



DRIPLINE



PNDU

Parenteral Nutrition Down Under

This issue celebrates 5 years of Dripline. The aim of Dripline, as PNDU's e-newsletter and important member resource, has always been to support Aussie and Kiwi HPNers and their carers. Firstly, Dripline connects them to other HPNers and carers via member stories, to share the happy, sad and frustrating times and the occasional triumphs that occur whilst living on HPN, something that only around 250 people in Australia and New Zealand know about, and to open a window into this life to clinicians who care for HPNers. Secondly Dripline aims to educate HPNers and clinicians about PNDU's work and activities as well as HPN related medical problems and research. Thirdly, Dripline hopes to encourage and inspire HPNers to have a go at enjoying life, by reading stories about members' travel experiences, hobbies, celebrations and achievements no matter how big or small. Hopefully, Dripline always has at least some articles of interest to all readers, and that it achieves its goals.

This 5th birthday issue continues with the usual mix of member stories, medical information about how chlorhexidine 'works' and the latest PNDU activities and information.

Gillian - Editor



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Working while Infusing with HPN – how this nurse made it work

WORDS BY JUSTINE

In April 2016, the decision was made to abandon my jejunal feeding and to transfer to Parenteral Nutrition (PN) on the home therapy program (Home Parenteral Nutrition or HPN) run through a tertiary hospital in Sydney. This was a decision I was grateful for, having endured 3 years of decreasing volume tolerance, with increasing pain and hospitalisations – almost 8 months in the previous 12 months. I was now an 'HPNer' and life would now continue in a different swing, but what about work? The HPN team were extremely supportive and encouraging of my plan to return to work within the health system, BUT how was I going to manage 14 hrs of HPN plus 10 hrs of IV hydration per day and IV medications as well as work in the busy hospital environment? Let me explain...

My hospitalisation surrounding my HPN induction had lasted 9 weeks – 5 of which I was basically NBM (nil by mouth) (losing vital muscle base, vitamins and minerals) and resulted in significant deconditioning. There was no way I was going to bounce back to 10 hour days as a Clinical Nurse Educator covering multiple wards and units, while also providing an informal nurse consultancy service for complex gastroenterology patients.

I was going to need a managed return to practice plan, involving my direct-line manager, Staff Health, Work Health & Safety, my GP and myself.

1. Talk to my Manager.

In the weeks preceding my Return to Work (RTW) I had several conversations with my manager to elucidate 'Divisional' support for my return; the parameters of a managed incremental RTW were defined; and I gathered the necessary paperwork from my medical team, indicating their agreement to the plan and any limitations for my RTW. Myself, my GP and my Manager agreed to a managed 3 month RTW, starting with 2x 6hr days/week introduction, with a 4 week formal review period. I was encouraged to contact my manager promptly if any issues arose, or I felt as though the plan was not working for me, or I met any resistance in the workplace (thankfully there was none). The plan was made.

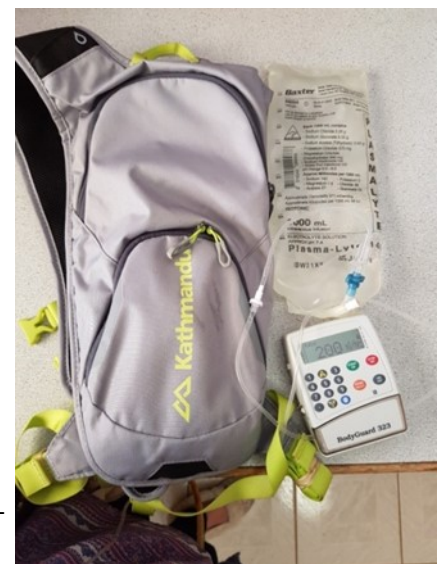
2. Talk to Staff Health

Informal and formal conversations with Staff Health explored the health risks to myself, my colleagues and my patients if I RTW while infusing via a Portacath/CVAD (Central Venous Access Device). It was decided that as long as I was fully seasonally immunised, and judiciously considered my direct exposure to known infective patients, that when in 'good health' my situational risk was only slightly increased. Staff Health also recognised and supported my low threshold for seeking Medical review due to increased susceptibility to infection.

3. Talk to Work, Health & Safety (WHS)

WHS (previously known as OH&S or WorkCover) was consulted to determine the most appropriate 'apparatus/device' for me to carry/wear to contain my IV bag, pump & emergency packs. It was agreed I would need to wear a backpack during my work hours. It was agreed that the backpack had to be: as small as practically possible; have a harness system that allowed me freedom of movement while restricting the movement of the bag; be fully washable without significant deterioration; and aesthetically acceptable within a clinical hospital setting. I supplied several backpacks for inspection/evaluation by my allocated WHS consultant – my previously used 'Infinity' paediatric bag, a generic compact size backpack and a Kathmandu hydration style backpack. It was decided that the Kathmandu bag met all criteria and was most suitable for my needs and it had the required 'chest strap' that must be secured when I was physically engaged with patients.

So ... plan defined, paperwork completed, managerial agreement gained, medical support established, occupational safety maintained – I was ready to return to the job that I love and have committed so many hours of study, tears, pain and joy to – BACK TO WORK I GO!



So for anyone considering returning to work or embarking on a new work situation as an HPNer, the message to take home is to TALK, TALK, TALK. Talk to the important people in your workplace – direct line managers, higher tier managers (if necessary), WHS, staff or occupational health if they exist in your organisation, your medical team, especially your GP (they are your first line of medical support). Be realistic about what you can physically/emotionally/socially manage in your proposed work hours but don't let your starting point be the end destination unless that is your choice.

Despite the physical fatigue (which is huge) and the demands that working place on my mind and body, I love being back at work – it is a great diversion from what we must do every day as people living with chronic health conditions. Working as an HPNer has also provided opportunity to increase knowledge and awareness among the populations I encounter – my colleagues, who have enquired, have been educated about a treatment program that is completely novel to them (my Local Health District does not manage an HPN program); patients who have asked why I carry a backpack have been given the short version of the story, with encouragement to ask more if they are interested; and even a clerical staff member who thought I must ‘carry my office’ with me in my backpack (due to my nomadic work area) has been gently educated without trying to increase her embarrassment, haha.

Being part of the workforce is possible if that is what you want, but like everything worthwhile, it takes planning and determination – but hey we are HPNers – that is our daily life!

PNDU’s newest resource for members – Toilet Card

WORDS BY KAREN

Following feedback from members regarding the difficulties accessing toilets when out and about, we decided to do something about it. People living with Intestinal Failure can at any time need a toilet urgently and/or may need the space and privacy of an Accessible Toilet. So we combined the two needs into one PNDU Toilet Card.

As with our PNDU Restaurant Card for members, there is no legal obligation for any business or premises managers to acknowledge the PNDU Toilet Card. It is however an easy visual aid which may help when a quick explanation is needed, and may give members greater confidence to ask.

So thanks to our members for your ideas and thanks to Ryan for his wonderful graphics! We are delighted with this new resource and are now finalising it and organising printing.

PNDU’s Toilet Card is free to Aussie and Kiwi HPNers, carers and HPN clinicians (for passing on to their HPN patients). If you would like a Toilet Card, please [contact us](#) today.



Perth Get Together

WORDS BY JODIE

Our Perth social gathering took place outdoors in a balmy atmosphere of mid 20°C's at the beautiful modern house of Mike, Clare, Elsie and Bertie in Greenwood. There were seven HPNers, accompanied by family, to make a total of eighteen guests: Clare, Mike, Nana Lyn, Elsie and Bertie; Jodie, Ryan and short Daniel; Kelly, Daryl, Alexander and Anastacia; Sharyn and Steve; tall Daniel; Gillian and Ray, and Karen. Little Bertie didn't make it into our photos because he was having a nap.

Elsie was ecstatic to meet other girls, like her, with a 'wiggly woo'. Karen and Gillian wore their purple 'drip' shirts. I managed to chat to most of the guests, for a few minutes each at least. I actually don't think I stopped talking for the entire three hours (except, of course, to listen to others speaking)! It was lovely to welcome Kelly and her family into our fold. We even heard her daughter sing a beautiful rendition of 'Hallelujah', before leaving. Unfortunately, like all of us, Kelly came to be on HPN only after a horrendous journey beforehand.

It was such a joy for me to be able to finally share my boys (husband, Ryan and son, Daniel) with my PNDU family. Thank you to everyone who came and made the afternoon so wonderful. And a big thank you to everyone who helped to organise the event. I might have missed out on Brisbane this year but I'm so glad I didn't miss out on this PNDU catch up.



HPNers: Steve, Kelly, Gillian, Daniel, Elsie, Jodie, Karen (Bertie asleep)



Silly time: Back: Ray, Daryl, Kelly, tall Daniel, Alexander, Jodie, Mike, Steve Front: Karen, Gillian, Anastacia, Clare with Elsie, Sharyn, Ryan with short Daniel



PNDU's latest member survey results – “a pilot observational survey of CVAD experiences by Australasian HPN patients”

– presented at AVAS conference in Perth, May 2017

WORDS BY KAREN

Why?

In January this year PNDU conducted a short member survey of experiences with central venous access devices (CVADs) and line infections. The original premise for the survey was to see if, despite the published data (on patients generally or other patient groups) and what some members have been told by clinicians ie that implanted ports have less infectious complications than Hickman®/Broviac® lines, whether that actually was the case in the HPN population. We surmised it may not be true for HPNers because of the different way we use CVADs (ie mostly every night, at home, infusing PN, etc.)

The study

We had some challenges with our study (limitations of the free survey platform, small sample size, limited number of questions, and relying on members' memories) and as a result, we weren't actually able to conclude anything regarding CVAD type and infection. That said, it was still an excellent snapshot of CVAD use for HPN in Australia and New Zealand, and we were very grateful for Sharyn's expert help with the analysis and Gil's with the abstract (and to Sharyn and Rachel for assisting early on with the survey design). As a result, Gillian and I were invited to present the results at the 2nd annual Australian Vascular Access Society's (AVAS) conference in Perth in May (see article below).

The presentation

Firstly Gillian spoke of her own CVAD experiences for Home Parenteral Nutrition and how in her own experience, a Hickman® works well and has had less complications, including line infections, than an implanted port (despite being told the opposite by a doctor). I then presented the results of our survey (numbers/types of current CVADs/practices/ numbers of infections/etc), and then explained that while we weren't able to draw any conclusions from our study results (except that no-one using TauroLock™ had experienced a line infection), there were two other published studies (one American and one European) that showed exactly what we originally surmised – that for the HPN population Hickman®/Broviac® lines have less infection risk than implanted ports! (These two studies are cited in our analysis.)

Our conclusion

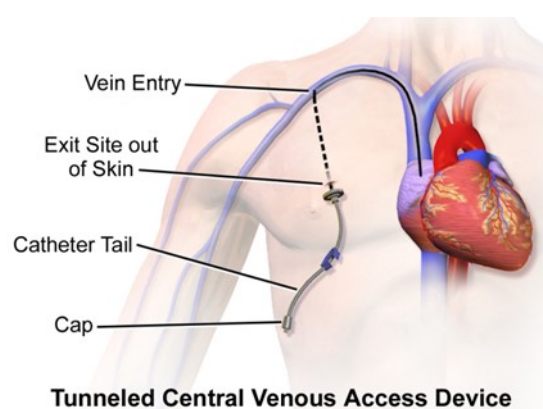
For those on HPN, our CVAD is literally our lifeline and in many instances needed for rest of our lives, so it's vitally important that decisions involving CVAD choice are made using relevant and best data, alongside patient preference. PNDU recommends further research into specific use of CVADs and contributors to infection risk for HPN, with results incorporated into future HPN guidelines and clinical practice.

The response

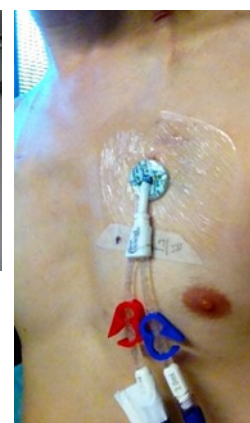
We were incredibly encouraged to find our survey efforts applauded by AVAS and many delegates, celebrating that a patient support group had a go at our own research of an issue that was relevant (and in this case, specific) to us. It was a wonderful opportunity to further raise awareness and understanding of HPN matters.

Please share

We encourage all our members to share the survey results (available on the [Documents page](#) of our website www.pndu.org) with their HPN teams. Besides it being an excellent snapshot of CVAD use for HPN 'down under', it is possible that some of our hospital teams aren't aware of the 2 published studies regarding CVAD and infection in the HPN population.



Above: Hickman® line
Right: implanted port



PNDU at AVAS conference in Perth, May 2017 – House of Cannulas!



WORDS BY KAREN

In the world of vascular access, the HPN community is very small, so it was really encouraging to once again have opportunity for HPN and PNDU to be seen at the 2nd annual Australian Vascular Access Society's (AVAS) conference at the Perth Conference & Exhibition Centre 10-12 May 2017, both through our exhibit and our presentation (see article above). We are really appreciative again of AVAS' welcome, inclusion and enthusiasm for the patient voice to be heard.

This 2nd conference was another great success for AVAS with many enthusiastic delegates. PNDU's presence as an exhibitor at the conference and especially our presentation were very well received. While not all vascular access clinicians attending the conference have HPN patients, this conference is important for PNDU for name recognition – one day they may have an HPN patient and will hopefully remember PNDU and recommend us to their patients. It's also a unique opportunity to fly the flag for the small number of HPNers in this part of the world and the specific vascular access challenges we face having long term central venous access devices.

There were 24 exhibitors besides PNDU showcasing all things vascular access, from PICCs to ports, skin cleaners to dressings, needles to cannula guiding devices. It was great to make contact with many of these exhibitors and while learning about their products, also explaining how PNDU fits into the vascular access picture.

There were also new and innovative products on display like the two below. PNDU does not endorse any specific products but we include these to show the innovative products available:



LimbO Waterproof Protection (for PICC lines). As the name suggests, this arm cover protects a PICC line when bathing or showering. There are different sizes available and the product is made in the United Kingdom. Interested consumers can contact the Australian distributor directly at www.healthsaver.com.au.



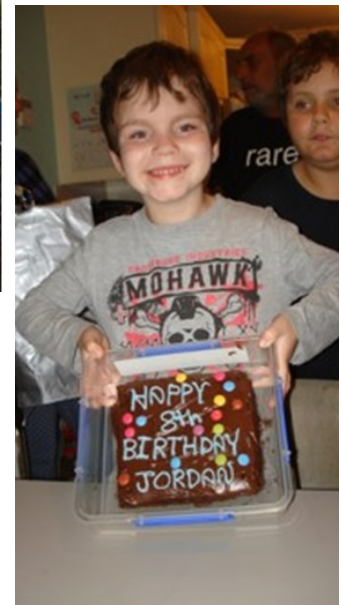
Cath Tag.

This Australian invention is an electronic alert system to remind hospital staff to review or remove medical devices such as peripheral IV cannulas, etc. The labels, with a battery-operated flashing alarm, work on whiteboards or in paper medical charts.

www.cathtag.com

Birthday Corner

Jordan celebrated his 8th birthday with family and friends at Blackbutt nature reserve. Jordan invited his 2 best friends from school, Pearl and Emma. Everyone enjoyed the picnic BBQ, with lots of fun and games. The piñata was a highlight for the children - the fire engine took a good beating before it gave up its treasure of treats. Jordan asked Aunty Katie to make a stingray cake for the party and a chocolate cake for the family at home.



PNDU's Annual Social Gathering – Brisbane

WORDS BY JACQUELINE (ONE OF OUR FOUNDING MEMBERS)

One of the reasons PNDU was created was to enable HPN consumers and their families to connect with others who have similar health and/or treatment issues, thus reducing the feeling of isolation in an otherwise difficult situation.

Each year PNDU offers 2 travel sponsorships for its members to apply for to help with the cost of attending the AuSPEN HPN Consumer Workshop and the annual PNDU social gathering held alongside it. After considering it for some time and deciding to apply, I was overwhelmed to discover I was one of the sponsorship recipients. That enabled my husband, David, and I to attend this year's Brisbane social gathering and AuSPEN's HPN Consumer

Workshop held in May. With much support from my new employer (who gave me time off work), our son and daughter-in-law who dog sat, my GP, who spent some time organising things and from the sedation and travel sickness tablets I gobbled down with gusto, we travelled well with no hiccups.

The social gatherings help facilitate a stronger bond between PNDU's members and offer an understanding that is unique between people in similar situations. As we all know, Home Parental Nutrition (HPN) is a rare treatment to feed persons who are unable to eat enough to sustain life and due to its rarity, the need to connect with others who understand our trials and tribulations is great.

The annual social gathering was held at the Roma St Parklands in Brisbane city on a warm (actually a stinking hot 24 degree) sunny Friday, and I must say they are the most beautiful and relaxing parks, offering a kiosk, easy walking paths, beautiful vistas, flowing waters and peace in an otherwise noisy and bustling city. The mix of people at our gathering included HPNers, carers and family. Whilst some were locals, others had travelled from interstate – Tasmania, NSW, ACT, Victoria and, of course, Queensland. There weren't any Kiwi members this time. Altogether, there were 12 of us – myself (HPNer) and husband David, Chris and Tanya (both carers to HPN grandsons), Kerri (former HPNer), Noel (HPNer) and Jill, Daniel (HPNer), Fay (HPNer) and Lindsay, Jerri (HPNer) and sister Nola. We all talked excitedly with each other and not just about health related issues but topics such as our social interests, jobs and holidays- oh yes and Daniel's train rides. David and I are also train buffs but there are no passenger trains down on the island (ie Tasmania) so we are very envious to hear of his train trips. Some of us had met previously and so rekindling old friendships was a great success, while others who are new to HPN and PNDU were eager to talk about their journeys, families and their hopes for the future. We even discussed at length the concept of street parking, downloading apps and paying by credit card.something David and I are not familiar with. Time seemed to go quickly and after a few hours, several photo shoots (not by David and me, we always forget that bit), lots of laughter and support, and the sad farewell hugs and handshakes, we all went our separate ways home.

We had walked to the city and then on to the Parklands from our hotel and had taken our time sight- seeing along the way and sampling 'Mainland coffee', which by the way is pretty good! We found it all a bit exhausting, so to bed quite early ready for the next day which offered the AuSPEN HPN Consumer Workshop.

This again was held in the city but at 'Mantra on Brisbane'. Just a hint if you are up in Brisbane...there are 7 Mantras in the city of Brisbane! Luckily, with the aid of our trusty map, (for some of you that's a piece of paper with lines and words on it ☺) we managed to find the correct one.

It was a very informative time, details of which are in the following article by fellow member, Fay.

The workshop ended at 1630 and as we had to drive to the Sunshine Coast, we didn't have much time to stop and talk with other participants which was disappointing, but couldn't be helped. We said our goodbyes armed with lots of information, inspiration and new friendships. We stayed on the Sunshine Coast until Wednesday and visited two sets of old friends while there. One of our friends has been an HPNer since 1980's and has been a true inspiration to me. She is an amazing person but due to now being blind, is unable to use the computer to join our forum.

I honestly think this trip will be the highlight of 2017 for us. We're very grateful for the PNDU travel sponsorship and to PNDU and AuSPEN for organising these events.



HPNers (L to R)
Jaqueline, Fay, Kerri, Jerri, Daniel, Noel



AuSPEN HPN Consumer Workshop, 2017

WORDS BY FAY

Editor's Note: The 2017 AuSPEN HPN consumer workshop in Brisbane in May was the 3rd such event. The event is provided free-of-charge for consumers and carers and provides opportunity to learn more about Intestinal Failure (IF) and HPN from experts working in the field. We are unaware of any other PN clinical society worldwide which holds these workshops for HPN consumers and carers.

I was fortunate enough to attend the annual social gathering of PNDU members and carers in Brisbane as well as the AuSPEN HPN consumer workshop held on 12th and 13th May, both free events for us as HPN consumers and carers. The social gathering was great: as always it was good to speak with other like minded people and share experiences. I think everyone attending enjoyed the day. The weather was lovely and the venue was in the gardens at Roma Street parklands, very pleasant. For more details, read the article above 'PNDU's Annual Social Gathering – Brisbane', by Jacqueline.

The workshop the following afternoon was attended by 18 consumers and carers from Queensland, NSW, ACT, Victoria and Tasmania. It was opened with a welcome from the Chair for the day, Sue Larsen, nurse specialist at North Shore Hospital, Auckland and AuSPEN Council representative. Sue introduced Ibolya Nyulasi, who is a dietitian at the Alfred hospital in Melbourne and AuSPEN President. Ibolya gave us information on who AuSPEN is and its role for enteral and parenteral nutrition in Australia and New Zealand, and also explained what the new Intestinal Failure Committee is doing and aims to achieve. Ibolya was followed by Alison Culkin who is a dietitian from St Marks Hospital in London and she spoke about getting the most out of your gut. Essentially what the different foods do and what type of diet is best suited particularly to those with Short Bowel Syndrome (SBS) and Intestinal Failure (IF).

Mary Dillon from Baxter Healthcare was next on the speaker list and she spoke about Baxter's role for those of us on HPN in Australia and New Zealand, and the results of the recent survey organised by Baxter. That was quite interesting, especially for those of us who had contributed to the survey.

Dr Simon Gabe, gastroenterologist also from St Marks Hospital spoke about the experience St Marks has in HPN. As a centre for gastroenterology and IF, they currently have, I think, around 335 patients on HPN with many and varied types of causes of IF, but mostly as a result of SBS. He explained the differences between some of the different types of IF and the treatments for them. Dr Gabe's topic for the workshop was 'Managing Intermittent IF (motility issues)' and for me he was the most interesting speaker. It was fascinating to hear more about motility problems, and I would have loved to have a little one on one time with him, but he had commitments at the concurrent workshop being held for health professionals.

After a little break for afternoon tea, Sue Larsen conducted an interactive session on what HPN in 2027 might look like. Lots of ideas were shared by those attending on what we think could be improved in HPN in the next year, 2 years and 10 years. A worthwhile opportunity for us as consumers and carers to brainstorm and give ideas.

Next to speak was Mia Small, Nurse Consultant in Nutrition & Intestinal Failure at St Marks Hospital in London who came with a bag full of Hickman® central lines. She explained the uses for each different type and passed them around the table. I had no idea there were so many different types of lines.

Our PNDU president, Karen spoke about all that PNDU does and what its aims are. This was followed by consumer, Alan Anderson who gave us a run down of his problems with gastric banding surgery gone wrong, which led to him being put on HPN for a year. A wonderfully positive account of what was obviously a very difficult time for Alan and his family.

The workshop was then closed by Sue. All in all it was a very valuable and informative afternoon. Thank you to AuSPEN for organising the event and providing us with the opportunity to increase our understanding.

Dr Stanley J Dudrick: Pioneering Researcher in Parenteral Nutrition for over 50 years

WORDS BY PROF GIL HARDY

Professor Gil Hardy of PNDU and the chairman of the ASPEN (American Society for Parenteral and Enteral Nutrition) International Clinical Nutrition Section (ICNS) was a speaker at the recent 19th congress of the Polish Society of Parenteral and Enteral Nutrition and Metabolism (POLSPEN) and was honoured to spend time with the great Dr Stanley J Dudrick MD, 'Godfather' of Parenteral Nutrition (PN). The conference, attended by several hundred delegates from all over Poland was held at the charming lakeside resort of Jachrance, outside of Warsaw and was organised by Dr Stanislaw Klek and his colleague Dr Kinga Szczepanek.

Dr Dudrick's pioneering work in the 1960's demonstrated that beagle puppies fed intravenously could thrive and grow at the same rate as control animals receiving normal dog chow. Subsequently Dr Dudrick and the team at Penn State University Hospital in USA, successfully employed PN for hospitalised premature babies and children with short bowel syndrome, leading to their classical and much cited paper in the Journal of the American Medical Association in 1968.

Encouraging early ambulation during PN eventually led to one of the first Home PN programmes in the USA for intestinal failure (IF) patients that established protocols and procedures, since emulated throughout the world. Dr Dudrick is a Fellow of the American College of Surgeons, a Nobel Prize nominee, designated one of the 50 most influential physicians in history, was the first President of ASPEN



and has received over 100 honours and awards, including the first ASPEN Lifetime Achievement Award in 2017.



Dr Klek [far right] and Dr Szczepanek [3rd left] are respectively, chief surgeon and anaesthetist, at a major IF/HPN centre, with over 130 HPN patients, in Skawina, near Crakow Poland. After the POLSPEN congress, Dr Dudrick, still active at 82 years old, accompanied by his wife Teresa, their old friend Gil Hardy from New Zealand and other international colleagues from Australia, Brazil, Mexico and the Philippines, visited the hospital, which was officially named **The Stanley J Dudrick Memorial Hospital** in 2012.

Also presenting at POLSPEN, was Marek Lichota, President of **Apetyt na Zycie**, the Polish sister organisation to PNDU [Marek pictured with his PN bag in backpack, with Gil and fellow Polish HPNER Sebastian]

Gil's POLSPEN presentation, entitled "HPN Troubleshooting: Back to the Future" paid tribute to the pioneering work of Dr Dudrick in USA and other HPN innovators from UK, Europe and Australasia. He covered development of HPN and the birth of PNDU in Australia and New Zealand then reviewed international data concerning catheter-related bloodstream infections, including (with permission) summary slides of PNDU's recent *Pilot Observational Survey of CVAD Experiences by Australasian HPN patients*. Other international speakers included, Ibolya Nyalusi, President of AuSPEN and Mia Small, Nurse Consultant in Nutrition and IF at St Mark's Hospital London.



Let me count the ways

Timing alcohol/chlorhexidine drying time

COMPILED BY GILLIAN

Editor's Comment: One of the recent topics on our private email group was about waiting for sterile alcohol or chlorhexidine, which we all seem to use at some point when setting up, to dry, as it needs to be dry to be effective. (see the following article 'Importance of Chlorhexidine drying') The discussion began with this post: "I'd like to know how others count during their set-up/disconnect procedure? You know – how do you count to 15 seconds/30 seconds etc?" **These were some of the ideas to count the seconds/minutes and pass the time while waiting for the alcohol/chlorhexidine to dry. NB people have quoted different times. Discuss times with your hospital team if you are unsure.**

- I've been doing it a couple of different ways for years – 1 Mississippi, 2 Mississippi, 3 Mississippi ... as well as 'Row row row your boat gently down the stream ...' (x 2), depending on what I'm doing. BUT, I've recently decided that I can rattle through 'Row row row your boat' so fast, it's probably 10 seconds rather than 15. So I'm now doing everything with a 1 Mississippi, 2 Mississippi, 3 Mississippi...
- I am a " and a one and a two and a three....." ☺... If I do lose count, with my OCD and no immune system, I get clean swabs and begin again rather than risk any infections!
- We have a clock up on our wall so we have something concrete to look at. I was finding without it, I would be going quicker than the 30 seconds.

- We have a \$7 Kmart clock up in XX's room so watch the seconds on that.
- I don't sing or look at a clock. I just do the handwash as taught and know the approximate time it takes for the chlorhexidine to dry. My husband and I often get chatting about our day and the time passes quite quickly while we wait.
- I can't remember if I was taught to count or not, but I don't know. I clean my hub thoroughly first, then hold it up while I do the rest of my setup (drawing up saline etc) and figure that's probably long enough. Occasionally it touches something or I drop it and have to start again, but that's rare these days.
- A tip I was given was to dab some point on my skin with the swab after cleaning the hub or whatever (inside of the arm is good as it is sensitive). Then you can feel when it is dry.
- I just wait for it to dry, but I thought of these ideas:
- you could always try a different song for variety, such as 'kookaburra sits in the old gum tree' a few times, or 'Give me a home among the gum trees',
- or play a CD and wait for a song to finish,
- or recite a poem
- or read something on an e-book – 'turning the pages' by elbow.
- Audiobooks. Or podcasts. I always have one going when I do PN, or change my stoma. Just be wary of ones that are too funny, it can lead to issues.

The Importance of Chlorhexidine Drying – The microbicidal chemistry of alcohol

BY KINN CHAN

The air drying is essential to effective microbicidal activity. When alcohol contacts with a microbe, it is getting into the "shell" of the bacteria, or intercalating between bonds of the virion's proteins. When it dries, the oxygen-hydrogen portion of the alcohol binds with hydrogen in the air to form water; the bigger water molecule explodes the cell/virus particle, then rapidly goes back to separate hydrogen and oxygen molecules, further ripping apart the bacteria/virion it has bathed. The speed that OH comes off is what they call 'volatility'. So ethanol is more volatile than isopropyl alcohol (dries faster), and more expensive.

Because ethanol is so volatile, even in solution (as a line lock), the OH is seeking another H to bond to, so in the line it will form water molecules and is able to burst cells.

Some bacteria (like mycobacteria, found in dirt or as TB) can actually live in alcohol even if that alcohol dries, because they protect themselves inside a very tough/thick coat called a spore (some fungi are also spore-formers). Spore contamination doesn't really react to alcohol no matter how long it dries however, most of the Staph bugs that threaten our children tend not to be spore-forming bacteria, so this remains relatively effective for our needs.

Funny Ward Stories

Editor's Note: These are from a selection of posts on PNDU's private email group.

- On my last very recent stay, I was on a ward which insisted that "quiet" was beneficial to healing. I was in a 4-bed bay. It was the most pleasant (AND QUIET) bay I have ever shared! TV sets were kept on low volume; visitors didn't "share" their visit with all of us. If I have to go back, please may it be another "Quiet Ward!" (Bear in mind that I have shared with some "behaviour challenged" people. Some, I needed to seek out a clean bathroom elsewhere on the ward. Do you know how many people do not wash their hands after using the loo? Yuk! I have had "the constant screamer". I shared with 3 dementia ladies. And I have shared with some lovely people too. However, the "Quiet Ward" was peaceful. I like peaceful!!!)
- Oh! A quiet ward sounds like heaven! I was in over the end of last week and the weekend in a 4 bed room and it certainly wasn't quiet. I agree on the fact that a lot of people don't wash their hands, which disturbs me, but it's even worse when it's people from other rooms who wander the halls and use the first bathroom they find empty. (I was on a rheumatology and orthopaedic ward, which meant a lot of people having knee and hip replacements and morphine, and then being given laxatives to counteract the morphine. I thought the toilets on gastro wards got a workout but sheesh!)
- I had a guy in the bed opposite me who was the 'helpful' type. As in, one who is overly friendly and talkative, and jumping out of bed to open the bathroom door for other people on his brand new hip, but just not because he

ACTUALLY wanted to help. He just wanted everyone to compliment him on what a nice guy he was. Instead of going back to bed while I was in the toilet he would stand out in the hall telling passers by how he was 'helping', which was super weird because a) I clearly didn't need the help, I was quite capable of opening the door and b) it felt like he was monitoring my time in there. And then he forcefully butted himself into conversations with me and my visitors to the extent that we had to leave the room to talk without him. I cannot over emphasize how annoying this guy was. He probably thought I was very rude because by the end, I left my curtain shut all the time and refused to make eye contact whenever I ventured out, but there are limits to my politeness.

- My last admission was in a three bed room the size of a postage stamp. Both of my roommates had MASSIVE families and were there visiting at all hours of the day (and all took it in turns using the communal bathroom) and then one of them had her husband stay ALL NIGHT. They were very quiet most of the time, but they got up around 5 am to pray and then didn't go back to sleep afterwards, so their lights and TV were going from then on. I take earplugs and a sleeping mask, but there's only so much they can filter out!
- Over the years there have been the ones who spit on the floor, are under police guard, who decide that yelling at the nurse is more efficient than the call bell. And the poop on the floor! So much! So many times! I don't judge those people because I know we're on a gastro ward, things aren't going well and usually the person responsible is as horrified as me, but believe me I never put bare feet on the floor in hospital and I never put my shoes or slippers on the bed!
- I have had some doozies! One woman was so bad-so unbelievably badly behaved - that I honestly and truly believed that she was waiting for a bed to become available in the psych unit. My resident came in and she was out smoking. I said that I knew from my daughter's work how difficult it was to get a bed in the mental health unit but really, I would have thought there would have been one for an in-patient sooner. He cracked up and went on to tell me that she was not waiting for such a bed and behaved this way all the time!!! He thought it was hilarious! Sharing with her was not! That bay was like a revolving door. Everyone who went in begged for a room change-I know I did!
- And then there are the "come any time" visitors, because visiting hours don't apply to them. The "hoard visitors" who come in groups bigger than 12 and practically sit on your bed with you; the "screaming/yelling/whinging children" visitors - who like to stay all day, eat your jelly and watch your TV! If given any encouragement at all they will never leave you alone for that visit or any other. Then there is the "deaf patient" who doesn't "have your young ears love" and has the radio, TV and mobile ring tone blaring at full volume. Usually these patients talk loudly because of their deafness. They never, ever use headphones and don't think you are going to miss out on any details of the intimate working condition of their innards!!!!
- My most hilarious admission was sharing with three dementia ladies. There were some memorable moments. We had the most gorgeous and wonderful nurse with a delightful accent-I don't know what part of the UK she hailed from. One lady was quiet and just wanted to hold her teddy bear. One lady was a big boned lady who was deaf and found it necessary to shout every word she spoke. The third lady reverted to her native language of French. She was in her 90s and was so tiny - about 4 feet in the old measurement. She was so "naughty?" And boy could she run. The whole time I was in hospital (a long admission) I would hear this gorgeous accent calling out: come back my little cherub! Come back! I woke up one morning to find her directly in my line of sight, stark naked! During the night, instead of going to the loo, she would pee on the teddy bear! So most mornings this lovely RN would shower the bear, blow dry him and wrap him in a towel so his owner wouldn't be upset without him! Oh! I have some hilarious stories about that admission including this little lady guarding the doorway. She thought all the nurses were "Ladies of the Night" and she wasn't letting any of them into our house or on her corner!!!!
- Having had a grandmother with dementia, I am sympathetic to those dementia sufferers who are in my room or down the hall; I make myself cope with the confused calling out all night because I think to myself that it could be me one day. BUT sharing a room with a relatively young, and therefore active, dementia sufferer was a real problem, because she kept climbing out of bed (over the raised rails) when she was supposed to remain in bed unless accompanied by a nurse so that she didn't fall, so several times a day I had to go and get a nurse, as ringing the buzzer would have taken too long for response. Luckily I wasn't in pain or really ill myself at that point.

PNDU gets the Tick

WORDS BY MIRANDA

You will soon start to notice this symbol appear on PNDU's printed and digital media. The symbol is known as the Registered Charity Tick, and is an endorsement of compliance with the Australian Charities and Non-Profit Commission (ACNC). We are proud to display the Registered Charity Tick as assurance to our members and the public that PNDU is a transparent and accountable charitable organisation which is listed on ACNC Charity Register. Ongoing compliance with the ACNC regulations is the result of the hard work of many of our volunteer members in official and unofficial positions who undertake lots of different tasks, big and small to ensure that PNDU stays true to its mission and conducts its business with integrity....thank you to everyone for your hard work and to our members and supporters for making PNDU a great organisation to be involved in!



The Australian NDIS (National Disability Insurance Scheme) and the HPNer

COMPILED BY GILLIAN

Editor's note: As HPNers and carers, we are very grateful that in Australia and New Zealand our HPN is provided free of charge for most members (some Australian members still have difficulties accessing all the needed ancillary items without cost). However, the advent of the NDIS as it rolls out across Australia has had an adverse effect on some of our members, with previously accessible benefits, to assist with day to day living, no longer available to them. This is due to the fact that the NDIS is purely meant for non-medical disabilities, while IF (Intestinal Failure) and its cause in individual cases, is a medical condition. When those medical issues cause a physical inability requiring assistance, some members are finding that as soon as the word 'medical' is used, access to the NDIS services is denied. While we understand there are others encountering difficulties accessing services through the Scheme in these early days, it would seem that those with a primary medical condition, who also have social/work/capacity for self care impacts, are living in the twilight zone. Applications to the NDIS have to be worded very carefully (but honestly, of course) and even then it is extremely difficult to get the help some members need. Hiccups are bound to occur during any new program roll-out, especially one of such magnitude. However the negative impact and stress on some members during this time is difficult to say the least. Some of these comments on PNDU's private email group may be of interest and hopefully, of help.

NB PNDU and its members are not experts in this area and these comments are based on individual's experiences. The comments are not to be considered as professional advice.

- I've been chasing my current providers ... I spent a lot of time on the phone yesterday. Everyone I speak to agrees that people receiving any kind of support before the NDIS should continue to receive it after, whether they're accepted to the new scheme or not. But who now provides that support is a bone of contention. NDIS obviously say it's not them (even though they contacted me and told me to apply, because based on the services I've been receiving I should be eligible). The city where I live, which currently provides my Homecare, say their funding has been slashed and diverted to the NDIS, so they can't help anyone under the age of 65 anymore. They suggested I complain to the Department of Human Services, but a long discussion with a nice man there came to the conclusion that it's nothing to do with them, and it's up to [my city] to continue providing for me as they have been. Have been in so many circles with this I'm getting dizzy. An hour of Homecare a week probably doesn't sound like a big deal to people, but it makes a huge difference in my life and the thought of it being cut off is causing me a lot of sleeplessness.
- With all applications for the NDIS, it is not whether you have a disability or medical condition, it is about how your condition affects or impacts on your daily life and your ability to integrate within society as opposed to a healthy individual. I suggest not using the term medical or health condition, in favour of underlying condition. Set goals, "I would like to attend the movies, dine out at night with friends, go shopping, clean my house", etc. It all has to be spelt out for the NDIS.

Obtaining medical reports from your multidisciplinary team is very complicated and time consuming, but try to obtain as many as you can. During your appointments, spell out the need for the wording in the reports to reflect the impact your underlying condition has on your everyday life. Engaging an OT (Occupational Therapist) is also a good idea.

List any aids, house modifications and government rebates you may have, although there is a chance that if these aren't documented, you will have to wait 12 months to have them included when your pathway is reviewed.

The application process is more complicated than it should be, so if you can obtain help from your social worker or a team member such as an OT, all the better. Become familiar with the NDIS website and find the successful appeals that are already posted on this site; chances are someone has already appealed a decision that you have been rejected for and your NDIS planner isn't aware a successful appeal has already been made.

- We never go to an NDIS meeting without our case manager and at least one of our health workers, usually the OT.

You can also ask to have the NDIS planning team come to you - having them in your home is much more comfortable for you and you can easily show and explain the impacts on your daily life, especially if you are still infusing at the time of the visit.

- Another source of very good support can be your local MP. Make yourself known to them; it may take a while for them to understand your condition, but the time spent is very worthwhile.
- It really helps with the process [applying to the NDIS] to have an OT (Occupational Therapist) spell out clearly the affect your condition has on your ability to do everyday tasks, compared to a healthy person, such as self care, housekeeping, engaging in social activities, etc. Include in your goals the things you really want to be able to do, such as travel, go shopping, engage in community activities with other people by going to clubs, movies etc.

- My initial application was rejected; they said they could see I have a medical condition but not that it impacts on my capacity in any meaningful way. I didn't know whether to laugh or cry (I went with cry). I was quite shocked to be honest, because everyone had assured me I was a shoe-in and I thought my application was strong. Apparently there's an issue with medical conditions; if they see that they say no automatically, even if there's just reason for support. I'm in the process of appealing the decision, but it's a lot of stress and paperwork and chasing doctors etc. It also means that I may lose the support I currently get, which isn't supposed to happen, but will. It's all pretty disheartening.

PNDU Awards 2017 – nominations are now open

WORDS BY KAREN

It's that time of year again when we ask our members to nominate people in their/their loved one's HPN world who deserve thanks, recognition and congratulations for their great work. And it's great to see the nominations are coming in.

Nominations close on Thursday 3rd August, and **the winners will be announced at PNDU's Annual General Meeting on Thursday 17th August 2017.**

There are 2 types of awards:

1. **Lifetime Membership Award** is a special award for any member who, as an HPN consumer, parent or carer, has given their time "over and above" for PNDU.
2. **PNDU Professional Awards** recognise positive efforts by health professionals and industry to provide high quality service to HPN consumers (a favourite HPN clinician and/or a helpful soul at the HPN homecare company). There are 3 categories members can nominate for:
 - a. Adult Parenteral Nutrition Professional of the Year
 - b. Paediatric Parenteral Nutrition Professional of the Year
 - c. Commitment to Care – Company Employee of the Year



The nomination forms have this year been simplified and are now online! If you are a PNDU member, please [contact us](#) today for the nomination form links. The form links are also accessible [on our website](#). For the HPN Professional Awards categories, members can even nominate winners and nominees from previous years.

Members: don't miss out on this chance to recognise great work in HPN 'down under'.

Save the date & start planning: HPN Awareness week – 15-21 October 2017

WORDS BY KAREN

To coincide with the new World Home Artificial Nutrition Awareness Day (Home Parenteral Nutrition & Home Enteral Nutrition) on 15th October, we will now be celebrating HPN Awareness Week annually in October. **So how can you celebrate and be part of the HPN Awareness Week?**

Resources: PNDU will again be providing various resources for our members and HPN hospitals to use, including a short video clip, social media profile, pro-forma email for sharing, pro-forma newspaper article, posters, stickers...

HPN Hospitals: we are asking HPN hospitals to organise a morning tea during Awareness Week for staff on the gastro ward (or pharmacy department, or whichever ward mostly deals with PN) and for an HPNer or carer to be invited to come and speak to the staff about what it's like living with HPN – a bit of 'show & tell'. HPN hospitals may also like to organise a gathering for all their HPNers and families during that week.

And, we are asking our HPNer and carer members, to propose this idea to your own HPN team and offer yourselves to come and speak!

PN Pharmacy Tours: Following last year's success, both Baxter Healthcare and Biomed (in NZ) will be partnering with PNDU to host pharmacy department tours during Awareness Week. Anyone who went last year (or previously) knows how



fascinating these tours are, and we are very grateful to both Baxter and Biomed for their willingness to support HPN Awareness Week in this way.

For those in New Zealand receiving PN from **Biomed**, to book in a pharmacy tour anytime during Awareness Week, please ring Jessica Gordon on 027 688 9921.

For those in Australia or New Zealand receiving PN from **Baxter**, Baxter has kindly provided the following dates for tours, is also opening the tours to PN clinicians, and is giving the opportunity for an HPNer or carer to talk for 15 minutes to the staff about their HPN journey. There is ample time to make arrangements so you can attend! Please RSVP to book your place by [emailing PNDU](#) with names of attendees and which pharmacy location.



PN Pharmacy Tour 2016 (Photo courtesy of Baxter Healthcare)

Baxter pharmacy tour dates		
State	Address	Date
VIC	9-29 Syme St, BRUNSWICK, VIC	Friday 20th October 11.00am – 12.45pm
NSW	1 Baxter Dr, OLD TOONGABBIE, NSW	Friday 20th October 11.00am – 12.45pm
SA	Tennyson Centre 520 South Rd, KURRALTA PARK SA	Friday 20th October 10.45am – 12.45pm
WA	46 Vinnicombe Dr, CANNING VALE WA	Tuesday 17th October 10.45am – 12.30pm
QLD	Unit 2/1115 Stanley St, COORPAROO QLD	Friday 20th October 10.45am – 12.30pm
NZ	33 Vestey Dr, MT WELLINGTON, AUCKLAND	Wednesday 18th October 11.15am – 12.15pm
NZ	98 Treffers Rd, WIGRAM, CHRISTCHURCH	Friday 20th October 10.15am –

Let's make 2017 the best HPN Awareness Week yet! And look out for more ideas and resources to come.

HPNers' War on Waste

Editor's Note: The recent ABC TV series in Australia '[War on Waste](#)' prompted some of our members to share on PNDU's private email group how they minimise the waste from dressing packs, delivery boxes, etc.

- We donate the tweezers from the dressing packs (since we don't use them at all) to schools, daycares and the like. They love them for fine motor development and experiments.
- I reckon you could make a good sculpture out of syringes.
- I think what can be recycled varies from council to council. But I'm not sure, unless they have the number on them to say what type of plastic it is, how to tell what is recyclable? It used to be 1,2,3 and 5 here. Now I think it is 1-7.
- I usually go through stages of trying to be diligent, then I find out that something I thought was recyclable is actually not. For instance the coffee cups, or foil lined cartons (like long life milk cartons).
- As for the blue dressing pack sheet, I don't know, but I would think it's not recyclable (and potentially a problem for machines). I use my sheet for tying up the leftovers including a swab squirted with blood draw-back, so mine goes in the bin. A member's friend uses them for her stoma bag change, and then I assume for tying up the rubbish for disposal. Better than using a nappy bag for disposal.

- I recycle my blue sheets from my dressing packs. Give the clean ones to my Aunty, who requests them for her aroma cleaning.
- I have just found a new outlet to dispose of my blue plastic dressing tray covers....a friend who has a second hand shop locally uses them to wrap china extra.....boy am I pleased. She also takes bubble wrap and boxes.
- The law is different down on the island (Tasmania) as plastic shopping bags were banished several years ago and you pay for some sort of environmentally friendlier bag or bring your own. But now I work in a hospital theatre and I'm amazed and very disappointed at the waste. Blue tea towels, kidney dishes, large drapes, single use tourniquets and large plastic bowls....all clean and thrown away. So I collect the lot and redistribute them.
- My calligraphy group take the pill containers, syringes and paper towels. My artisan group takes trays, tweezers and ampoule tops (the miniatures group use them). My bookbinding group takes glove wrappers, plastic bag covers and trays. My gardening group takes gloves, and empty Hartmann's bags and giving sets (they are refilled with water and drip irrigate pot plants). My felting group takes plastic aprons and cotton balls. My fabric art group take the tourniquets for the elastic and the fight is on for the tea towels and bowls.
- The ice packs are the biggest waste. Like everyone, I get at least 6 weekly. At work we get 30+ can you believe that? I take them to the tip shop, but even they are getting picky. I'm so thrilled when I drop stuff off and there's a new person receiving, as I know they will accept them.
- The plastic protective covers are good as rubbish bags and the clear PN bags are grabbed, too, as my bookbinding glue doesn't stick to them.
- I use the dressing towels for painting, the blue tray for paint, the cotton balls to a manicurist and to my Minister's wife for craft, all boxes to a local second hand shop for posting sold articles, bubble wrap to same shop, can't think of anything else!!!
- Since watching the War on Waste and our recent discussion on what's recyclable, I have gone from about 5 large bags of rubbish in our bin to 1-2. I take all the soft plastic to our Coles and recycle all the paper from our medical waste. I have cotton gauze not cotton wool balls in our dressing pack and we use everything except one of the tweezers. We use the used sterile towels from drying our hands, as cloths in the garage for cleaning oily hands or just wiping things and dusting things etc. My husband uses the gloves as well for getting dirty work done on the bus and cars. He has even been known to use the IV line as a belt, when we were away on the bus once. IV line makes good tubing for syphoning things too and he recently one of my Clexane syringes and filled it with rust converter to get into a tiny rust patch on our daughter's car. So you are only limited by your imagination!
- My husband uses the syringes to put rust converter into our coaster bus too.
- My nurse has been showing me a whole lot of new products they are rolling out to reduce waste and infection risk. Instead of dressing packs, we will now be getting sterile sheets... just a flat piece of plastic with a piece of gauze folded into it. So much less waste, and far less bulky (no more filling half a suitcase just with dressing packs when I go away!). Then instead of using the bottles of chlorhexidine to clean my port site before needling, I'll now be getting pre-impregnated swabs, that look similar to a big cotton bud. So I won't need the tray or cotton balls that come in the dressing packs either. Finally, we're getting the pre-filled saline syringes. It's certainly going to leave me with a lot more cupboard space, which is exciting.
- I give my bubble wrap to a friend who uses it to keep the chocolates that he sells over the internet cool during postage. 'My' bubble wrap has been to many parts of Australia, but also to Hong Kong, Singapore, USA, Netherlands and New Zealand. I don't know what happens to it then, of course, but at least it's been used again once more.



One member's son's sculpture

Notice of 2nd Annual General Meeting PNDU

PNDU will be holding its 2nd Annual General Meeting (AGM) on the Thursday 17th August, 2017, 11am Australian EST (1pm NZ; 10.30am Australian CST; 9am Australian WST).

Due to the geographic spread of our members, the AGM will be held online via Skype. The AGM agenda and dial-in details will be distributed to members in the next few weeks. We will require members to RSVP by 14th August to enable us to ensure that the meeting is adequately technically supported. This is a great opportunity to hear PNDU's year in review, as well as the announcement of our 2017 PNDU Awards winners (see article on page XX) and the launch of our new website (see article below). We hope you can make it!

To RSVP, please email us at contactpndu@gmail.com.

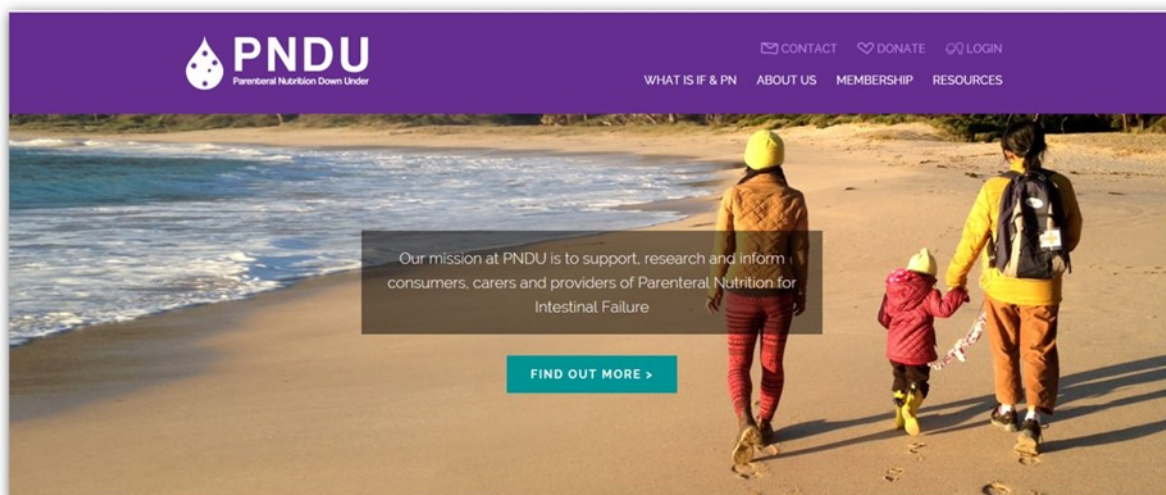
PNDU's new website is ready to be launched!

WORDS BY KAREN

We are thrilled with our new website, and are very excited to be ready to launch it at our Annual General Meeting on Thursday 17th August 2017. A great deal of hard work has gone into the new site, including bespoke icon graphics, and to incorporate membership to PNDU Inc. The latter will greatly reduce the current manual workload of our Members' Secretary, Miranda, when joining up new PNDU members.

We are incredibly grateful to [OrangeLine](#) for providing all this amazing work as a gift to PNDU. Thank you!

Below is a sneak peak of what the new website will look like. Come and visit www.pndu.org again when it's launched.



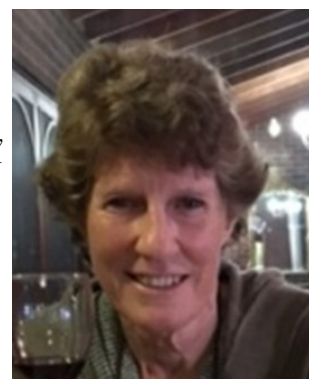
A day in the life of an HPNer – being vigilant with skin abrasions

WORDS BY GILLIAN

Now, I'll be upfront and say straight off that what you're about to read could happen to anyone at anytime; it's in no way related to being on HPN (Home Parenteral Nutrition). Having said that, though, for those of us who live with a central line for PN access, we have to be constantly alert to possible dangers of infection, because any infection can work its way to our line, causing a potentially life-threatening line sepsis. We need to be ever vigilant about wounds, and it is with this in mind that I have chosen to write about events that started only last week.

Last Saturday evening, I began to feel slightly achy all over and wondered if I was getting the flu, despite having had my flu vaccination about 6 weeks ago. I went to bed early, and felt the aches each time I rolled over in bed. By Sunday morning, all I wanted to do was to remain in bed. I barely had the energy to ring a friend to take over my role of leading the singing at church, rolled over and spent most of the day sleeping and dozing in bed. About 3pm I made myself get up and have a shower, and realised that the aches had gone. I still felt lethargic and just sat in my lounge chair reading. About 7:30pm, I touched my face and realised that my nose and cheeks were quite swollen. When I looked in a mirror, I was amazed to find that indeed, they were – my nose about twice or more the usual size, with a band of red skin across the puffy landscape. At this point I self-diagnosed 'allergic reaction!'... but to what? All I could think of was that I had been doing a lot of weeding and pruning during the past few days, so it seemed logical to me that something there had caused it.

By morning, my whole face was puffed up – eyes, nose and cheeks even more, and my top lip was a shelf above my lower lip. I didn't think of going to hospital as at no time was my breathing constricted. I was able to see my GP by noon, and the swelling and redness were still increasing, evidenced by the photos I was taking. As she couldn't diagnose the cause, she sent me hospital so that they could do blood tests and have results more quickly than she could.



Above: My usual face
Below: Monday morning



I emailed my hospital team and my HPN nurses requested that the ED nurses inform them of my arrival. Whilst waiting in ED, rigor set in and my temperature kept rising over the next several hours until it peaked at 40 degrees. Before being sent to a ward, I had a scan to check that my veins hadn't stenosed and that there wasn't a clot forming. Luckily, both these scans were negative and so it was decided that I had cellulitis, probably from a small cut on my nose that my HPN nurse noticed, which I hadn't even realised was there!

By night time, after admission, about 24 hours after I first felt the swelling, my eyes were almost swollen shut and my cheeks like chipmunks'. Luckily it didn't hurt, only when pressed. I have slightly confused memories of this time until Tuesday morning - I just wanted to be left alone and only had energy to respond to medical questions and requests.

I had another temperature spike of 39 degrees on the Tuesday afternoon, but luckily that was the last. Intravenous antibiotics had commenced at some point and on Wednesday morning it was decided to let me go home, retraining me in self-administering my antibiotics (my husband, Ray and I had been trained to do this several years ago). My nurse's main concern was that my eye-sight was compromised due to the swelling, so my perspective was out. It was hard to bring 2 things together to join up, so Ray was on hand to guide my hands together if necessary. For the first day or so this was invaluable assistance. I'm well on my way to recovery now, but a week later, I still have a 'shelf' under my right eye which is being extremely slow to heal.

My daughter's friend's mother has also had cellulitis in the face and, unfortunately, she has had it several times since.

My lesson is this: I will do whatever I can to prevent a return of this awful infection, so I will examine my exposed skin after gardening (or bush-walking, etc) for obvious nicks or grazes. I have always treated known cuts, but have never actively searched before. I will wash my arms and face and neck regardless. And since I have it on hand, I might even use a squirt of chlorhexidine hand lotion to wipe over as well!



At its worst- with leaking eye drops



A week later, almost back to normal

Scientists develop novel enzyme technology that prevents formation of biofilms

Source: News Medical Life Sciences (News-Medical.net); McGill University Health Centre (muhc.ca)

June 22, 2017

Have you ever heard of biofilms? They are slimy, glue-like membranes that are produced by microbes, like bacteria and fungi, in order to colonize surfaces. They can grow on animal and plant tissues, and even inside the human body on medical devices such as catheters, heart valves, or artificial hips. Biofilms protect microbes from the body's immune system and increase their resistance to antibiotics. They represent one of the biggest threats to patients in hospital settings. But there is good news - a research team led by the Research Institute of the McGill University Health Centre (RI-MUHC) and The Hospital for Sick Children (SickKids) has developed a novel enzyme technology that prevents the formation of biofilms and can also break them down.

This finding, recently published in *Proceedings of the National Academy of Sciences* (PNAS), creates a promising avenue for the development of innovative strategies to treat a wide variety of diseases and hospital-acquired infections like pneumonia, bloodstream and urinary tract infection. Biofilm-associated infections are responsible for thousands of deaths across North America every year. They are hard to eradicate because they secrete a matrix made of sugar molecules which form a kind of armour that acts as a physical and chemical barrier, preventing antibiotics from reaching their target sites within microbes.

"We were able to use the microbe's own tools against them to attack and destroy the sugar molecules that hold the biofilm together," says the study's co-principal investigator, Dr. Don Sheppard, director of the Division of Infectious Diseases at the MUHC and scientist from the Infectious Diseases and Immunity in Global Health Program at the RI-MUHC. "Rather than trying to develop new individual 'bullets' that target single microbes we are attacking the biofilm that protects those microbes by literally tearing down the walls to expose the microbes living behind them. It's a completely new and novel strategy to tackle this issue."

This work is the result of a four-year successful collaboration between Dr. Sheppard's team and scientists in the laboratory of Dr. P. Lynne Howell, senior scientist in the Molecular Medicine program at SickKids. They have been working to combat biofilms for several years, focusing on two of the most common organisms responsible for lung infections: a bacterium called *Pseudomonas aeruginosa* and a fungus called *Aspergillus fumigatus*. Infections with these organisms in patients with chronic lung diseases like cystic fibrosis represent an enormous challenge in medical therapy.

While studying machinery that these organisms use to make their biofilms, the scientists discovered enzymes that cut up the sugar molecules, which glue biofilms together. "Microbes use these enzymes to move sugar molecules around and cut them into pieces in order to build and remodel the biofilm matrix," says Dr. Sheppard, who is also a professor in the departments of Medicine and Microbiology and Immunology at McGill University. The researchers found a way to use these enzymes to degrade the sugar armour, exposing the microbe to antibiotics and host defences.

"We made these enzymes into a biofilm destroying machine that we can use outside the microbe where the sugar molecules are found," explains co-first study author Brendan Snarr, a Ph.D. student in Dr. Sheppard's laboratory. "These enzymes chew away all of the sugar molecules in their path and don't stop until the matrix is destroyed."

"Previous attempts to deal with biofilms have had only limited success, mostly in preventing biofilm formation. These enzymes are the first strategy that has ever been effective in eradicating mature biofilms, and that work in mouse models of infection," adds Dr. Sheppard.

"When we took the enzymes from bacteria and applied them to the fungi, we found that they worked in the same way on the fungi biofilm; which was surprising," says the study's co-principal investigator, Dr. P. Lynne Howell, who is also a professor in the Department of Biochemistry at the University of Toronto. "What's key is that this approach could be a universal way of being able to leverage the microbes' own systems for degrading biofilms. This has bigger implications across many microbes, diseases, and infections."

"Over 70 percent of hospital-acquired infections are actually associated with biofilms and we simply lack tools to treat them!" states Dr. Sheppard. According to both lead scientists, the potential of this novel therapy is enormous and they hope to commercialize it in the coming years.

Upcoming Events

3 rd August	Nominations close for 2017 PNDU Awards
14 th August	RSVP deadline for joining PNDU Annual General Meeting
17 th August	PNDU Annual General Meeting, including announcement of PNDU Awards 2017 winners and new website launch
15-21 st October	HPN Awareness Week
16-18 th November	AuSPEN Annual Scientific Meeting (for clinicians) on Gold Coast. PNDU will be exhibiting

Thank You

We wish to thank the following for their generous donation of \$75:

- T Vawser, VIC

PNDU Membership for Aussie and Kiwi HPNers and carers:

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

Benefits: Through membership you are invited to join one or both of our private forums: our Google Groups email forum is where conversation relevant to living 'down under' with HPN happens; and our closed Facebook group is more of a noticeboard where members can easily keep up-to-date with PNDU activities. You also have access to all pages of our website, and are on our mailing list to receive Dripline and notifications of other important occasions.

No computer? For those who prefer communication the 'good old-fashioned way' – by letter or card – PNDU offers correspondence with one of our members. If you are an Aussie or Kiwi HPNer or carer and are interested (or as a clinician, you have an HPN patient whom you think would benefit from letter/card correspondence), please contact us at contactpndu@gmail.com or PNDU, 128 Rainbow Street, Randwick NSW 2031, Australia to find out more.



For HPN clinicians, overseas HPNers, carers and those just interested:

We also welcome others to join PNDU as Associate Members, giving you access to all pages of our website as well as receiving Dripline and notifications of other important occasions. To join, please sign up on our website www.pndu.org

Donations

If you would like to support the work of PNDU, we would welcome your donation, no matter how big or small. All donations over \$2 made to PNDU in Australia are tax deductible!

Now that incorporation has been achieved(!), PNDU has its own account!

When making direct deposits, please provide your name as a reference. If you require an acknowledgement/receipt of your donation, please email us at contactpndu@gmail.com.



AUSTRALIA:

Direct deposit (Australian dollars only) to PNDU Inc.'s bank account:

Bank: Westpac
Account name: PNDU Inc.
BSB: 032056
A/c No: 482738

NEW ZEALAND:

For our Kiwi members, our sister charity IPANEMA (Charities Commission Registration CC21178) kindly continues to receive donations on our behalf:

Online donations: PayPal via our website www.pndu.org

Or **direct deposit** (New Zealand dollars only):

Bank: ANZ
Account name: IPANEMA
A/c No: 0602730308799-00
Payment Ref: IPANEMA "PNDU"

Management Committee members

President – Karen
Vice-President/Editor – Gillian
Secretary/Public Officer – Miranda
Treasurer – Chris
Assistant Treasurer – Gil

Contact us

Parenteral Nutrition Down Under Inc. ABN 49742201085

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

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

DISCLAIMER: PNDU 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 PNDU 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.

Designer: Sal

In Memoriam



PNDU remembers past HPNers

Over the years, PNDU has been reminded of the fragility of life, especially for those with Intestinal Failure. Sadly, PNDU has shared with family and friends in saying good-bye to these precious loved ones who have passed away, but who have also left wonderful memories of love, strength and courage.

Emma – 9 April 2017, aged 35 years

Lara – 16 February 2017, aged 7 years

Teresa – 15 February 2017 aged 58 years

Natalie – 18 September 2016, aged 27 years

Sam – 13 September 2016, aged 14 years

Carol – 2 September 2016, aged 67 years

Jessica – 24 January 2014, aged 20 years

Tynesha Rose – 29 October 2012, aged 5 years

Aria – 20 June 2011, aged 5 years

Pauline – 29 April 2011, aged 38 years

Hebe – 3 January 2008, aged 2½ years

May the cherished memories of these dear ones never fade.

