DRIPLINE
PNDU
Parenteral Nutrition Down Under

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Welcome to our 9th issue of Dripline!

Our 5th Anniversary year has seen much happening, with exciting events still to come. Please ensure you read about our new logo, our road to incorporation, our upcoming PNDU symposia in Auckland, NZ in November, and our next Sydney gathering.

There are also personal articles by, and about, some of our members; read about Jane's art; Gil's performance in Vicar of Dibley; and about 3yr old Ariel. Read about a typical Tuesday in my life; and Karen's trip to represent PNDU at an international conference in Switzerland.

Take the opportunity to nominate one of your PN hospital team for an inaugural PNDU award. Read about bioprinted organs; about 3M Tegaderm™; and the dangers lurking on elevator buttons. We also thank generous donors to PNDU and learn of a couple of interesting ways to collect money.

PNDU Management Committee would like to thank Miranda for her hard work and perseverance in overseeing a change of logo for PNDU, as well as, with Renee's assistance, doing the research and hard work involved in PNDU becoming incorporated.

Gillian - Editor

IN THIS ISSUE:

LOGO

MANAGEMENT COMMITTEE

You may have already spotted it during HPN Awareness Week in August, but to go with our newly incorporated status (see article below), the Management Committee is very excited to announce the launch of PNDU's brand new logo!

We have chosen to simplify the PNDU logo to make it more easily identifiable to the PN community that we support and also to help establish a clear identity as we expand the group's activities to working more closely with the professional healthcare sector and government.

Elements of our logo explained:
The Purple: warm but with impact, PNDU's approach wrapped in colour!
The Southern Cross: in keeping with our united front and presence in both Australia and New Zealand, the Southern Cross was a natural feature in our logo
The Drip: the drip is, of course, our reason for being.

To those who have grown up with the Pendoo, don't despair…….our beloved Pendoo will remain PNDU's mascot along with PNDU's animated ambassador, the formidable skateboarder, Down Under Dan.

Thank you to all those who contributed their ideas to the new logo; we hope you enjoy sharing it, as much as we have enjoyed creating it!

PNDU
Parenteral Nutrition Down Under

PNDU INCORPORATED

WORDS BY *MIRANDA*

As some of you may be aware, there has been a lot of discussion and work going on in the background over the past few months to develop the organisational structure of PNDU. Having celebrated our 5th birthday at the start of the year, and reflecting on the ways in which our group has grown since its foundation, the Management Committee felt it was an appropriate time for our group to operate under a more formal structure. ……PNDU is going to become an incorporated association!

PNDU Inc will now be a separate legal entity to its individual members. This new structure will ensure that there are strong governance controls in place to ensure that members can be confident that the activities of PNDU are the considered outcomes of a properly managed and representative body. Importantly it will also provide persons and organisations that deal with PNDU, confidence and trust in PNDU's accountability.

The incorporation of PNDU will not change the range or manner of our activities. The objectives and aims of the newly incorporated PNDU have been carefully reviewed and updated by the Management Committee to reflect our current activities, which encompass both our established support function, and our growing role working together with the healthcare sector and other organisations for the benefit of HPN consumers and carers living in New Zealand and Australia. In order to better serve those objectives, we will now have three tiers of membership: "ANZ members" being Australian and New Zealand HPN consumers and carers, past and present; "Associate Members" to include interested individuals and overseas HPNers and their carers; and also "Corporate Members" for corporate entities or associations in the health and medical sectors.

PNDU Inc. will remain a not-for-profit organisation, with any income or donations to the organisation put towards activities to achieve the goals for which it has been established. In the coming months, PNDU will be registering for deductible gift recipient status. This will allow donations to PNDU to be tax deductible in Australia and encourage potential sponsors and donors to support our activities.

The Management Committee is very excited about this development and look forward to growing the activities of PNDU. As PNDU Inc, we hope and anticipate that our activities will have more impact and reach to the communities with whom we want to engage, so as to secure recognition as the key support group for HPN consumers and their carers in Australia and New Zealand.

The PNDU Constitution will be available on our website shortly.

PNDU SYMPOSIA 2014: DEVONPORT AND SKYCITY AUCKLAND NZ

We are pleased to present PNDU's upcoming Symposia to be held in Auckland, New Zealand on November 24-25, 2014. We have put together a relevant and varied program of topics from Australian, New Zealand and international speakers, including updates on in-line filters, paediatric intestinal failure and pros and cons of swimming with catheters. Plus there will be many opportunities to meet and share information with other HPN consumers, carers, as well as PN healthcare professionals.

The draft Symposium program is below and on our website. It will be further updated as more details are confirmed.

Speakers:	Patrick Ball (PB)	Prof of Pharmacy Charles Darwin Uni	Darwin Aus
	Lyn Gillanders (LG)	Sr Dietitian ADHB	Auckland NZ
	Gil Hardy (GH)	Prof of Clin Nutition Massey Uni	Auckland NZ
	Fritz Schwenk (FS)	Prof of Paed Endocrinology Mayo Clinic	USA
	Karen W (KW)	Convenor PNDU	Sydney Aus
Contributor:	Kathy Gura (KG)	Sr Pharmacist	Boston Children's Hospital USA

Event Details:

Day 1: Monday 24th November, 2014
Venue: Rose Centre Belmont North Shore (Devonport, Auckland)

10.30 am	Welcome	
10.45 – 11.00 am	Results of PNDU survey of HPN set up procedures	KW/GH
Discussion		
11.15 – 11.45 am	Update on Filters for PN	PB
Discussion		
12.00 – 12.20 pm	To swim or not to swim	KG/GH
Discussion		
12.30 – 12.45 pm	International HPN consumer collaboration	KW
Discussion		
1 – 1.15 pm	Announcement and Presentation of PNDU awards	
1.15 – 5 pm	Social gathering and networking for HPNers, carers and families only	
5 – 5.30 pm	AGM for PNDU Management Committee and Members	
6.30 pm	Dinner at a venue in Devonport	

Day 2 Tuesday 25th November, 2014
Venue: Skycity Convention Centre, Canterbury Rm, Lvl 5 (CBD Auckland)

10.00 am Welcome		
10.05 – 10.35 am	Paediatric HPN and management of IFALD	FS
Discussion		
11.00 – 11.20 am	Quality of HPN Care and NIFS NZ	LG
Discussion		
11.30 am*	Symposium close	

**Please note that the AuSPEN Consumer Conference commences afterwards at 12.30pm on Day 2 (Tuesday 25th November) at the same Skycity venue.*

The symposia are free for HPN consumers and carers. For others, attendance at the morning sessions is NZD30 for one morning or NZD50 for both mornings.

To register and for more information, email us at contactpndu@gmail.com

EVERYONE LOVES A PNDU GATHERING. SO WHEN'S THE NEXT ONE?

We frequently receive requests from our members to organise social gatherings so that HPNers and their families can meet together for a natter with others who totally understand what life with HPN is like. As our membership is so spread out across our two countries, sadly, it's not possible to do this for everyone. We do however let our members know when one is happening, usually in Sydney, so that any others who can and want to travel, can join us.

Our next social gathering is again in Sydney and will be taking place on **Saturday morning, 15th November 2014, in Hornsby Heights, in Sydney's north**.

Followed by our Kiwi gathering in **Devonport on Auckland's North Shore on Monday afternoon, 24th November 2014**

If you are an HPNer or carer and would like to come along, please contact us at contactpndu@gmail.com for more details.

We're looking forward to meeting together and would love to welcome new members.

A FUNNY THING HAPPENED ON THE WAY TO SETTING UP…

WORDS BY *GILLIAN*

Sometimes our best laid plans are waylaid, no matter how careful we are. Here are a few amusing anecdotes shared on our private forum by our members. Have you had similar frustrations/interruptions? Let us know on our private email forum or Facebook page, or email us at contactpndu@gmail.com!

- Had just finished opening up the dressing pack and preparing it all when suddenly, a 'nerf' bullet lands in the middle of the open sterile dressing sheet! Start again! (Sal)
- For us, it was a cannon ball from a Lego castle set the other day. You have to laugh!! And start again! (Mel, mother of Emily)
- I nearly ended up with two grandson's noses in my sterile field last night … so I know how it is!!! (Jane)

PILOT SURVEY OF HOME PARENTERAL NUTRITION (HPN) SET UP AND CONNECTION PROCEDURES IN AUSTRALASIA ABSTRACT

KAREN W, *SHARYN INGARFIELD* AND *GIL HARDY* FOR PARENTERAL NUTRITION DOWN UNDER (PNDU)

The AuSPEN (2008) and ESPEN (2009) HPN guidelines recommend that the HPN patient be trained in management of HPN. Other guidelines make recommendations regarding the frequency of replacing catheters, dressings, administration sets, and fluids but a recent UK report suggests there is no specific guidance provided for other practical aspects of the parenteral nutrition (PN) set up procedure.

METHODS

To ascertain HPN set up procedures in Australasia, we conducted an online survey of the Parenteral Nutrition Down Under (PNDU) support group for HPN consumers/parents/carers between June and July 2014.

RESULTS and DISCUSSION

There were 21 respondents, including 13 (61.9%) adult HPN consumers and 8 (38.1%) parents or carers of children dependent on HPN. Two (9.5%) respondents resided in New Zealand and the remaining 19 (90.5%) lived in Australia. Approximately half lived in New South Wales.

The survey confirmed a wide variability in PN infusion times, ranging up to 24 hours with the majority infusing for 10-12 hours. Priming volumes for PN administration sets ranged from 8-30ml with the majority choosing 20ml. One third of respondents did not use gloves for connecting their PN and a third did not use gloves for changing dressings. While two thirds used gloves for connecting PN, less than half of all respondents used sterile gloves. It would be interesting to know whether use or non-use of gloves reflects the nursing practice at the hospitals which manage the HPN patients. The use of in-line filters was fairly evenly split: 43% used filters versus 57% who did not. Heparinised saline and saline were the most frequently used catheter locks (57%). An alcohol-based lock was used by 14% and Taurolock® was used by 19%. Approximately half drew back before connecting, whilst the remainder simply flushed or connected directly.

Over 90% used a chlorhexidine-based disinfectant for either or both the PN connection and the skin site, in line with AuSPEN recommendations. The majority waited at least 30 secs for the disinfectant to dry but surprisingly some did not wait at all and others waited 'a couple of minutes'. Perhaps guidelines on appropriate drying times to maximise the effectiveness of particular disinfectants are needed.

CONCLUSIONS

Although this was a small study, our on-line pilot survey reached approximately 10% of known HPN consumers/parents/carers across the majority of Australian states and New Zealand, and we believe the results are reasonably representative of the wide variability of HPN set up procedures used in Australasia. It is not possible to ascertain what effect these differences might have on infection rates. However, these data suggest that further study is warranted to determine the best evidence-based procedures for more standardised HPN training programmes.

ACKNOWLEDGEMENTS: Thank you to those HPN consumers/parents/carers who participated in the survey.

A CRAFTY LADY

WORDS BY *GILLIAN*

One of our members, Jane, has enjoyed painting in her leisure time for many years, although it wasn't until after retirement that she was able to set up a dedicated spot in a spare bedroom for this. Over the years she has sold several paintings, as well as entering them into exhibitions. Her preference is to paint in oils, but she has recently had two successful exhibitions in acrylics.

Jane joined the Hornsby Art Society, and through this, learned of Hornsby Council's annual recycled art exhibition, which runs along-side their mantra 'reduce, recycle, reuse'. Entries can be 3D works, or multi-media paintings/collages.

Jane exhibited a collage of her medical supplies. She made it into a face representing a self-portrait, using packaging from pills that help to keep her alive. A photograph of the finished artwork was then submitted to the council to see whether it was of a high enough standard for acceptance, which it was!

More recently, Jane participated in a miniatures workshop with the Hornsby Art Society, where she painted a miniature of a cottage garden with acrylics on cheese box (a very thin wood). Miniatures need to have a perimeter of no more than 16 inches. To Jane's delight, not only did she receive a highly commended award, but it came with a cheque for $100! Hopefully this will keep Jane in paint for a while to come.

Jane's Highly Commended 'Cottage Garden'

Jane, working on her 'Self- Portrait'

Jane's 'Self- Portrait'

SCIENTISTS ‘A STEP CLOSER’ TO PRINTING TRANSPLANTABLE TISSUES

Medicalsearch.com.au 4th July 2014

Researchers have made a giant leap towards the goal of 'bio-printing' transplantable tissues and organs for people affected by major diseases and trauma injuries, a new study reports.

Scientists from the Universities of Sydney, Harvard, Stanford and MIT have bio-printed artificial vascular networks mimicking the body's circulatory system that are necessary for growing large complex tissues.

"Thousands of people die each year due to a lack of organs for transplantation," says study lead author and University of Sydney researcher, Dr Luiz Bertassoni.

"Many more are subjected to the surgical removal of tissues and organs due to cancer, or they're involved in accidents with large fractures and injuries.

"Imagine being able to walk into a hospital and have a full organ printed - or bio-printed, as we call it - with all the cells, proteins and blood vessels in the right place, simply by pushing the 'print' button in your computer screen.

"We are still far away from that, but our research is addressing exactly that. Our finding is an important new step towards achieving these goals.

"At the moment, we are pretty much printing 'prototypes' that, as we improve, will eventually be used to change the way we treat patients worldwide."

New study has revealed the potential of ‘bio-printed’ organs and tissues

The research challenge - networking cells with a blood supply

Cells need ready access to nutrients, oxygen and an effective 'waste disposal' system to sustain life. This is why 'vascularisation' - a functional transportation system - is central to the engineering of biological tissues and organs.

"One of the greatest challenges to the engineering of large tissues and organs is growing a network of blood vessels and capillaries," says Dr Bertassoni.

"Cells die without an adequate blood supply because blood supplies oxygen that's necessary for cells to grow and perform a range of functions in the body."

"To illustrate the scale and complexity of the bio-engineering challenge we face, consider that every cell in the body is just a hair's width from a supply of oxygenated blood.

"Replicating the complexity of these networks has been a stumbling block preventing tissue engineering from becoming a real world clinical application."

But this is what researchers have now achieved.

What the researchers achieved

Using a high-tech 'bio-printer', the researchers fabricated a multitude of interconnected tiny fibres to serve as the mold for the artificial blood vessels.

They then covered the 3D printed structure with a cell-rich protein-based material, which was solidified by applying light to it. Lastly they removed the bio-printed fibres to leave behind a network of tiny channels coated with human endothelial cells, which self organised to form stable blood capillaries in less than a week.

The study reveals that the bioprinted vascular networks promoted significantly better cell survival, differentiation and proliferation compared to cells that received no nutrient supply.

Significance of the breakthrough

According to Dr Bertassoni, a major benefit of the new bio-printing technique is the ability to fabricate large three-dimensional micro-vascular channels capable of supporting life on the fly, with enough precision to match individual patients' needs.

"While recreating little parts of tissues in the lab is something that we have already been able to do, the possibility of printing three-dimensional tissues with functional blood capillaries in the blink of an eye is a game changer," he says.

"Of course, simplified regenerative materials have long been available, but true regeneration of complex and functional organs is what doctors really want and patients really need, and this is the objective of our work.

HPN PROFESSIONAL AWARD NOMINATIONS

WORDS BY *KAREN*

Following our announcement in the last edition of Dripline of the three recipients of our inaugural Lifetime Membership Awards, the Management Committee would also like to initiate annual awards for outstanding support by health-care professionals and company employees to provide good quality service to HPN consumers in Australia or New Zealand.

We wish to acknowledge the care given by outstanding healthcare professionals and those in the HPN industry, and this is your chance to nominate someone you work with or who is involved in your/your child's HPN care. There are four categories with only one winner in each category:

Adult Parenteral Nutrition Professional of the Year
Paediatric Parenteral Nutrition Professional of the Year
Commitment to Patient Care – Company Employee of the Year
Outstanding Achievement Award.

For more information on each of these categories, please see our nomination form on our website at http://www.parenteralnutritiondownunder.com/pndu-annual-awards (under the "Get Involved" tab.)

The 2014 winners of the professional awards will be announced and the Lifetime Membership Awards presented during the PNDU symposia this November.

All PNDU members can vote, so if you have someone whom you wish to nominate for one of the HPN Professional Awards, please complete the nomination form on our website and email it to contactpndu@gmail.com by 31st October 2014

Going forward, we will be calling for nominations to be submitted for all of our PNDU awards – Lifetime Membership Award and HPN Professional Awards –by 31st August each year, with the winners to be announced October/November and posted on our website. The Lifetime Membership Award nominations will be judged by all attending members of PNDU's Management Committee and Professor of Pharmacy at Charles Darwin University, Patrick Ball. Professor Ball and PNDU's Professor Gil Hardy will adjudicate nominations received for the HPN Professional Awards.

We look forward to acknowledging, through our PNDU Professional Awards, the great work and care of so many involved in HPN provision in Australia and New Zealand.

PNDU—FROM IDEA TO REALITY

WORDS BY *JACQUELINE*

After eight years of weight loss, multiple surgeries, poor health and many hospital admissions, I was placed on enteral feeding in 1996. But due to increasing intestinal failure and decreasing health in 1999, I migrated from enteral feeding to parenteral feeding (PN). Along with that came a difficult and confusing time for me and my husband, David.

I knew of no-one else being fed this way, had no true PN team to refer to, and no real access to information, help and guidance.

We spent many years feeling fairly isolated from support and information, because at that time I didn't realise there were other groups throughout the world who offer consumers internet contact, until one day, David found The Oley Foundation on the net. But it still lacked the personal contact that I looked for.

Travel and holidays had been foreign to us since 1992 until 2008, when we built up enough courage, and decided that for our 30th wedding anniversary we would go on a long desired holiday to New Zealand. It was a difficult decision for us to make, and along with all the usual planning that is required for an overseas trip, there was all the medical preparation.

A pharmacist who had, at that time, been preparing my PN, gave me contact details for Gil, (a Professor of Clinical Nutrition in New Zealand), and we emailed each other a few times. The pharmacist also put me in contact with Brenda, who, too was an HPNer (Home Parenteral Nutrition), living on the North Island of New Zealand. We corresponded several times by email, and were originally intending to meet in person when we were in NZ, however, we weren't able to. I had mentioned to her that I thought it would be wonderful if we started an internet group, and found that she, too, had been thinking of the same thing. From these initial comments, PNDU was born.

I'll be quick to add that all the hard ground work was done by Brenda and Gil in setting up the group. As I'm challenged with computers, the name, logo, Googlegroups setup, other contacts and information posted was mostly done by Brenda.

For some time, there remained just a few people who had regular contact with each other, but over the last five years the group has grown to what it is now. I don't think any of us had ever expected PNDU to become such a large and dynamic group of people with a dedicated and capable Management Committee.

In the early stages of the group, Karen joined us, and what an amazing help she has been. The amount of time and effort Karen has offered has allowed the group to expand, develop powers, deliver support and show commitment to better treatment outcomes.

In 2012, David and I travelled to New Zealand again, this time managing to meet up with Brenda at her home, where she offered us accommodation for the night and showed us around her local area.

We had met Karen, Gil, Brenda and a few others at the Gold Coast PNDU meeting a year earlier, which was a wonderful event. The internet is a great way to make contact, exchange ideas and offer help, but meeting people offers that personal touch in a way that helps ground your relationships, and we are very grateful of the chance to have personal contact with other members and their families.

ARIEL'S STORY

WORDS BY *MIRANDA AND DAVID*, PARENTS OF 3 YR OLD *ARIEL*

First published in "The Patients' Voice" Summer 2014 edition, a publication by the Australian Patients Association

Our daughter Ariel was born prematurely at 25 weeks whilst we were on our honeymoon in Tel Aviv, Israel. In her first few weeks of life, she was diagnosed with necrotising entercolitis (a condition which affects the development of the gut, causing parts of it to die) and underwent three successive abdominal surgeries, the last with the catastrophic result of leaving her with only 7cm of small intestine. We were advised to look into transplant programs and told that her life expectancy was cruelly short. After a total of 5 months in neonatal intensive care, an international medical transfer back to Sydney, and a further 6 months in hospital, we brought our baby home.

Ariel is now 3 years old and loves to sing and dance. She attends daycare a few times a week. She has never eaten food and cannot derive any nourishment through her digestive system. Ariel has a catheter tunnelled into a vein next to her heart, and every night before she goes to bed, we connect the catheter to a bag of PN (Parenteral Nutrition) to provide the nourishment she needs for the next day. In the daytime, Ariel carries a pump in a little backpack, which pumps a special formula directly into her stomach steadily and constantly as part of her intestinal rehabilitation. There are many complications and side effects to living life in this way, and we are grateful for every day that she is well.

Ariel is still too young to know that she is different, but certainly, caring for her has not been like any parenting experience that we had heard of or anticipated for ourselves, and oceans apart from the experience of our friends and family.

We were very fortunate to be put in touch with PNDU (Parenteral Nutrition Down Under) early in our journey, and that has helped us better understand and carry out our new responsibilities as parent carers. PNDU members welcomed us with a kind, attentive ear and generous advice (from their own personal experience) which has helped us enormously in dealing with practical issues such as how to secure a catheter from curious little fingers, as well as more profound ones which loom in our family's future.

Being connected to people who live with a similar medical routine has been an incredible support for us, and also a much needed outlet so that we can continue to live "normal lives". We have been so inspired by the people we have met in PNDU in many different ways, and our interaction has abated the feeling of unforgiving loneliness which comes with dealing with a complex and rare medical condition. In PNDU we have seen strong role models for leading rich lives, despite severe health issues, and we hope that with our borrowed wisdom we can help Ariel grow to carry the same courageous, joyful spirit and lead a full life of her own design which we have witnessed is possible.

Ariel on the left, with Emily, also on HPN

HPN AWARENESS WEEK 2014

WORDS BY *KAREN*

August 3-9 was the 4th annual HPN Awareness Week and we once again had the privilege of celebrating this important week in PNDU's calendar with sister organisations overseas, including in the USA, UK and Poland.

Being such a small patient group in Australia and New Zealand (about 200 adults and children), HPN and Intestinal Failure continues to remain, for the most part, unknown. Thanks to the efforts of our members and all the friends of PNDU however, gradually awareness is growing.

Many thanks to all of our members who were able to take part in this year's HPN Awareness Week. Having conversations about HPN, sharing your stories, sharing our professional YouTube clip put together by Miranda and Jen http://youtu.be/7LPhYzH5oL0, and our poster, as well as using the Awareness Week logo on social media – all of this works together to help others in this part of the world learn what life is like on HPN and to spread the word that PNDU provides much needed support and information.

One of our aims during HPN Awareness Week is for more HPN clinicians to learn about PNDU, so they can then pass on PNDU's details to other HPNers and carers. Our hospital teams play a vital role in our care, but the value of connecting with and giving/ receiving support from other HPNers and carers simply cannot be overstated. PNDU complements the wonderful work and support of our HPN hospital teams.

Many thanks to all those HPN clinicians who readily let their HPN patients know about PNDU.

We are also very appreciative of all the support we receive from many who work with PN and many who are 'just interested', as well as of the generous donations we received during HPN Awareness Week 2014 (see "Thank You" article below). This enables us to continue our mission to support, research and inform consumers, carers and providers of parenteral nutrition for intestinal failure in Australia and New Zealand.

We look forward to celebrating HPN Awareness Week 2015.

HealthPACT REVIEW INTO INTESTINAL FAILURE IN AUSTRALIA AND NEW ZEALAND

WORDS BY *KAREN*

Over the past year, DLA Piper in Melbourne has been carrying out a government review on "Intestinal Failure in Australia and New Zealand – current services, gap analysis and service planning guidelines". PNDU was referred to DLA Piper last year by the Australasian Society of Parenteral and Enteral Nutrition (AuSPEN) and we were very grateful to be able to give input into the review by way of the HPN consumers' experience and perspective. This took place through one-on-one telephone interviews with various PNDU members and a detailed PNDU submission on the current HPN services and PNDU's recommendations for improvements.

We received a copy of the final report in August 2014 and are delighted to see included in full PNDU's survey results on HPN consumers' opinions on the levels of compliance by Australian and New Zealand HPN centres with the published AuSPEN Clinical Practice Guidelines for HPN Patients in Australia and New Zealand.

The report itself, at 74 pages, is very comprehensive and PNDU welcomes the results and recommendations included.

It is also very encouraging to hear from DLA Piper that "most of the jurisdictions were happy with the report … and are already putting measures in place to address some of the recommendations".

Thank you DLA Piper for taking into consideration the HPN consumer perspective and to AuSPEN for referring us to DLA Piper.

If you would like to see a copy of the report, email us at contactpndu@gmail.com

A DAY IN THE LIFE OF AN HPN-ER

WORDS BY *GILLIAN*

I thought that this month I would literally look at a typical day in my life. I've chosen a Tuesday, which is my PN (Parenteral Nutrition) delivery day, which has extra implications for my husband, Ray. However, I don't think that this would be typical for all HPNers, as we all have individual health problems that necessitate HPN (Home Parenteral Nutrition), which cause variations in what would constitute a 'typical' day.

Tuesday is a work day for me, so it begins when the alarm on my PN pump sounds at about 6:10am. When I set up my PN each night, I decide how many hours I wish it to run, and use it as my morning alarm clock.

- I turn off the pump, clamp off my PN line, and disconnect it from my central line into a major vein in my chest (Hickman's).
- I take the used bag from the backpack and throw it out.
- I get the next night's PN from the fridge and hang it for the day on my hospital pole, which I keep in a spare bedroom.
- As with many people on HPN for Intestinal Failure, I have Short Bowel Syndrome, and as a result, have a high output ileostomy, so I then go to the bathroom to change the ileostomy bag.
- I keep my week's supply of HPN peripherals, such as dressing packs, lines (to administer the PN), syringes, etc, together in a box, which has to be stocked each week from my supplies. I get a syringe, saline injection and alcohol wipe and, after carefully washing my hands, flush the Hickman's with the saline to prevent blockages.
- I take my oral medication.

At work, the only issue related to my health is that my ileostomy bag fills frequently, as my body doesn't absorb the food that I eat, so I have to visit the toilet several times during the day.

Meanwhile, since this is a Tuesday, my PN is delivered either by a Baxter courier or by another courier company. The time of delivery is often about 1-2pm, but has been as early as 11:00, and as late as 4:30pm. Since Baxter policy states that someone must be home to accept delivery, this makes it very hard for Ray to make any away-from-home arrangements for that day. However, we are thankful that it is delivered, because up until the recent past some of our members in other states have had to collect it themselves from their hospital.

My weekly PN arrives in 3 boxes, as my night's PN is 3L, which weighs approximately 3kg, so the boxes are quite heavy. The boxes have to be unpacked, which means that between 9 and 12 chiller packs, 3 sheets of foil sided bubble wrap, and 3 sturdy boxes have to be disposed of, because sterility is so important at Baxter that they can't recycle these and risk contamination. In my case, every so often I take the chiller packs to work and give them to people for chilling lunch boxes, but otherwise, they get thrown out. I've found someone who takes the bubble wrap to use for his business, but unfortunately, unless I have friends moving house, the boxes end up in the recycle bin.

After dinner, I have to do my night-time routine.

- Take oral medication.
- Cut the protective bag off the PN (PN is light sensitive) and mix the chambers together.
- Collect 'setting up' supplies from my weekly supply box: a dressing pack, giving set, syringe, saline injection, a valve to connect the line to, surface and hand alcohol.

Setting up means connecting my PN to my Hickman's, and must be done in a strictly sterile manner, as any germs can enter the central line, and thus the blood stream near the heart, and cause potentially life-threatening infections. NB Each HPN patient receives their training from their hospital, and so variations in procedure may occur.

- The kitchen bench gets wiped down with the surface alcohol and paper towel.
- The dressing pack is opened, with the other bits and pieces, such as the giving set and syringe, carefully opened onto the dressing pack's sterile sheet, taking care not to touch anything. Chlorhexidine in alcohol is poured onto the dressing pack tray.
- I wash my hands, scrubbing like the doctors you see on TV preparing for surgery, dry my hands with paper towel, then squirt hand chlorhexidine in alcohol onto them.
- The equipment is then able to be handled: the giving set undone from the paper bands, the sterile cotton balls soaked with surface alcohol and the syringe filled with the saline solution.

- The connector point of the PN bag is swabbed with surface alcohol, the cap removed, then the bag spiked with the end of the giving set.
- The giving set is placed into the pump, which is primed to get the PN flowing through it.
- The end valve on my Hickman's is replaced, the syringe attached, a bit of blood drawn back into it to check the line isn't blocked, then the saline pushed into the line.
- The end of the giving set is then screwed into the valve on my Hickman's, and all is ready to run.
- I then put the bag of PN and pump in the backpack, which makes it portable to walk around and/or go out if I wish.
- The pump is set for the time I wish to wake up the next morning, and all is done for that day.

The PN and pump ready to set up

The opened dressing pack.

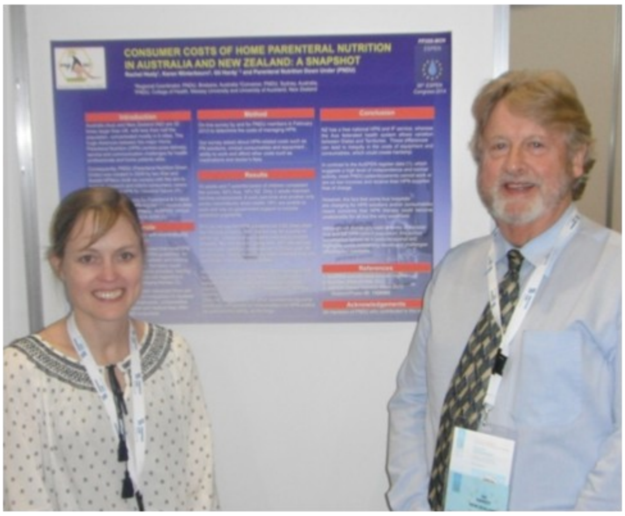
Above: *The giving set connected to the pump*
Right: *My weekly packaging*

PNDU MIXING IT ON THE WORLD STAGE

WORDS BY *KAREN*

In early September 2014, the annual Congress of ESPEN (The European Society of Clinical Nutrition & Metabolism) took place over 3½ days in Geneva, Switzerland. Our own Prof Gil Hardy had already received acceptance for poster presentation during the conference of an abstract of PNDU's survey on HPN costs to consumers. In addition, as a last minute added bonus for PNDU, I was given travel funding by NPS Pharmaceuticals Inc. to attend the conference as PNDU's Convenor.

So with a huge amount of mad-dash organising, I set off to Geneva with 3 suitcases (nearly 70kg of luggage) containing all my HPN needs for 2 weeks and every possible authority letter I might need. There wasn't sufficient time to organise for PN or ancillaries to be made available for me over there.



Above: *Karen and Gil with the poster on PNDU's survey*
Left: *I made it!*

The conference was BIG, with an amazing array of sessions, industry exhibits and over 3000 delegates. So many people! It was a privilege and quite an experience to be amongst so many clinicians, industry representatives and academics with an interest in nutrition, including artificial nutrition.

To give one example of the sessions presented, I attended a very interesting seminar entitled "Enhancing understanding of the intestinal immunological response to parenteral nutrition". The presenter, Dr Daniel Teitelbaum (President of ASPEN), looked at mouse trials in food-fed vs PN-fed mice as well as human studies on fed vs unfed intestine and the resulting differences and changes in the intestinal microbiome and gut barrier function. Although highly technical, it was still fascinating to be able to grasp the basics and learn of the studies and areas of interest that are being pursued for the ultimate benefit of those of us living with Intestinal Failure and HPN.

The exhibition hall was something to behold with so many things on display relevant to our lives. One exhibitor, Micrel, displayed a super light-weight and easy to use PN infusion pump and charger as well as wonderfully bright backpacks, alongside their classic black backpack, with detachable wheels for trundling. I really look forward to products like these making their way down south.

Micrel's stylish black
infusion backpack on wheels

One of Micrel's colourful backpacks, also on wheels and
their super light infusion pump and charger

The main event for PNDU however, came on Day 2 when, representatives from 6 HPN/HEN support groups from around the world met to map a way forward for international collaboration. Not only PNDU but also the chairs of these other HPN support groups received travel sponsorship from NPS Pharma to attend ESPEN and, more particularly, this meeting. It was a very long, but positive and productive meeting and we look forward to what this international alliance of HPN/HEN support groups can achieve, including sharing of information to assist those travelling with HPN, and being available to the medical field to provide the patient perspective on various studies and developments. In attendance were representatives from Oley Foundation (USA), PINNT (UK), Un filo per la vita [A thread for Life] (Italy), Život bez střeva [Life without Intestine] (Czech Republic), Appetite for Life (Poland) and us – PNDU (Australia/New Zealand). In time we hope that the number of member organisations will increase.

Support group international collaboration – nutting out how it will work

The following morning this alliance of HPN/HEN support groups was introduced during an open meeting of the ESPEN 'Home Artificial Nutrition – Chronic Intestinal Failure' working group and given an opportunity to explain who we are and what we hoped to achieve, as a complement to the medical profession. We were really encouraged with the response and the ideas put forward for us link in with ESPEN.

All in all, the conference and particularly the collaboration meeting were very worthwhile and productive, and a privilege particularly for PNDU and this little Convenor, to be involved in.

To round off my 2 week trip abroad, after spending wonderful time with extended family in London and with PINNT Chair, Carolyn Wheatley, in the south of England, I was honoured to be able to attend the BAPEN South Region Nutrition Day, before flying home.

This was another day of informative presentations, not the least of which was our Gil's presentation on "A case of lipid choice in parenteral nutrition". I finally got to hear Gil present! Unknown to me until arriving, this study day was held in the grounds of Peppa Pig World and Carolyn and I took advantage of every break to make the most of this fun-filled theme park.

A big thank you to NPS Pharma for their travel sponsorship, and also particularly to Carolyn, Gil and Miranda for their support and assistance to make this amazing last minute opportunity become a reality.

Right: *Peppa Pig in 'attack' or 'cheeky' mode?!*

The representatives from the 6 support groups present.

REPORT ON THE ANNUAL NNNG CONFERENCE IN UK

WORDS BY *GIL*

Over 100 delegates and 20 sponsoring companies/organisations attended the annual conference of the **UK National Nurses Nutrition Group (NNNG)** conference at the Chesford Grange Hotel, Warwickshire, UK in July 2014.

The NNNG was established in 1986 and is a registered UK charity for nurses dedicated to promoting excellence in all aspects of nutritional care and promoting good nutritional practice for nurses across all specialities.

Topics at the conference included; eating and drinking by older people, the use of restraint devices for nutrition support, nutritional perspectives of dementia, a liquid feed symposium with practical demonstrations of blenderising food for enteral feeding tubes, a Baxter breakfast symposium on home patient education and a PN symposium, that included invited presentations on 'Comparison of HPN provision in Australia, New Zealand and the UK' from **Gil Hardy** and by pre-recorded video presentations from **Karen and Shirley/Sam/Candace** on 'Living with HPN Down Under: the Aussie and Kiwi patient perspective'.

In the PN Symposium, **Dr Jeremy Nightingale**, Consultant Gastroenterologist at St Marks hospital London (the largest intestinal failure (IF)/HPN centre in Southern England) presented an excellent review of the important issues relating to IF and the liver. Hepatobiliary problems associated with IF give rise to steatosis or 'fatty' liver or cholestatic liver disease or gallstones. Abnormal liver function tests (LFT) may be due to the underlying disease or the treatments given. PN related liver disease in children usually relates to intrahepatic cholestasis and in adults to steatosis, which may be consequent upon an excess of carbohydrate, lipid or protein or upon a deficiency of a specific nutrient. Chronic cholestasis as defined by 2 of 3 LFT being more than 1.5 times the upper limit of normal for more than 6 months is most commonly associated with excess lipid in the PN.

In his comparison of HPN in Australia, New Zealand and the UK, Gil first described how the first published cases of PN-associated Zinc deficiency in some of the early HPNers and other pioneering observations were reported in 1970's by innovative clinicians down under. Since Aus and NZ are 32 times larger than UK, with less than half the population, concentrated mostly in 6 cities, these huge distances between our major HPN centres pose delivery, service and communication challenges for health professionals and home patients alike. Consequently, PNDU was created in 2009, with the aim to support, research and inform consumers, carers and providers of HPN.

Gil summarised the survey by PNDU revealing that most centres comply with the AuSPEN HPN guidelines, doing best at selecting/ placing a central catheter and training patients before going home. However, there is a need to improve training to manage line complications; emergency repair kits; providing written information for emergency hospitalisations; assurance that a multi disciplinary NST is coordinating care; after-hours technical support for pumps; advice about drug-nutrient interactions and confirming suitable home environments before discharge. He also presented a poster on the second PNDU survey of consumer costs (pictured in Robin Hood fancy dress required for the NNNG conference dinner) and was invited to judge and award prizes to the best of the other nursing posters.

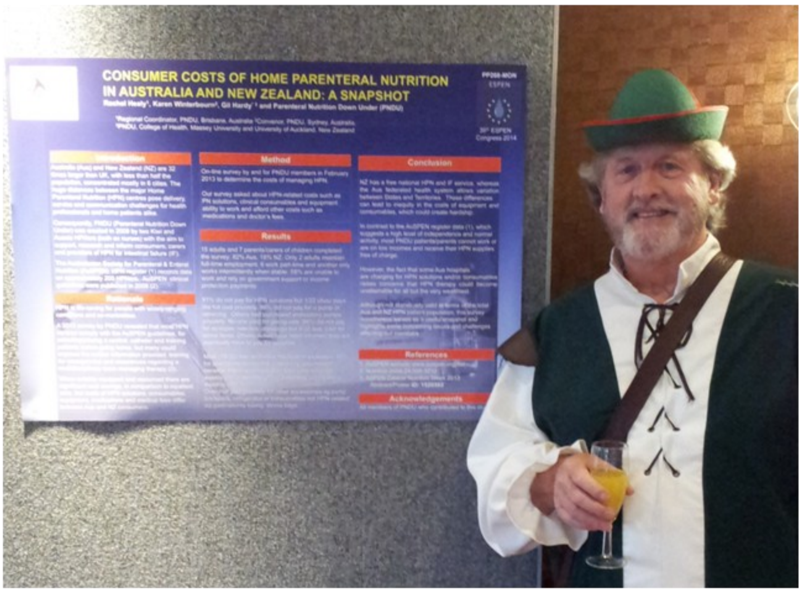
Personal perspectives of life on HPN were then presented in two video clips by PNDU members Karen, followed by Shirley and little Sam with big sister Candace . Karen firstly spoke of her own journey to Intestinal Failure, starting HPN and now convening PNDU, and then moved on to some of the HPN experiences and challenges patients live with in a country as large as Australia, with a relatively small population and low prevalence of HPN, long distances to HPN centres, federated states/territories resulting in variations of HPN care, as well as what the hot temperatures can mean for patients. The need for support and contact with other HPNers was clearly expressed.

Considering the challenges for HPN provision in Australia, Karen expressed gratitude for what has been achieved and looks forward to further progress for all HPNers, overseas and in Australia. A warm invitation was issued on behalf of PNDU to those present at the conference to visit 'down under'.

With the assistance of her budding cinematographer daughter, Candace, Shirley introduced the audience to young Sam and briefly explained his complex health condition. Sam was in hospital at the time of filming. Shirley then walked through the practicalities of what HPN means for them as a family in New Zealand – the challenges of Sam's needs in a family environment, including space for his supplies, juggling family and hospital commitments, different PN systems for home and hospital, what planning a simple holiday entails. Shirley also expressed the importance and value of PNDU's support. Candace added her perspective on life with Sam, attesting to the family's great love for her little brother. Shirley concluded with a note of appreciation to all those who make it possible for Sam to live at home with the family, when well enough. Shirley's video can be watched here:

http://www.youtube.com/watch?v=O1JDZVsXhBw

PNDU greatly appreciates the opportunity to share the 'down under' perspective and looks forward to stronger links with NNNG.



Gil "Robin" Hardy with the PNDU poster at the NNNG Fairy Tales Evening Function

COLLECTION BOXES

WORDS BY *GILLIAN*

Two of our members had an idea for collecting funds. Gil, in New Zealand, put a box decorated with PNDU pictures and information (see pictures below) in the foyer of the theatre where he was acting in The Vicar of Dibley over a few nights (see pictures in separate Vicar of Dibley article). He collected approximately $70!

I put a box decorated with PNDU information at the counter of my local nursery. Thus far, $41.35 has been collected.

All moneys and donations to PNDU are used to increase awareness of our support group. Much of the money goes toward the cost of printing information flyers/leaflets and advertising items, such as mugs, pens, and our Pendoos (a stuffed toy of our mascot).

Decisions on this spending are made by our Management Committee at our regular Skype meetings

VICAR OF DIBLEY

WORDS BY *LISA*

Earlier in the year I had the privilege of watching Gil perform in the Vicar of Dibley at the Rose theatre on the North Shore. It was very funny and Gil's performance was superb. He could have another career in acting! I really enjoyed myself. It was a great night.

The cast, with Gil on the right with cap

The cast; Gil, as 'Owen', wearing sunnies.

3M'S TEGADERM ™ CHG I.V. DRESSING IS FIRST TRANSPARENT DRESSING INDICATED TO REDUCE CATHETER-RELATED BLOODSTREAM INFECTIONS

[adapted from 3M I.V Team Press Release]

Global technology company 3M announced in March 2014 that its Tegaderm™ CHG (chlorhexidine gluconate) I.V. securement dressing is the first transparent antimicrobial dressing to be clinically proven and indicated to reduce catheter-related bloodstream infections (CRBSIs).

Its performance has been validated following an extensive randomised controlled trial led by Professor Jean-François Timsit that has been reviewed by the UK Medicines and Healthcare products Regulatory Agency and CE mark certification awarded by the British Standards Institution.

Tegaderm™ CHG dressing combines the antimicrobial power of chlorhexidine gluconate with the transparency, reliability and simplicity of 3M's Tegaderm™ film. Designed for central venous, arterial and other intravascular catheters, it is intended to reduce skin colonisation and catheter colonisation and to suppress regrowth of microorganisms commonly related to blood stream infections.

The study by Timsit et al (Am J Resp & Crit Care Med 2012:186;1272-1278) based on over 34,000 catheter days, compared three types of I.V. dressing and showed that the chlorhexidine dressing had a 67% lower major catheter-related infection rate than the non-chlorhexidine dressings. Tegaderm™ CHG dressing was also shown to be more cost-effective than the comparators.

In vitro testing has shown that chlorhexidine gluconate has broad spectrum activity against, and is a barrier to, a wide variety of gram-positive and gram-negative bacteria and yeast. These include the majority of pathogens of most concern to epidemiologists and infection control practitioners.

As Tegaderm™ CHG dressing is now clinically proven to reduce catheter-related bloodstream infections, and becomes a highly valued addition to a multi-faceted approach to patient safety. However it may not be available yet in your country.

ELEVATOR BUTTONS

The study was published July 8, 2014 in *Open Medicine Journal*.
Source: Sunnybrook Health Sciences Centre, Toronto, Canada

Elevator buttons are more likely to be colonized by bacteria than toilet surfaces, a new Sunnybrook-led study of three large urban hospitals has found.

"Elevators are a component of modern hospital care, and are used by multiple people with ungloved hands who will later go on to make contact with patients," says study co-author Dr. Donald Redelmeier, a staff physician in the division of general internal medicine at Sunnybrook Health Sciences Centre and a researcher with the Institute for Clinical Evaluative Sciences (ICES).

At each hospital, 120 randomly selected interior and exterior elevator buttons were swabbed over a 10-day period. These were compared against swabs of toilet surfaces in men's washrooms, including exterior and interior entry-door handles, the privacy latch and the toilet flusher.

Sixty-one percent of the elevator button samples showed microbiological growth, compared to only 43 percent of the toilet surface samples. Bacteria cultured from the elevator buttons and toilet surfaces included Staphylococcus, Streptococcus, coliform bacteria, Enterococcus and Pseudomonas, though they are unlikely to cause specific diseases in most cases.
"We were surprised by the frequency of bacterial colonization on the elevator buttons, but we were also struck by how easily it could be avoided, specifically by the use of good handwashing or hand hygiene," says co-author Dr. Andrew Simor, chief of the department of microbiology and infectious diseases at Sunnybrook.

The authors suggest several strategies for reducing the frequency of bacterial colonization on commonly touched surfaces. "Use alcohol-based hand sanitizer before and after touching the buttons, or avoid touching them altogether by using the tip of a pen or your elbow," says lead author Dr. Christopher Kandel, a fellow in the department of infectious diseases at the University of Toronto. "Educating the public about the importance of hand hygiene when in a hospital may also help reduce the rate of colonization."

THANK YOU

WORDS BY *GILLIAN*

We have had several generous donations during the last few months, partly as a result of HPN Awareness Week, partly from participation in the NNNG conference in UK (see article in this issue), as well as general donations.
We'd like to thank:

From the UK,
Brian Wood, Cambridge
Pauline Belgrove, Sudbury
Robert Hardy, Devon
Rachel Hardy, Devon
From NNNG, for Karen and Shirley's video presentations
From Gil Hardy, a donation of half of his NNNG travel expenses.

From Australia
R. Koonin, NSW
W. Winterbourn, NSW
J. Lee, NSW
F. Munro, NSW
Hornsby Heights Baptist Church Ladies' Friday Bible Study, NSW
Fresenius Kabi Australia and New Zealand

The donations total approximately $3,000. We'd like to thank these people and organisations for their generosity, which allows us to continue our support work.

We would also like to thank NPS Pharmaceuticals Inc for their generous travel support for PNDU's Convenor, Karen, to travel to ESPEN Congress in Geneva in September in order to gain and to share experience with equivalent patient organisations from around the world. (See article in this issue.)

OUR PRIVATE FORUMS FOR AUSSIE AND KIWI HPN-ERS AND CARERS

Any Aussie or Kiwi HPNers or carers who would like to join one or both of our private forums (Googlegroups email forum and/or closed Facebook page) where you can chat with others living with HPN, please email us at contactpndu@gmail.com, telling us about yourself

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.

NZ 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

Online donations:
PayPal via our website www.parenteralnutritiondownunder.com
Or direct deposit (New Zealand dollars only) to IPANEMA’s bank account with the notation “PNDU”:
Bank: ANZ
Account name: IPANEMA
Payment ref: IPANEMA “PNDU”
A/c No: 0602730308799-00
SWIFT code for foreign payments: ANZBNZ22

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Minute Secretary: Gillian
Treasurer: Gil
Regional Reps; *NSW:* Gillian/Karen, *VIC:* Kelly, *TAS:* Jacqueline, *NZ:* Jodee, *US affiliate:* Jodee
Paediatric Coordinator/Advocate: Chris, Kelly
Adult Coordinator/Advocate: Karen, Gillian
Incorporation/Registration: Miranda
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

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