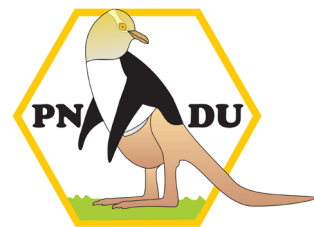


DRIPLINE

PARENTERAL NUTRITION DOWN UNDER



Parenteral Nutrition - Down Under™

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

PN-DU has had a busy few months, being involved in several events which you can read about in this bumper New Year's issue. There are two articles based on chats on the forum; about dehydration and swimming. And we find out a bit about two of our members, one of whom is only two years old. Very sadly, one of our newest young members lost her battle with illness and died, shortly before her 6th birthday. We have a moving testimony of her young life written by her foster mum and dad. 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.

Gillian,
Dripline Editor

ISSUE 3
FEBRUARY
2013

IN THIS ISSUE

- OUR SPECIAL DAUGHTER, TYNESHA ROSE
- PN-DU'S SYDNEY PICNIC
- GILLIAN ASKS, MANOJ ANSWERS
- SWIMMING ON PN
- ARIEL'S STORY
- NEW PN-DU PULL-UP BANNER UNVEILED
- GENEROUS GIFT FROM BAXTER STAFF
- SAL'S STORY
- DEHYDRATION AND PN
- GESA CONFERENCE IN ADELAIDE
- RACHEL AND GIL AT THE HOSPITAL NUTRITION & HYDRATION SUMMIT IN MELBOURNE
- PN-DU'S CONSENSUS STATEMENT
- KAREN AND SUZIE CO-PRESENT AT THE 2ND AUSTRALASIAN CLINICAL NETWORKS CONFERENCE
- MEDICATION AND NUTRITION INTERACTION
- FRESENIUS KABI'S NEW PREMISES



LIFE WITH THE GORGEOUS TYNESHA ROSE

WORDS BY MARK AND CHRISTINE



Tynesha Rose

Our lives changed forever the day the beautiful Miss Tynesha Rose arrived. She came to us when she was 7 weeks old and was a very unwell little poppet. She contracted Strep B Meningitis at two weeks old and this had a profound impact on her and left her with severe brain damage, cerebral palsy and epilepsy. Her birth family were not able to cope with her and Child Youth and Family had her under their care. It would be fair to say that we never saw her coming – I was 46 and Mark was 56 and not looking for a little cutie to come along. I love the way God has His way of working things out.

With a fairly bleak predicted outcome for her – not expected to walk, talk or be independent, we took her home. Oh my goodness what an incredible kid she is. So determined, brave, and quirky. She was feisty right from the very beginning. She did walk, a funny chaotic frantic, fragile walk. She did talk at 3 1/2, she repeated phrases that she heard and got them in the right place, even the ones that shouldn't be repeated! Like "don't touch Daddy's bum" was one of her favourites and would shout this at everyone at the supermarket or anywhere else for that matter. This is what I would say to her every day when Mark got out of the spa pool and T would lunge for his togs and rear end so was a phrase that locked in and got repeated. We have a lot of Tynesha isims that we all repeat now.

Our life with her was very busy and filled with Doctors, therapists and hospital visits. There was also a lot of "normal" like Kindy, trips to Australia and Canada, and huge amount of fun with family and friends. She had a way of engaging everyone that met her. They may not have understood what she was saying but that didn't seem to matter.

Her body was never really very friendly to her and we had always had a hard time feeding her and poohing was a mission to say the least. May 2011 we put in a G-Tube as we no longer were able to feed her. After many hospital stays she was more and more unwell and we went into hospital on December 31st 2011 and spent the rest of 2012 there. After many investigations, tests, surgery, trial and error everyone realised that Tynesha had an intestinal system that did not want to work and no idea why. There was no structural reason and then we thought it was a part of the damage to her brain and the messages had just stopped working.

In May 2012 we started her on PN as we had lost all options of feeding her. I was very worried about this and how we would ever be able to go home. We were given the lovely DVD on Hebe that Tina and Andy made so that gave me hope. I also found out about PN-DU, joined and read everything I could find. You were all a life line to us and we are so very thankful for this, I can't even express to you all how much.

Tynesha's body still was not being friendly and there were line infections, ileostomy needed, ICU stay etc. The biggest struggle we had was with pain and we never ever got on top of that and this was brutal for Tynesha. The only way she had to show that she had pain was to bang her head, bite or pinch. Intestinal failure is brutal. She was so brave, much braver than me for sure. No matter what was going on or horrible thing needed to be done she just showed such trust and put up with a lot.

It became obvious that her body was not tolerating PN for some unknown reason. Our aim was always to get her home, somehow. What a fantastic medical team we had around us and their care for Tynesha and our family was unbelievable. With a huge amount of work and care we brought T home on the 27th October. All her favourite people came to stay and were with her when we lost her on the 29th October.

Life without Tynesha is very close to unbearable and I would have to be honest and say that Mark and I are shattered. I just need her back so badly. I miss her so much I can't breathe.

I know, with all my heart that God bought Tynesha into our lives and gave us the most wonderful gift. His love will get us through this. I struggle with the plan that God has in this but know that He has us in His care. She has taught me so much and made me a much better person. Meeting you all on line had opened our eyes to a world we never knew and am in awe at what you all go through.

You are all in our thoughts and prayers and we tell everyone we meet about PN and what this means.

Love to you all
Mark & Christine

✱

SYDNEY PN-DU PICNIC AT BLAXLAND RIVER PARK

WORDS BY RENEE

What is the collective noun for a group of HPNers? A stream...a collection of drips? Never mind – a group of Sydney HPNers and their families had the wonderful opportunity to meet on Saturday 10th November for a picnic at the Blaxland River Park in Silverwater, near the Sydney Olympic Park. It is a great location for families with lots of excellent play equipment to keep the young ones entertained. We demonstrated our resilience by smiling through unseasonably cool and windy weather.

Ariel (with parents Miranda and Dave in tow) and Emily (together with parents, Mel and Malcolm and younger brother Matthew) were the youngest in our group and inspired us all with their tenacity and energy for life! They were joined by Gillian, who organised the meeting with husband Ray; Karen, Jane, Sal (with husband Matt and four glorious children, Bradden, Callum, Juliet and Jolyon) and Renee (and husband Mervyn). (By the way, Mervyn noted that all the HPNers present were female. Is this bias true for people on HPN generally?)

It was fantastic to meet each other, share our very different stories and marvel at the endurance and strength and courage that we see in others and that are essential for a life on PN. What is most inspiring is to see how well HPNers just make the most of their lives, continuing with work, family responsibilities, volunteer and church activities and hobbies, despite the challenges. We shared plenty of laughter, food – for those who could eat - and stories of hospitals and doctors (both excellent and uncooperative), encouraging each other to shoot for the highest quality of life possible.

Sal baked a cake in the shape of the PN-DU logo which was both a work of art and simply delicious (a gorgeously moist chocolate jaffa cake with fondant icing for those who can only look at the photo) – even though she cannot eat it. Thanks for your generosity Sal.

We all know the difficulties of life on PN and it can be an isolating experience. So it was a really precious opportunity to be together with others who truly understand – both HPNers and their families who are simply amazing in their love and support. We will certainly get together again...and encourage other members of PN-DU to do the same if that is practical in your region.

Thank you to everyone who participated for making it a memorable day. ✱



Sydney PN-DU Picnic at Blaxland River Park

GILLIAN ASKS, MANOJ ANSWERS

WORDS BY GILLIAN

I asked my HPN(Home Parenteral Nutrition) co-ordinator, Dr Manoj Saxena, intensive Care Physician, St. George Hospital, Kogarah, NSW, if he would answer some general questions about HPN and TPN (Total Parenteral Nutrition). He very generously agreed to do this for our newsletter.

1. At what point is it decided that a patient needs PN?

This decision takes into account how long a patient has had with inadequate oral nutrition, a current assessment of their nutritional status, and, the predicted course of the illness that is impacting on their oral intake. There is a large amount of variability in practice, but generally by about 5-7 days of an inadequate oral intake we will start to think about starting PN, but this will be less if the patient is already malnourished.

2. At what point is it decided that HPN is necessary?

Home PN is a fairly involved decision that involves an assessment of whether it is actually feasible to practically consider HPN for an individual patient given social, geographical and other issues not related directly to the need for PN. Generally if the problem with the bowel is permanent or unlikely to resolve, then HPN can be considered, but it is intimately intertwined with the factors mentioned above and the actual prognosis of the underlying condition that is causing the bowel problem.

3. What are potential medical problems associated with patients on long term HPN?

The key one is infections related to the line through which the PN is delivered, and maintaining and preserving vascular access; others include vitamin or mineral deficiencies and abnormalities of liver and bone tests.

4. Who is involved in working out the exact formula for the patient's HPN?

Generally this is a combined effort involving several individuals: the doctor, nursing staff, dietitian and the pharmacist.

5. How is the patient's progress monitored?

Regular follow up with a number of individuals – the key ones are a Physician/nursing staff team, and other specialists (endocrinologists, gastroenterologists and dietitians)

We check the levels of the various vitamins and minerals every 6 months, also check liver function tests regularly and bone densitometry every few years.

6. When are the amounts, and types, of additives in a patient's HPN adjusted?

The decision to change the levels of vitamins and minerals is complex. Often what we can measure in blood tests may not truly reflect the levels in the body's cells – which is the key thing that we would like to know. So we have to correlate the levels we find in the blood with any new symptoms that may be relevant and choose to alter the additives in the PN.

The amount of protein, fat and carbohydrate is easier to estimate (there are standard formulae that can be used).

7. Does age play a factor in the body's ability to adjust to HPN?

I am not sure!

8. What training do doctors have in monitoring HPN?

In Australia it may be (in general) a Gastroenterologist, a Surgeon or an Intensive Care Physician who looks after patients with PN. Training in PN is usually done through the individual specialist training schemes and through being mentored by senior physicians with expertise.

9. Do policies regarding the monitoring of HPN vary from hospital to hospital, depending on who is in charge, or from doctor to doctor depending on their background experience?

I would think that there is some variability that will be influenced not only by the health care facility, the doctor and their experience, but also on the types of conditions that the patients themselves actually have.

10. Do you know what, if any, plans are being developed for HPNers as they age and are no longer able to care for themselves?

I do not know of any plans for this.

11. Are you aware of any studies on the affects of other lipids than ClinOleic, such as fish oil, on the health of the liver?

This is an area with considerable uncertainty. There does appear to be an association between the need for long-term PN and the development of liver abnormalities. The best evidence that we have of an intervention that may modify this is ursodeoxycholic acid. The evidence for different PN formulations being beneficial is not strong and of high quality. We really need more high quality studies to help us here. *

SHOULD WE TAKE THE PLUNGE?

WORDS BY GILLIAN

One topic on our private PN-DU email forum for Aussie and Kiwi HPNers and carers, which generated much interest and discussion, was the topic of swimming with a central line. I'll tell you immediately that reading this article won't give you a definitive answer, but will give you some insight into the decisions faced by HPNers, and parents of children living with HPN, and some ideas to consider if you are in this situation. This discussion was triggered by a parent of a child on HPN, who had been given conflicting advice from two children's hospitals, asking for feedback from others on HPN.

'To make the decision more complicated, is the differing opinions between medical teams at different hospitals. One children's hospital says a definite 'No!', and doesn't even like [my child] showering once a week and having a daily bath with her brother. Another children's hospital says [about the same child], that it is absolutely fine for her to swim, that they have three other children on HPN who swim, and that for children with such an 'abnormal' life-style, swimming is an important part of being 'normal'. Their advice was to cover the site with three 'Opsites®', then wrap 'Tegaderm™' around the connections. Place a 'rashy' vest (swim shirt) on the child, and let them swim anywhere – beach, public pool, etc. After the swim, it is important to do a thorough dressing and cap change.'

Obviously, these parents are left with the difficult decision of which advice to take! The following paragraphs summarise some of the responses made over the next few days.

'I have had a Hickman line for many years and have never had a bath or spa or swim since then. I do, however, have no dressing on my line, and I do shower without any problems. The explanation my team gave me was that whilst getting the site wet is not a problem, soaking it for a period of time increases the chances of getting an infection. I do think if I covered it I could probably swim safely, but I'm not much of a swimmer anyway. The only thing I really miss is the spa, and I think that is the greatest risk, since it is hot water and long soaking. Line infections are simply no fun, so I abstain.'

'We haven't let (our young child) in the water yet, but am thinking about it for this summer with a triple dressing and ocean water. Still, we are quite paranoid, so not sure if we will go ahead. It would be a dream come true for us too [if she could swim]. We have been pretty strict with her so far- she has a half bath only so her dressing and bung stays dry when we wash her. She loves kicking and splashing around, though, when she is in, so I'm pretty certain that she will take to a dip in the sea if we let her!'

'Regarding the swimming issue, I LOVE being in the water. I swam a lot before I became sick. Whilst I am not well enough to really swim now, I love just being in the water. I live a few minutes from the beach and in summer time I will frequently go down for a dip. I have a Hickman's and always have a dressing on and change it as soon as I get home. I have tried it without a dressing and found I instantly got skin infections around the insertion point. (These are not the same as line infections – it's an infection in the skin not in the blood, however it becomes really sore and I've needed antibiotics to clear it). I have swum a few times in the pools but not very much. My medical team told me the beach was much safer. I have never had a line infection on PN. I would encourage you to give the swimming a go, taking all the precautions you can. The joy and freedom of being in water is not something [we on HPN] should miss out on unless we find it really doesn't work.'

'I'd be asking for evidence-based practice on the infection rate of CVAD sites from children going swimming in cold running water, and showers. [They] will only be able to find some rare remarks for kids on chemotherapy, and very little statistical research on the matter. Post swim, my thoughts would be [to put on] on a dry Tegaderm™/Opsite® post op dressing, then when you get home, do a proper dressing.'

'Update on the swimming....we have braved the local pool but only let [our child] splash, not fully submerge. We protected her line with press and seal on the connections and several layers of Opsite®. Then put the whole lot in her little 'water resistant' crop top and then a rashy (swim shirt) over the top. [She] coped really well for about 20 mins of fun time. We then went straight home, let her have a LONG play in the shower and then did a full dressing, colostomy and cap change...checked her temp every 20 mins (pathetic, I know) and all was fine...but as I said, no submersion, just splashing! We have decided next sunny weekend to approach the beach! We are still extremely cautious, but willing to experiment a bit more.'

'I can understand how scared you must be, especially with the hospital's view point of definitely not allowing it. I just use my normal dressing (3M-1655 Dressing). I don't do anything special with the bung. I think you should be okay living an hour from the beach. I have swum out on the west coast a few times (and got to experience the surf!) which is an hour from where I am. I have also at times swum and then been on the beach for a while before going back in for another dip. I have always been okay. Ultimately you have to make the decision you think is best with the information you have been given. My medical team said to me there was a lot of controversy amongst professionals as to whether swimming was okay or not. They were okay with it, provided the dressing was changed.'

'I use a dressing called Bioclusive®, which is clear like Opsite® and is quite pricey, but is good for sensitive skin. It sticks really well and is watertight.

'RE swimming with a tunnelled line, for what it's worth, the official position of our hospital is no swimming or submersion. BUT, my clinical nurse, whom I trust, has said she thought there came a time when parents had to weigh quality of life against risks, and allow swimming and bathing as normal. The doctors agreed but everyone left it as something we had to decide – ie they couldn't officially endorse it!

The nurse's suggestions were:

- Do it on dressing and bung change day and do these immediately after swimming.
- The exit site of the line is not an issue and does not require any dressing if it's well healed. Some adults don't use dressings at all over well healed tunnelled lines– the dressing is more to prevent tugging and line fracture, especially in children, or to protect a healing surgical site in the period after insertion.
- The options were: wrap up the whole line and bung in sterile gauze to absorb any stray bits of moisture (wouldn't help with a full blown leak through the dressings) and cover the whole thing under a giant Tegaderm™

I know of two children on PN with ports, who very much appreciate the chance to swim, shower, go kayaking etc and have a normal life on their one day a week when the port is de-accessed. But they are older than [my child].'

Our big sister support group in the USA for those on HPN and HEN, Oley, provides information regarding swimming with a CVC. Here is a link to the actual article they have with guidelines for swimming with a CVC, but I've summarised below for those who just want an overall idea of it. It was updated in August 2011. <http://www.oley.org/Swimming.html>

Because there is no evidence that swimming has caused a central venous catheter (CVC) infection, many large home parenteral nutrition (HPN) programs allow their IV-fed consumers to swim once their catheter site is healed. (Allow at least 30 days after line placement.) They advise performing site care as soon as the consumer is finished swimming. (Note: a surgically implanted port that does not have a needle accessing it and has a healed site does not need to be covered before swimming. For this reason avid swimmers may prefer this type of catheter.). Use common sense to judge the quality of water you may swim in.

Swimming is normally safe in the ocean, although some beaches are polluted and should be avoided. Swimming in a well-monitored, private pool that is not used by pets/animals should also be fine. Properly treated swimming pool water should pose no greater risk than shower or bath water. At a public pool, however, your risk increases. Ask the pool manager for the bacteria count before diving in.

Lakes and ponds are not a good choice because the water is potentially stagnant, and likely has fecal matter from birds, ducks, geese, etc. Hot tubs, and the like, are out of the question. The level of microorganisms growing in this warmer water makes them too risky for consumers with an IV catheter and most consumers on tube feeding.

As you can see, no-one can promise you that swimming won't cause an infection; you will need to weigh up the evidence, thoughts and suggestions and decide if it is worth trying. Obviously, you need to discuss it with your medical team as well. ✨

ARIEL'S STORY

WORDS BY HER MOTHER, MIRANDA

My daughter Ariel was born prematurely at 25 weeks when my husband and I were on our honeymoon in Tel Aviv, Israel. My pregnancy had followed a normal, unremarkable course so when my labour came on spontaneously on our second day of touring the city, we did not expect that she would survive, but she did.

Ariel spent the next 5 months in an incubator in the neonatal intensive care unit at the central hospital in Tel Aviv. During that time, she was unwell with a number of issues commonly suffered by extremely premature babies- open ductus, retinopathy of prematurity, punctured lungs, intraventricular bleeding, and necrotizing enterocolitis- that miserable condition affecting the development of the intestines, the impact of which affects us now.

Ariel underwent 3 operations to her abdomen, the last with a catastrophic result that left her only with 7cm of small intestine and which changed our lives forever. We didn't know at the time what that meant for her or for us, we felt only relief that she had survived the operation. After some weeks of recovery and stabilization, we had a medical transfer back to Australia through NETS (Newborn and paediatric Emergency Transport Service).

Ariel spent a further 6 months at Sydney Children's Hospital and we were discharged after being trained to administer home parenteral nutrition (essentially an intravenous drip, fed directly into her veins through a catheter surgically inserted into her chest), which Ariel requires daily, and also continuous tube-feeding which is administered via a tube running via her nose into her stomach).

Ariel does not eat or drink. Ariel's condition means that every evening, we must perform a sterile medical routine to attach her to her IV drip so that she can be provided nutrition overnight. In the morning when the drip bag is empty, we detach her from the IV line so that only her "milk" pump remains (ie the pump which pushes special formula through her nose tube into her stomach). For the moment, the milk pump is attached to Ariel 24-7 which means, for us, constant untangling of tubes from little limbs, not to mention, toys and table legs! We joke to each other about Ariel's pesky personal "robot" when we refer to her IV pole with its assortment of flashing and beeping machines.

Ariel turned 2yrs old a few weeks ago. She is cheeky, strong-willed and kind. She is an enthusiastic and silly dancer. She makes us laugh. The medical routine of caring for her central venous catheter and her nasal gastric tube has become normal for my husband and I, so much so that, but for questions from curious strangers about her various attached medical equipment, we all but forget her condition at times. She delights us, frustrates us and challenges us daily. I am constantly in awe of her tolerance, her bravery and her patience and though caring for her may be hard some days, she shares her strength through her irrepressible and beautiful energy.

Ariel became a big sister to baby Eadie late last year and the transition to older sibling in our family has been lovely to witness. She is Eadie's biggest fan and giver of limitless cuddles.

Ariel will be attending a mainstream daycare in a few weeks, a big milestone in a little girl's life. We are so proud of her! I dare to believe now that I might see my daughter grow old enough to go to school and even to university one day. I hope for so many things for her and every day I am grateful for this daughter that I never dreamed of. ✨



MEDICALERT®

WORDS BY KAREN

During conversation today, the MedicAlert® bracelets/necklaces were discussed. They're something you can wear (adults and children alike) which states on the back your primary conditions/alerts (in the case of an accident), a phone number and member number. All ambulance officers know to look for them. MedicAlert® keeps details of your treating doctor, hospital, next of kin, medical conditions, allergies and medications.

For anyone interested, we have a link on our website <http://parenteral-nutrition-down-under.webs.com/WEBPROTECT-wheelingdealing.htm> to MedicAlert®'s site, as well as a \$10 discount off their initial \$55 membership fee (there is an ongoing yearly fee which isn't discounted). The initial membership discount offer was obtained a couple of years ago and I'm not sure if anyone has taken advantage of it. So if you want to use it, let me know and I'll find their initial discount offer to us. contactpndu@gmail.com

I'm aware of other companies out there now offering similar facilities so you may want to look around. *

ESSENTIAL MEDICAL EQUIPMENT PAYMENT

WORDS BY KAREN

My Mum was just reading her December issue of News for Seniors and came across an article about the Essential Medical Equipment Payment (in Australia). It's only for those on a pension or income support, and it must be claimed ie it is not an automatic payment.

'Essential Medical Equipment' includes 'home parenteral or enteral feeding device' and the payment is \$140 tax free, indexed annually by CPI.

The information leaflet about it is at <http://www.humanservices.gov.au/spw/customer/forms/resources/ci016-1209en.pdf>

(go to www.humanservices.gov.au ; type in "essential medical equipment payment information you need to know" in the search field; click on the first document listed "Information you need to know about your claim for - Clean Energy Future Household Assistance Package - Essential Medical Equipment Payment form (CI016)"; click on the link "Information you need to know about your claim for - Clean Energy Future Household Assistance Package-Essential Medical Equipment Payment"), or you can phone 13 2468. *



We have a bright, attractive advertising banner, to be used at conferences or events where PN-DU is being promoted. Many thanks to Glenn Warr, who created 'Down Under Dan', Carla, who designed the layout, and Gil, who arranged for the printing, and is storing it for us. *

A GIFT FROM OUR GENEROUS BAXTER FRIENDS

WORDS BY KAREN



We were notified in November that during October the Baxter Pharmacy Services staff in Sydney had raised money and chosen PN-DU as the recipient of these funds! We were also invited to come to a staff meeting in order to receive the donation.

So on Wednesday 14th November, four of our members – Miranda, Jane, new member Sal (and mum-in-law, Judi) and I – visited Baxter Pharmacy Department and were guided around the facilities by Nutrition Team Leader, Andrew. We then joined the staff meeting (up to 120 people) where we were presented with an envelope and Jane and Sal were given the opportunity to briefly share with the staff their stories of being on HPN. The staff were very attentive and afterwards complimented them both and asked questions.

Over lunch at the Baxter cafeteria we were able to catch up with Customer Support Specialist, Bev. We also had time to look at the cheque and discover just how much the pharmacy services staff had raised for PN-DU – \$950!!, as well as find out how they raised the money – a raffle with two prizes: time off on Christmas Eve or New Year's Eve (usually very busy times for the staff). What a creative and fun raffle!

We are very grateful to the Sydney Pharmacy Services staff for their generosity to PN-DU and for their warm welcome to us on yet another PN-DU visit. ✨



Sal, Bev (Baxter Customer Support Specialist) and Karen (standing), Jane and Miranda (with the cheque)

SAL'S STORY

WORDS BY SAL

Hi, my name is Sal- I am officially Sarah, but most people know me as Sal. Married to Matt, I am a busy Mum of 4. Jolyon is 14, Juliet is 13, Callum is 11 and Bradden is 9. Before kids, I was a Registered Nurse specializing in child and family health. Now I work for Matt doing accounts and payroll for our audiovisual installation company, Inphase Audiovisual. I work from home and that has been wonderful, especially since becoming sick, early 2010. I went from being able to eat and drink normally to struggling to eat anything at all over a year.

It took over a year of going from doctor to doctor, blood tests to scans and more and it took a surgeon removing my gall bladder to diagnose Gastroparesis. He discovered my stomach was huge and ordered gastric emptying studies which showed food just sat in my stomach. It took a further six months of deterioration, only tolerating small amounts of soft liquid nutrition, before I got to the point of collapse and ended up in hospital. I had lost almost 20kgs, almost a third of my weight, since becoming sick. I left hospital with a jejunostomy, a small stoma into the jejunum with a tube coming out of the jejunum for nutritional feeding. It enabled me to bypass my stomach and get much needed nutrition. I had a pump in a backpack which I was connected to for 23 hours a day. Sadly pain plagued me and I wasn't able to put on weight and ended up in hospital in April last year, and after much heartache, left in May on HPN (home parenteral nutrition).

I have also finally had a diagnosis given last year of Autonomic Neuropathy, a rare condition where the autonomic or automatic nervous system doesn't work very well. My stomach and colon are affected, as is my heart rate, and as I don't sweat, I have trouble with temperature extremes, plus a few more symptoms. They think it was triggered by an auto immune reaction and I am currently trialling infusions of immunoglobulin (antibodies from blood donors). If it works, it opens the door to other immunotherapy treatments. Matt cares for my HPN needs and has been awesome. HPN has enabled me to not have to carry a backpack all the time, put on weight and get more energy to do what I love doing, which is being a Mum, cooking and making cakes. My cakes are just a hobby that is slowly expanding to being for more than family and close friends. (Happy to make cakes for others, I don't have a website but can be contacted through my email, jujujol@yahoo.com). Pain from the jejunostomy is slowing me down, but my cakes are great diversional therapy. With having four children, and lots of birthdays, I taught myself how to create cakes. My cakes have become my art and creative outlet, and I love a challenge. We also purchased an old Pioneer coach fitted out as a motorhome, to enable me to travel with the HPN more easily. It needs work on the mechanics and upgrading inside before we get to go anywhere, but it's been a great family project so far. Matt has restored several Morris Minors in his lifetime, and knew what he was getting into, except on a bigger scale! We love travelling as a family and look forward to our first trip.

Our life may have been turned upside down with my illness, but we have been blessed by wonderful family, friends and our church along the way. Who knows if I'll be able to eat again, or what tomorrow brings- life is a gift and I am making the most of today. *



Some of Sal's cakes.

GIVE ME A DRINK (HIC!)

WORDS BY GILLIAN

The issue of hydration was discussed on our forum, and may have some ideas for you to think about. Of course, **before trying anything different, check with your medical team that it is suitable for you, or your child, to use.** The comment which started the discussion was as follows.

A quick question...does anyone here feel very dehydrated towards the end of their time off PN...(My young daughter) is disconnected around 7am but we have noticed around 3-4pm her behaviour changes. She gets tired, cranky, whinges and this is independent of normal 3year old sleep and behaviour. It is quite out of character. Her specialist says he will look at her blood results from today, and adjust the 'fluid' in her PN. Any tips to help with this dehydration? It wasn't too bad in winter but seems to be rearing its ugly head again now, in Spring.

Some responses include:

- I feel the same, although some days are better than others. This evening I've felt very dry and have just wanted to drink, drink, drink. I find by having a cup of hot tea, it slows down how much I drink. Obviously you can't use that with (a young child), though. I also use a hydration drink throughout the day – not Hydralite™, but powdered Gatorade® and sea salt and I love it. I have some extra bags of saline for use if I'm feeling really dry.

- Yes dehydration is definitely a problem for me. I have just had a call from my PN nurse saying I need to have extra fluids (I have bags of saline as well as the PN as needed) It is definitely worse in hot weather. I do drink St Mark's Solution - 1.5 litres per day. St Mark's is a specialised hospital in the UK for people with intestinal failure and they developed this recipe which is apparently much better than water or Gastrolyte® or similar. (See Suzie Daniell's article on 'Oral Rehydration Solutions', following, for the recipe.) It tastes like sea water so kids are unlikely to drink it. That is why I had a little DIET lemon cordial to add to it - definitely not regular cordial as these salt/sugar proportions are important.

Of course, check with your medical team. I have no idea if it is suitable for children.

- We would say (our young daughter's) day would end at 4pm no matter what time she had woken up – she had been known to sleep until then too. Her oomph! had just run out by then (she usually came off PN about 7 am).

Her lab results would be in the normal range; however, her urine would be a true test of what was really going on. She was consistently low in sodium and potassium.

I would also give extra normal saline when she looked dehydrated (dark circles under the eyes, high output etc). She drank a lot of water, as it was the only thing she could somewhat tolerate, but it did nothing to hydrate her, she needed the extra saline.

If you can tolerate oral fluids, there are some suggestions on the Oley website (<http://www.oley.org/lifeline/ORS.html>), which a lot of HPN folk use to stay hydrated in the summer – however, **do ask your doctor first, as the extra electrolytes may affect the kidneys.** *

ORAL REHYDRATION SOLUTIONS (ORS)

WORDS BY SUZIE DANIELLS

Oral rehydration solutions (ORS) are often used in the management of Short Bowel Syndrome (SBS). SBS reduces the capacity of the small bowel to absorb fluid and nutrients resulting in dehydration and electrolyte imbalances, particularly for those without a colon.

Drinking hypotonic (water, tea, coffee) or hypertonic fluids (soft-drinks) leads to a loss of sodium and fluid from the body into the intestine and passed out with the stool. Oral rehydration solutions which contain an optimal balance of water, glucose and sodium take advantage of a transport system in the small bowel where sodium and fluid is transported across the bowel by coupling with glucose. ORS are therefore important in assisting with hydration and can help reduce the need for intravenous fluids. The optimal mix for sodium absorption is about 90-120 mmol/L (the sodium content of small bowel contents) and glucose about 10g/L.

Sports drinks alone (Gatorade®, Powerade®) are too high in sugar and too low in sodium and may increase stool output.

Tips for improving hydration in short bowel syndrome:

- Limit intake of hypotonic (tea, water) and hypertonic (soft drink, juices) fluids to 500-1000ml per day.
- Replace these fluids with oral rehydration solutions sipped over the course of the day. Start with 500ml and slowly increase.
- Separate intake of ORS and other fluids from food to assist absorption.

St Marks Electrolyte Mix (Sodium 90mmol/L)

6 level teaspoons of glucose powder
1 level teaspoon of salt (sodium chloride)
½ teaspoon (heaped) of sodium bicarbonate
Mixed in 1 litre tap water.

(Note 1 teaspoon = 5ml)

Powders are available from supermarkets and pharmacies.

Make up the solution fresh each day. 2-3 litres/day may be needed to maintain hydration.

Improve taste by:

- Storing in the fridge to keep it cold
- Add a small amount of fruit juice or lemon or lime cordial
- Sip through a straw.
- If the bitter taste continues to be a problem, replace the sodium bicarbonate with sodium citrate.

Double-strength Gastrolyte® (Sodium 120mmol/L)

2 sachets of Gastrolyte® per 250mls

Note – Contains potassium (40mmol/L) which can be a problem for some people (talk to your health professional) and is expensive!

Modified sports drink recipe

Whilst not the exact chemical make-up of ORS, this may be more palatable for those unable to tolerate ORS and a better substitute for other more dehydrating fluids

2 cups liquid Gatorade®

2 cups water

½ teaspoon salt

Disclaimer: This is intended as general information only and does not apply to individuals as nutritional needs will vary depending on your medical condition. Always consult a health professional prior to making dietary adjustments.

References

NHS UK Medicines Information (2012). What is St Marks Electrolyte Mix (solution)? www.nelm.nhs.uk/en/NeLM-Area/Evidence/Medicines-Q--A/What-is-St-Marks-Electrolyte-Mix-solution/

Rees Parrish C (2005). The clinician's guide to short bowel syndrome. *Practical Gastroenterology*, September 2005: 67-106. *

GREETINGS FROM ADELAIDE!

WORDS BY GILLIAN

On Tuesday 16th October, Karen, Gil and I arrived on different flights in Adelaide, to man a stand for PN-DU at the annual GESA (Gastroenterological Society of Australia) and AuSPEN (Australasian Society of Parenteral and Enteral Nutrition) conference for Australian Gastroenterology Week. After settling at the hotel late afternoon, Karen and Gil headed to the Adelaide Convention Centre to set up the stand in preparation for Wednesday and Thursday's events. The organisers had done a wonderful job with the community stands, including printing a huge copy of our logo on the wall behind us. We coveted this panel, but none of us could think of a way to get it on board a plane, so sadly it had to remain. I arrived at night, ready for the next day's work.

Arriving before 7:30am for an early start, to add some Pendoos to the stand (and yes, they did attract attention and some discussion), as well as pamphlets and business cards with our group's contact details, and copies of our newsletter. It was a large conference, with about 900 delegates and exhibitors each day.

We felt it was very successful, as many clinicians came to the stand and discussed HPN from their hospital's experience, and found out about PN-DU. Visitors included dietitians, pharmacists, nurses and gastroenterologists. They came from around Australia and New Zealand – including Perth, Fremantle, Ballarat, Melbourne, Launceston, Adelaide, Canberra, Sydney, Newcastle, Hamilton and Auckland. Most had at least a few HPN patients, so hopefully the information about PN-DU will be given to them.

We had informal chats to Kensi and Ross from Baxter in Sydney, as well as their NZ and South Australian colleagues, and spent some time with Charlotte and Candice from Fresenius Kabi, a large pharmaceutical company like Baxter, which, at the current time in Australia, manufactures PN for hospitals only.

We met and chatted informally with Pamela and Briar AuSPEN delegates from NZ, and importantly a few members of the AuSPEN HPN Working Group, including Lyn, Margie, and Andrew, plus Azmat, the AuSPEN Treasurer, while she was 'manning' the AuSPEN stand (next to us) which allowed us (and them) to put faces to names. Sarah, Stefan and operators of neighbouring stands representing support groups for other gastroenterological disorders, were very friendly and interactive and we learned some potentially valuable information from them about what can be achieved in groups such as ours.

Representatives of GENCA (Gastroenterological Nurses College of Australia), who had the adjacent stand to us, were supportive and welcomed the submission of an information article about our group for their magazine.

We enjoyed the delicious food provided by the Conference Centre, and also shamelessly helped ourselves to the ice-creams, chocolate bars, coffee, smoothies and pens offered by the various exhibitors.

Both days were quite long – beginning at 7:30 and ending at 6pm and 4pm. As the room where our stand was situated was booked for another function on the Friday, Karen and I attended one session from AuSPEN relating to HPN and found it very interesting. Gil had flown back to NZ in the morning.

Gil and Karen were both great companions for these days; as well as achieving our goal of disseminating information about PN-DU to HPN clinicians, we had time to chat and have a few laughs as well. Karen and I would both like to thank Baxter for delivering three nights' of our PN to Adelaide, as well as our other four nights to our homes in Sydney. ✨



One of our many visitors, with Karen and Gillian



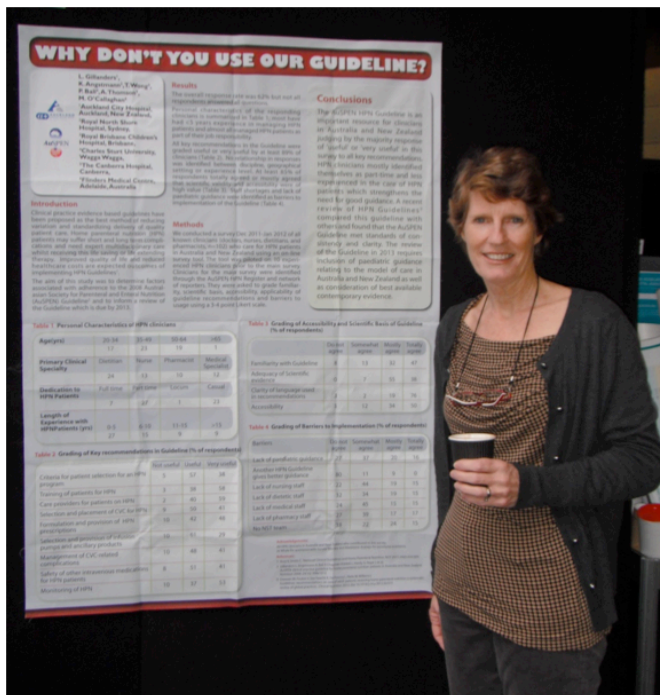
Gillian and Gil manning our stand.



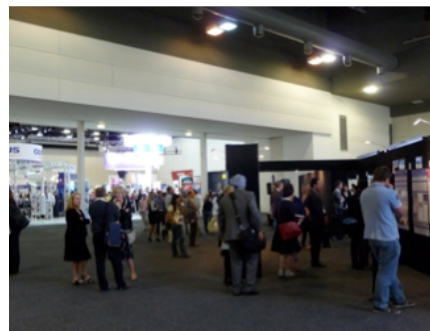
Karen (with chocolates), Ross (from Baxter) and Gillian



Gil and Karen meeting with Charlotte and Candice of Fresenius Kabi.



Gillian beside AuSPEN's poster.



TOP: Break time, which was our busiest time.
BOTTOM: The end of a long day - the picture says it all, really.

HOSPITAL NUTRITION & HYDRATION SUMMIT IN AUSTRALIA

Rachel Healey, our Queensland and Paediatric Coordinator, and **Gil Hardy**, Treasurer, recently represented PN-DU, at the **3rd Australian National Hospital Nutrition & Hydration Summit held in Melbourne VIC on 29/30th November 2012** together with over 50 medical, dietetic and nursing delegates. The conference theme of 'enhancing nutritional care within your organisation' was applied by the various speakers to all aspects of nutrition and dietetic practice from workforce planning and dietetic management to research and clinical practice.

The comprehensive two day programme examined: the revised Australian Dietary Guidelines; how to implement and maintain nutrition standards from hospital to home; successful and innovative malnutrition prevention programmes; clinical updates on vitamin D deficiency and breast cancer; re-feeding syndrome; nutrition for bariatric surgery; gestational diabetes; and strategies to work in partnership with patients to achieve better patient-centred care.

Gil made a short introduction, outlining the current international guidelines for Home Parenteral Nutrition (HPN), then Rachel superbly presented the results of our recent PN-DU survey examining the patient's and carer's perspective of HPN quality standards when measured against the current Australasian Clinical Practice Guidelines, published in 2008 by the Australasian Society of Parenteral and Enteral Nutrition. Despite the fact that the PN-DU presentation was the last on the programme, at the end of a long Friday session, many delegates stayed and participated in the lively Q&A and discussion about the key results of our survey.

Our data will also be presented in February 2013 at Clinical Nutrition Week in the USA and have been summarised in a PN-DU consensus statement that follows below.

The summit was officially endorsed by the Australian Council on Healthcare Standards and the Royal College of Nursing Australia.

PN-DU's Consensus Statement

Recommendations for improving the quality of services provided to HPN patients: a consensus statement from PN-DU*

Introduction:

*Parenteral Nutrition - Down Under (PN-DU) is a support group for adults and parents/carers of children on Home Parenteral Nutrition (HPN) in Australia and New Zealand.

In June 2012, PN-DU conducted an on-line survey of its members' opinions on the levels of compliance, by Australasian HPN centres, with the Australasian Society of Parenteral and Enteral Nutrition (AuSPEN) Clinical Practice Guidelines for HPN Patients in Australia and New Zealand (Nutrition 2008) (the guidelines).

This consensus statement is based on the data collated from our pilot survey. The survey results have been provided to major stakeholders, such as AuSPEN and commercial providers of HPN products, and have been accepted for presentation at multidisciplinary scientific conferences of health professionals, at the 3rd National Nutrition and Hydration Summit in Australia, November 2012 and at Clinical Nutrition Week in USA, February 2013.

Description:

The survey was devised and conducted by patients for patients and included questions with 'Yes/No/Don't Know' answers, relating to the 10 aspects of HPN addressed by the guidelines.

The aim was to ascertain consumer perspectives of their standard of homecare, to complement any future survey of clinicians involved in HPN management by AuSPEN, before the next revision of the guidelines. Participation was voluntary, anonymous and confidential.

Results:

A total of 15 consumers/carers started the survey with 13 completing all questions. Just over half (53%) were adults dependent on HPN, with the remainder being parents/carers of a child on HPN; all referred to as "patients".

10 patients have been HPN dependent for at least 5-10 years, 4 of these for >10 years. 71% reported their care involved a nutrition support team (NST) but only 1 team included a pharmacist.

All patients reported being closely involved in the decision to go home on HPN, however, 21% of patients felt they did not have the risks and benefits of HPN explained to them, and 1 (7%) felt they did not have all treatment options explained nor the opportunity to ask questions. 29% reported that their HPN centre did not confirm any aspect of their home set-up prior to discharge.

Practical training was given to all, but less than half reported receiving advice on high risk events (line blockage 36%, febrile episodes 43%). Notably only (43%) received written information to assist in expedited hospital triage.

All HPN pumps were reported easy to operate and clean, but less than half of the respondents (46%) had been required to demonstrate competence, before discharge.

Of concern is that only 23% have contact details for a 24/7 pump troubleshooting service and none reported being able to access an after-hours service.

Discussion:

Our pilot survey suggests overall most HPN centres comply with the guidelines, doing best at selecting/placing a central venous access device (CVAD) and training patients before going home.

However, there is a need for more concerted efforts in relation to:

- training in the management of emergency situations and life-threatening complications associated with HPN and/or a CVAD, with provision of emergency repair kits
- confirming patients have suitable home environments before discharge
- providing written information, to facilitate rapid triage and treatment in the event of emergency hospitalisation
- assuring patients that a multidisciplinary NST is coordinating their care
- providing information on after-hours technical support for pumps
- more involvement of pharmacists to advise about HPN and drug interactions.

Conclusions:

Options for improving HPN practices might include:

- development of checklists to empower patients to advocate for the best possible care
- what patients should expect before discharge
- what sort of monitoring should occur and with what frequency
- parallel checklists for clinicians within HPN centres may be useful.

Although not statistically valid in terms of the total Australasian HPN patient group, these data nonetheless serve as a useful pilot snapshot.

Our results highlight areas where a wider survey could provide more valuable comprehensive insights into HPN practices and care management that may need improvement.

PN-DU would appreciate and value feedback on our survey results and our recommendations for service improvement, from relevant health professionals and other stakeholders, involved with HPN.

The full survey findings are on our website <http://www.parenteralnutritiondownunder.com/apps/documents/> *

PN-DU AT NETWORK TO NETWORK 2012 – THE 2ND AUSTRALASIAN CLINICAL NETWORKS CONFERENCE

On the 23rd November, PN-DUer Karen Winterbourn and Suzie Daniells (Dietitian, Prince of Wales Hospital) presented at the NSW Agency for Clinical Innovation (ACI) hosted *Network to Network Conference* on the development of the ACI patient information pamphlet *Parenteral Nutrition: An information guide for patients and carers*. Over 300 delegates attended over the 3 days of the conference, held at the Sydney Conference and Exhibition Centre, Darling Harbour. Suzie and Karen presented at a session focussed on consumer experiences with health services and how health service providers can better engage the community in clinical practice improvement.

Karen and Suzie's presentation was entitled *Parenteral Nutrition – The consumer engagement journey*. In 2008 the ACI Nutrition and Gastroenterology Networks began developing best practice guidelines for the use of PN in hospitals. Consumer working group members identified the need for a resource specifically aimed at consumers. Following the launch of the ACI PN Pocketbook for clinicians in November 2010, the two Networks approached consumer support groups PN-DU and IBD Support Australasia Inc to develop a patient and carer resource. With their endorsement the ACI formed a working group consisting of consumer group representatives and clinical experts, co-chaired by Karen.

Throughout 2011, the working group created a pamphlet providing introductory information to patients on PN and their carers. Consumers from PN-DU and IBD Support Australasia Inc were involved in all stages of the process to ensure that the clinical content reflected consumer needs.

Suzie reflected on the consumer engagement journey from a clinician's perspective. She noted that the needs of consumers were central to the end-product as they are the end-users: "including consumers brings everyone back to what it is all about". Including representatives from consumer groups, rather than independent consumers, enabled access to the input and ideas of a range of consumers. They were able to represent the broad views of a diverse group, not only their own experiences. Indeed, the ideas brought about by consumers challenged some of the clinicians' own thinking and expectations regarding what clinicians think consumers need. She noted the importance of mutual respect and value – that consumers and clinicians are given equal opportunity at the table. Having Karen up-front co-chairing the working group meant that consumer experiences could not be discounted.

Unfortunately because of planned surgery (one of the many and varied challenges of an HPNer), Karen was unable to attend the conference. However, ACI kindly pre-recorded Karen's presentation in a one-take wonder! leaving Suzie to co-present on the day with a video clip! During this pre-recorded video, Karen began by telling her own story of ending up on HPN, joining PN-DU, and ACI's invitation to be involved in the pamphlet project. The need to understand the consumer perspective was highlighted by reference to PN-DU's recent survey of members on the level of compliance by hospitals to the HPN Clinical Practice Guidelines published by the Australasian Society of Parenteral and Enteral Nutrition (see PN-DU Consensus Statement). Whilst the survey found that many reported being involved in the decision to commence PN, it revealed concerns a percentage of consumers had when first introduced to PN in hospital. Amongst other concerns, some did not feel they were given the opportunity to ask questions. Karen's own experience of starting PN also revealed a significant lack of understanding of PN and she cited this lack of understanding as great motivation to be involved in the ACI pamphlet project. She spoke of the desire of many consumers to work collaboratively with clinicians "to improve experiences and outcomes for other consumers" and thanked ACI for the opportunity to represent PN-DU. Being able to bring a consumer's perspective to the pamphlet project was a great way of ensuring that the pamphlet was going to be relevant to consumers, addressing the concerns and questions of patients (which may be completely different to those of medical professionals). Whilst Karen admitted to finding the project rather intimidating – a non-medical person working with highly qualified clinicians on a medical pamphlet – ACI facilitated the whole process and it proved to be a great opportunity to bring the consumer perspective to an important project.

The pamphlet is being piloted in 5 NSW hospitals before being made available to clinicians and consumers. Once finalised, the pamphlet will be available on the ACI website www.aci.health.nsw.gov.au and will include PN-DU's and IBD Support Australia Inc.'s web addresses. *

NUTRITION AND YOU

Medication and Nutrient Interaction Awareness: How to Play It Safe

Home enteral and parenteral nutrition (HPEN) consumers must be always mindful of possible medication interactions, ever striving to minimize the number of medications used. Since it is not possible for any health care professional to recognize all medication interactions, the HPEN consumer can play a weighty collaborative role in identifying and understanding interactions.

The following suggestions will help you identify and potentially avoid medication-medication or medication-nutrient interactions.

Maintain a List

Be vigilant in updating the list of all your medications, prescription and over-the-counter (OTC). Make a master list of these medications, including all HPN prescriptions (keep a label or ask the provider to provide a copy) and HEN regimens.

Keep a Diary

Consider keeping a perpetual diary (as timely and as continuous as practical), so you can note changes that may be helpful in determining when a probable medication interaction impacts on well-being. Diary entries should include not only significant changes, but all deviations from the norm. These entries can more easily be incorporated into your existing daily record keeping (i.e., weight, temperature, pulse, blood pressure) using automation (i.e., computers, voice recognition software, recorders). Medication interaction screening can be more adequately evaluated if the consumer or caregiver has collected accurate information.

Write down and record any changes in OTC or prescription medications, medication administration, dosing, herbals, and foods.

The quantity and ingredients of food or drink intake should be meticulously noted, especially if taken with medications or outside the normal ingestion. Remember that all changes may be significant, so even social activities, mood, stress, seasonal changes, weather, or body cycles (menstrual, menopause) need to be indicated.

Common signs and symptoms of an interaction are: anorexia (loss of appetite), polyphagia (increased appetite), cough, dry mouth, edema, fever, headache, insomnia, quickening or slowing of food in the intestinal tract, urinary excretion, lethargy, itching, rash, nausea, vomiting, or diarrhea. If these symptoms are associated with a change in medication or a change in how the medication is being applied, ingested or injected, speak to your physician and/or pharmacist.

Nutrient-Medication Interactions

One of the most widely studied food-medication interactions concerns grapefruit. It is clear that grapefruit and especially grapefruit juice can increase medication blood concentrations up to fifteenfold with high doses of grapefruit, and twofold with lower doses in some medications (i.e., statins).

It is also important to know that other juices will have varying effects. For example, lime, star fruit, and pomegranate juice may also inhibit intestinal enzymes. (Note: orange juice does not have a similar effect.) This means that some drugs will not be broken down by the enzymes and may be absorbed in a more potent form than necessary. Always ask about any interactions with your medication, especially if grapefruit juice is a common component of your diet.

Speak to your doctor, pharmacist, or dietitian about your medications and your diet to be sure you are **playing it safe**. Although dramatic advances have been made in the study of medication interaction mechanisms, there is much to learn. The consumer and his or her health care team must work together to recognize beneficial, and avoid adverse, medication-nutrient interactions.

Resources

The Internet is a valuable tool for both the patient and the clinician to provide confirmation for any proposed interactions. Although Internet domains that are government (.gov) or educational (.edu) are preferred, there are numerous other credible domains (see table below for some recommended sites).

Making Changes

Finally, all suspected interactions should be discussed with your primary health care providers before any curtailment of medications or changes in diet are made.

Written by Thomas G. Baumgartner, PharmD, MEd, RPh, RCPH, FASHP, President and Chief Executive Officer of Consultant Pharmacists of America, Inc. Reviewed by Carol Ireton-Jones, PhD, RD; Laura Matarese, PhD, RD; and Cheryl Thompson, PhD, RD. References are available upon request.

Table 1. Selected Medication Interaction Web Sites

- www.fda.gov/Drugs/DevelopmentApprovalProcess/DevelopmentResources/DrugInteractionsLabeling/ucm110632.htm
- www.nlm.nih.gov/medlineplus/druginformation.html
- www.cdc.gov
- www.med.unc.edu/medicine/edursrc/drug_int.htm
- www.ext.colostate.edu/pubs/foodnut/09361.html
- reference.medscape.com/drug-interactionchecker?cid=med
- www.drugs.com/drug_interactions.html
- www.hanstenandhorn.com *

FRESENIUS KABI CARING FOR LIFE

Cancer and hospital patients to benefit from new state-of-the-art Pharmaceutical Compounding Centre

Construction has begun on a new and innovative Pharmaceutical Compounding Centre that will supply high quality chemotherapy drugs and parenteral nutrition products to hospitalised and out-patients throughout Australia.

The \$19 million facility located in northern Sydney, being built by pharmaceutical company Fresenius Kabi Australia Pty Limited will span 8,500 square meters and will house high tech compounding technology to produce cancer medication and parenteral nutrition for hospital patients in need.

More than one hundred people will be employed at the Mount Kuring-gai site during construction and over one hundred and fifty Fresenius Kabi Australia staff when the facility is operational.

Marking the start of construction, Ms Zita Peach, Managing Director and Executive Vice President South Asia Pacific said, "The significant investment in this site in Australia is dedicated to the needs of critically and chronically ill patients, and will provide access to state-of-the-art products through increased capacity and benefits gained through innovative technology."

"Fresenius Kabi Australia currently provides compounded oncology and parenteral nutrition products to patients in over 180 hospitals and clinics throughout Australia, inclusive of public and private hospitals. This new facility will enable the availability of more medicines to more people," said Ms Peach.

Fresenius Kabi Australia is part of the worldwide health care company Fresenius Kabi and is one of Australia's fastest growing and innovative healthcare companies, providing high quality medicines and technology.



Top Left: A panoramic view of the Fresenius Kabi Australia pharmaceutical compounding centre site. Bottom Left: Local Mayor Nick Berman and Fresenius Kabi Finance Director Juan Villar unveil the foundation stone at the pharmaceutical compounding centre construction site. Right: An artist impression of the Fresenius Kabi pharmaceutical compounding centre.

Fresenius Kabi Australia Pty Limited
964 Pacific Highway Pymble NSW 2073
Phone: 1300 732 001
Fax: 1300 304 384
www.fresenius-kabi.com.au *



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

AUD\$ A/C No: IPANTR-AUD20

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: Jodee/Brenda,
US affiliate: Jodee

Paediatric Coordinator/Advocate: Rachel, Vanessa, Kelly

Adult Coordinator/Advocate: Brenda, Karen, Gillian

Webhost: Jodee

Newsletter Editor: 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 www.parenteralnutritiondownunder.com

DISCLAIMER: PN-DU has made every reasonable effort to ensure that the content of this newsletter is accurate, but accepts no responsibility for any errors or omissions. The views expressed are not necessarily those of PN-DU and no reference to any product or service is intended as a recommendation or endorsement. You should always seek advice from your own team of healthcare professionals in relation to your specific needs/treatment.

