalf, I registered it with a fairly long name. This has actually been to our advantage as we are not likely to be spammed, jammed or whatever! Go to any search engine and type in at least 3 of our words in the name and up we come, so easy to find if you are looking for us. Jodee baptised the site with a great overview of children's care and the journey to being on the transplant list. Karen said yes, she'd help, having no idea that my computer doesn't talk to the website ones, and landed up with the job of setting up the site, which she did very well, and also being PN-DU's secretary.

We are now three years old, and slowly the numbers are increasing. As a group, we have held several meetings, which is hard to do, due to size of our countries and the health of the group. We have achieved improvements in our care, pushing for those having to use hospital designated pumps instead of the ambulatory pump system. For those in NZ, we gained approval through Pharmac for those who have hyper- or hypo-glycaemic spells to have the glucometer and strips subsidised. We've shared the good and the bad, including instant warnings when equipment, especially disposable items, are found to be faulty. There does not seem to be a recall system for those at home using complex equipment to be on the same notification list as the hospitals' intensive care units. Due to our agitation, both QANTAS and Air New Zealand have approved the Bodyguard pump to be going during both take off and landing and during the flight, meaning the integrity of the pump infusion and CVAD is not challenged. Other projects will be worked on with the intention of improving our quality of life. In the last 6 months, a management committee has been formed to share the load, and work on different topics according to one's ability. Weare now linked to PINNT and Oley, so we are truly part of the international scene. It is what was hoped for three years ago, a family of folk bonded by their complex treatment, making it simpler and safer for those who have to live with it.

Brenda - Floundering, um, ie, Founding, Member

James is a young adult on HPN who is making the most of his life.

James' Story

I was asked to write a bit about my life on PN. Funny really, as I have been on PN for so many years it just seems a normal life for me. The pain and vomiting is what I hate the most, but I guess that goes hand in hand with intestinal failure.

I was born in New Zealand, but for the last 6 years I have lived in Australia. I was born at 30 weeks gestation, weighing 708 grams and have a twin brother Tim, who was 1200 grams but is perfectly fine and he is my best friend. I had all the prem-baby problems and a small bowel that just didn't want to work. By the age of 2, and many surgeries later, it became obvious that I was

destined for a life on PN and all hope of eating was gone. I need to have PN 7 nights a week, and most days have 1 to 2 litres of saline. I have a Gastrostomy and Jejunal tube and have both on free drainage, so I don't vomit. Mum does all the clean stuff, PN and dressing changes and I do the dirty stuff.

PN hasn't stopped me travelling and when I was younger I was lucky to have a number of trips to a small island off Tahiti. We only had electricity for a few hours a day and it was common to lose all electricity for a week but we had ice flown in each day. Once we even had to free-run my PN for a few days as my IVAC broke. Baxter did their nuts at us for only taking one, but that's all we were allowed. We all took turns to watch the drips to make sure it didn't run too fast. My best trip was when we chartered a boat for 2 weeks and sailed around Fraser Island. It took mum a bit of sorting but was worth it. I have had lots of trips to Fiji and recently went to New Zealand.

I'm 20 years old now and I'm doing an IT course. Schooling was a bit patchy when I was younger as I was so sick, but I have always tried to lead a full life. I can't eat at all these days, I can only sip water, and this can drive me crazy. When I was younger, I could chew and spit a few mouthfuls, but now it's not worth the pain. I can't swim, but love to float in my boat on the pool. Somedays I guess I do get a little sad when I watch Tim go surfing, but I also laugh when Tim has a hangover knowing it's self-inflicted. PN has given me a life, and it's my life, and I'm as determined now as I have ever been to make the most of it. I love to give everything a go that my body will physically let me.

James

Although this story has nothing to do with PN, it's a great analogy for what happens when our lives take an unexpected turn.

Where Life Takes Us - Welcome to Holland!

I am often asked to describe the experience of raising a child with a disability – to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this…

When you are going to have a baby, it's like planning a fabulous vacation trip – to Italy. You buy a bunch of guide books, and make your wonderful plans. The Colosseum, Michelangelo's David, the gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting. After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess says, "Welcome to Holland". "Holland?!" you say. "What do you mean Holland??

I was signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy!"

But there's been a change in the flight plan. They've landed in Holland, and there you must stay. The important thing is that they haven't taken you to a horrible, disgusting, filthy place full of pestilence, famine and disease. It's just a different place. So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met in Italy. It's just a different place. It's slower paced than Italy. But after you've been there for a while, and you catch your breath, you look around… and you begin to notice that Holland has windmills… and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy… and they're all bragging about what a wonderful time they had there.

And for the rest of your life, you will say, "Yes, that's where I was supposed to go. That's what I had planned".

And the pain of that will never, ever, ever go away… because the loss of that dream is a very, very significant loss.

But… if you spend your lifetime mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things… about Holland.

Emily Kingsley C1987

Talk the Walk… Life on PN

A few weeks ago, June, Pharmacy Administration Coordinator, NSW, for Baxter Pharmacy Services, rang to ask if I'd be willing to give a talk at a staff meeting about life on PN. The idea was to give staff an insight as to what happens at our end, once they mix and send the PN. I accepted, and arrived at Baxter Headquarters, in Old Toongabbie, Sydney, with my husband, Ray, Thursday 22nd March. June met us and took us to the Pharmacy building and introduced us to Tracey, Team Leader Nutrition, who then took us for a tour of the pharmacy, which I won't write about now, as Karen is hoping to organise a group tour later in the year, so that can be written up in another newsletter. Suffice to say it was most interesting, and the staff to whom we were introduced were very friendly and intrigued to meet the face behind the name they knew so well.

I met up with Andree, Pharmacy Transport Administrator, who had come to the Sydney PN-DU conference last year, and who organises my PN deliveries when I am on holidays, as well as my courier, Jim, who was about to set off with PN deliveries, and his wife, Dimi, who is also a courier. Just before the 12:00 staff meeting, I met Jane, Pharmacy Manager, who escorted us to the meeting room that was filling up with staff members from Baxter Pharmacy Services, until there were about 80 seated mainly around the floor. I stressed a few times that I was unusually healthy, that many of their HPN customers were unfortunately not as well, some being quite sick, so that they didn't get the impression that PN was an instant get well remedy. I spoke on a variety of aspects of life on HPN to try to give an overall picture. I'll summarise my talk in dot points, rather than write about all that I spoke of in half an hour.

- Thanked them for their role in keeping me alive.
- Discussed what parenteral nutrition is, showed them my backpack and pump still set up with the previous night's PN and showed how the line connects to my central line; and showed them the other bits and bobs needed to set up.
- Explained why I needed to use PN.
- Told a bit about my life, and how I am able to live it fairly normally despite (and because of) PN – I'm still working and going on holidays fairly often.
- Told them about PN-DU and how it supports people with a chat group (for users), the website and this e-newsletter. Encouraged them to Google 'parenteral nutrition down under' and join the website.

  Told about some of the demands of HPN

  - Fridge space for PN packs
  - Storage of peripherals
  - Rubbish that fills your bin and recycle bin
  - Setting up, flushing lines, dressing changes
  - Regular blood tests
  - Possibility of damaged organs and/or bones associated with PN
  - Keeping track of equipment for monthly order
  - Unpacking and storing weekly and monthly deliveries
  - Line infections that can occur despite all care being taken, resulting in hospitalisation for at least several days.

The meeting finished with a question and answer session. The Baxter staff was very attentive and seemed quite interested. Hopefully the talk helped them to understand the importance HPN in our lives, and thus the importance of their work as providers.

Gillian

Regional News from NSW: Parenteral Nutrition Consumer Information

This article was first published in the Agency for Clinical Innovation (ACI) Clinician Connect April 2012 Newsletter. Reproduced with permission.

The pilot of the Parenteral Nutrition: An Information Guide for Patients and Carers pamphlet will soon be underway. The project has been jointly supported by the Agency for Clinical Innovation (ACI) Nutrition and Gastroenterology Networks, in collaboration with Parenteral Nutrition Down Under and IBD Support Australia Inc.

The pilot will include a series of patient and staff surveys to evaluate the content, readability and usefulness of the guide. The pilot sites will be Royal Prince Alfred Hospital, Prince of Wales Hospital, Bankstown Hospital, Sydney Children's Hospital Network - Westmead and Dubbo Base Hospital.

For more information about ACI and how to be involved, please contact:

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PINNT Article "Diet, Digestion and Drugs"

By Professor Gil Hardy PhD FRSC

"We are what we eat" but perhaps more accurately "we are what we digest and absorb". We all need food to live and we all take drugs as medicines at various times during our lives. Both food and drugs need to be absorbed into the circulation so they can reach their site of action. Understanding how the various nutritional components of food are absorbed helps us to realise why medicines need to be taken in different forms and require different directions on their labels.

Professor Gil Hardy PhD FRSC

PN-DU Founding Member

Food Digestion

Food is digested and absorbed in different regions of the body's digestive tract. In people with normal small and large intestines more than 95% of food energy is absorbed and about 5% is lost in the faeces. Most carbohydrates and proteins are absorbed in the upper part of the small intestine (jejunum) whereas fat is absorbed over a longer length of the intestine. Water soluble vitamins such as vitamin C, and electrolytes including sodium and potassium, are also absorbed in this region. Complex carbohydrates from potatoes, pasta or rice etc are digested by enzymes (proteins that initiate chemical changes) in saliva, breaking down first to simple sugars and then to glucose, which is partially absorbed in the mouth. Then most of any remaining sugars are absorbed in the stomach and upper part of the small intestine. Proteins from meat, cheese, beans etc are digested into amino acids (the building blocks of protein) which are classified as either essential or non-essential. These are also absorbed in the upper part of the small intestine. Bile produced by the liver pours into the small intestine and emulsifies fats into bile acids, which are water soluble and can be absorbed lower down the small intestine. Any unabsorbed fats bind to the electrolytes calcium, magnesium and zinc which are then lost in the stool. The large intestine extracts most remaining electrolytes and excess water from the rest of the food then the friendly bacteria that live in all our intestines help to solidify the stool. Ileostomists therefore have a more fluid effluent to collect than colostomists, though their fluidity depends on which part of the large bowel has been removed. The total amount of food energy absorbed by patients with a short bowel is not surprisingly reduced to about 60%. Thus, to maintain adequate nutrition on an oral diet it would be necessary to eat almost twice as much as other people!

Hence the need for enteral or parenteral support.
The fat soluble vitamins A, D and B12 are absorbed in the lower small intestine. Hence, patients who have had some of this region removed, may need to have B12 by injection, usually once a month. Stomal/stool losses are of course greater in short bowel patients and dietary advice has traditionally centred on fat intake in order to maximise absorption of nutrients without increasing stomal/stool volume. Energy absorption appears to be significantly greater with a high carbohydrate-low fat diet compared to a low carbohydrate-high fat diet. The former also results in more water absorption and lactose from milk or yoghurt is adequately fermented and absorbed by any remaining colon without causing diarrhoea. Nevertheless, high carbohydrate diets tend to be bulky and can lead to increased wind and/or bloating. Diets high in the commonest form of fat; long chain triglycerides (LCT) may worsen diarrhoea by reducing water and sodium absorption and increasing colon transit time. Fats can also kill off the gut bacteria thus reducing the amount of carbohydrate fermented. On the other hand, fat yields twice as much energy (double the calories) as carbohydrate and it also makes food more palatable. It is thought that ileostomists lose a lot of electrolytes and should take care to replenish them if they perspire excessively or have diarrhoea and vomiting. Rehydration sachets, obtainable on or off prescription, when made up with water as instructed on the label will provide a balanced replacement of electrolytes in a readily absorbable form.
Many doctors advise no liquid to be taken with a meal and for half an hour afterwards to improve absorption and digestion, but there is no evidence that this improves energy or fluid balance. Patients can generally work out their own preferred mix of food and drink to provide the nutritional balance recommended by their dietician.

Drug Absorption

From time to time we all take medicine in the form of pills, tablets or capsules. Like food, drugs are also absorbed in different regions of the digestive tract. It is essential that an oral drug is absorbed efficiently from the gastrointestinal tract and reaches the blood stream in a form which is therapeutically active. If absorption is poor or slow then the oral dose must greatly exceed the parenteral dose. If absorption is unduly fast then side-effects may be more acute. Glyceryl trinitrate tablets for angina need to act very quickly and should be allowed to dissolve in the mouth, where the drug can be absorbed through the mucous membranes straight into the blood. Most other drugs are absorbed through the lining of the upper small intestine, thus antibiotics such as Penicillin V and Ampicillin need to be taken on an empty stomach so that they can be absorbed quickly and completely. Conversely some anti-arthritic drugs have an irritant effect on the lining of the stomach. These should therefore be taken with meals or just after food.
Oral absorption depends on disintegration of the tablet, dissolution of the active drug, transfer across the gut wall and passage into the liver, from where it passes into the blood circulation. Some drugs cannot pass easily through the gut wall because of their chemical structure or poor solubility, others may react with enzymes in the gut or the liver so that little of the active drug reaches the circulation. Certain drugs are formulated into medicines in such a way that the drug is released slowly to exert a prolonged effect. If an ileostomist has a very rapid movement of food through the small intestine (intestinal hurry), then the tablet or capsule may be collected in the pouch and not reach the bloodstream. If you have intestinal hurry, do remind your doctor and your pharmacist so they can ensure that you receive the right preparation that is suitable for you.
Other medicines colour the faeces or urine and can cause alarm if not expected. Drugs likely to cause a colour change include antacids (white, grey or speckled), antibiotics (green or grey), iron (black), and aspirin (pink, red or black). Often labels will warn of this effect.
Diuretics are drugs used to remove excess fluid from the body. Some act by increasing the amount of electrolytes excreted in the urine whilst taking more water with them and are best avoided by ileostomists. There are other types of diuretics available, so do remind your doctor if you have an ileostomy. Drugs can also bind to blood proteins, such as albumin, before passing into body tissues. As a result, the levels of digoxin (for heart failure) can be 20 times higher in muscle (which accounts for 30-50% of total body weight) than in blood and as muchas 60 times higher in heart muscle. Conversely, most of the antibiotic, gentamicin remains in the blood and slowly permeates into tissues to attack the infection. Obviously, if albumin levels fall – as they may do in malnourished or kidney patients – this increases the amount of unbound drug in the blood which may affect its pharmacological action.
Other drugs can become chemically bound to certain foods and will, therefore, not reach the bloodstream in sufficient quantity to exert their proper action. The tetracycline antibiotics for example, combine with milk and should therefore only be taken with water. Read the Labels!
The dosage schedule for a drug represents the doctor's best appraisal of the patient's therapeutic requirements. The total daily dose should reflect the nature and severity of the illness, the age, weight and concurrent disease status. If a drug acts very quickly and efficiently, such as benzyl penicillin, then a large dose can be taken just once or twice a day. Other drugs may need to be taken in smaller doses and more frequently, especially if they cause gastrointestinal

disturbances.
Hence, many dosage schedules are based on the idea that medicines should be taken three times daily with meals. But this is not always necessary. A once-or-twice daily dosage, if suitable, may offer practical advantages and may also improve compliance by children or the elderly. It is more important, that the patient receives a clear explanation of the aims of therapy, details of the drug, its effects, the dose, frequency of dosage and anticipated duration of treatment. The nurse, the dietitian and the pharmacist can play a valuable role in reinforcing the drug information provided by your doctor and the manufacturer's Patient Information Leaflet. In this way patients can be better informed, better motivated to continue the course of treatment and better able to match their drug treatment with their food and nutrition for their own particular lifestyle.
All medicines, whether purchased over the counter or dispensed by your pharmacist are labelled stating the dose and how frequently to take, plus any special instructions or precautions. Please read them carefully and follow them. If in any doubt ask the pharmacist, and tell or remind them of your situation and ask if your lack of large intestine will affect your medication.

Acknowledgement
Parts of this information are taken from an article by Alan Eyles, Pharmacist Adviser to the Ileostomy and Internal Pouch Support Group, (UK).
Reproduced with permission from PINNT (UK). The article was first published in Online, 2002.

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. Donations can be made by:

- On-line donations directly to IPaNEMA's bank account with the notation "PN-DU":
  NBNZ 22 06 0273 0308 799
- Cash or cheques 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

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- NSW: Gillian/Karen
- TAS: Jacqueline
- NZ: Gil/Brenda
- US affiliate: Jodee

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