



Greetings from Far North Queensland! This issue is being written/edited/put together on a laptop whilst on a 7 week caravan trip. I've written my other pieces in Port Douglas, this in Atherton and it will be put in order and sent for editing between Townsville and further south. Again, we have a variety of articles, some reporting on conferences that PNDU have been involved in; two about HPNer get-togethers; read about our successful HPN Awareness Week activities; a few Google Chat Forum topics on issues raised by our members; and some historical perspectives on PN (Parenteral Nutrition) as researched or remembered by Gil. Also, some practical advice when visiting your medical team, or preparing for an unexpected trip to the Emergency Department at hospital. Even a few PN related gardening tips! Read and enjoy,

Gillian - Editor

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HPN Awareness Week 2015 – PNDU Involvement

WORDS BY GILLIAN

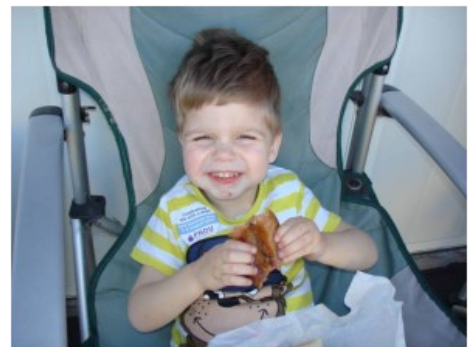
This year, as usual, PNDU's Management Committee (MC) developed a range of resources for its members to spread the word about HPN (Home Parenteral Nutrition) to friends, family, hospital team and community. These included poster, stickers, ideas for a media release, flyer and on-line survey for HPN clinicians, and our 2015 video clip. While many people contributed to these, a special thank you goes to Miranda and her friend Jen for the very professional looking HPN Awareness Week 2015 video. Click on the link to view: [HPN Awareness Week 2015 video](#).

One of our MC members, Chris, the carer for 2 young grandsons both on HPN, organised a great community barbecue with the help of the local Raymond Terrace Lions Club, as a thank you for all that the club has done for the boys in the past and linked it to HPN Awareness Week. Older brother, Dylan, was the 11th child in Australia to receive a Lion's Club 'Children of Courage' Award, remembering the siblings of those affected by rare medical conditions.

Other members used the Awareness Week logo as their social media profile for the week; shared their own stories on email and social media when sharing the video; wore stickers when they were out and about and were asked, in some cases, for an explanation, displayed the Awareness Week posters in offices, etc. Hospital teams were sent fliers, an on-line survey, stickers and the link to the video and were hopefully made aware of PNDU's role in supporting those on HPN.

Many members used the media release ideas, with five appearing in their local newspaper, both in Australia and New Zealand, helping to raise awareness of both HPN and PNDU.

Each year, Awareness Week takes members of the MC much time to prepare the various resources which are provided to members of PNDU in order for everyone to be involved in raising awareness and understanding of HPN 'down under', and it is heartening to hear how they have been used.



Patient Media Stories during HPN Awareness Week 2015

A collage of articles is over the page, click the article thumbnails to connect to the full articles online.



Congratulations to our 2015 PNDU Award Winners

WORDS BY KAREN

How good is it to be able to acknowledge great work! Especially when it comes to HPN! We were very pleased to recently announce our 2015 PNDU Award Winners (below). I have included here snippets about each of our winners taken from their nomination(s).

PNDU's Lifetime Membership Award – Jodee Reid

Jodee's name will be engraved on our perpetual Lifetime Membership Award trophy, is on our [Roll of Honour](#), and has received an Award Certificate.

Jodee is a founding member of PNDU and through her own journey with her daughter on HPN in New Zealand for 10 years before transplant in the USA, Jodee has always passed on PNDU's details to her many professional and patient contacts with the aim of HPN patients and carers having access to much-needed peer support.

Jodee was an original member of PNDU's Management Committee for over 3 years – a great advocate and representative of our Kiwi members! Jodee assisted with the website, e-newsletter and closed Facebook group, continuing to assist with this last role.

On a personal level, she has never hesitated to offer support and information to families who are travelling the HPN road as well as those heading towards, and coping with, transplant.

Five years on from her daughter's transplant, Jodee's life has moved away from the HPN world. Despite that, she has continued to be involved in and support PNDU's work, whenever she is able.

PNDU's Professional Awards:

- Outstanding Achievement Award - **Professor Ross Smith**
- Adult Parenteral Nutrition Professional of the Year - **Suzie Daniells**
- Paediatric Parenteral Nutrition Professional of the Year - **Merran Spargo**
- Commitment to Care - Company Employee of the Year - **Dimi Chrisafis**

The names of all our Professional Award winners are on our [Roll of Honour](#), and they will or have already received an Award Certificate for proud display. We also have [on our website](#) a wonderful set of photos from Prof Ross Smith's presentation.

Professor Ross Smith was an associate professor of surgery and gastroenterology at Royal North Shore Hospital in Sydney. Professor Smith has not only been one of Australasia's HPN pioneers over many years, he also looked after me for 15 years of my HPN journey. He was available 24/7 with care and concern always...not just ordinary care but "above and beyond". He was always honest and upfront and continued to work hard at keeping me alive. He was always easy to talk to, and always listened to my concerns and acted on them. I will always be grateful for his treatment of my Intestinal Failure. He did all this work in a lot of his own time and did not get paid for much of it. He kept abreast of all the test results and changes in formula of my PN. I was more than just a patient to him and he is still available for me to talk to even though he is no longer looking after my PN. I honour him.

Suzie Daniells is a Clinical Dietitian at Prince of Wales Hospital in Sydney. What I appreciate most is Suzie's passion for good HPN care. She has a special interest in artificial nutrition and this is obvious in her level of dedication to my care and that of her other HPN patients, as well as her commitment to learning more and keeping up-to-date with information/research. She is extremely professional and patient-oriented, always promptly responding to and following up requests/questions.



Jane presenting Prof Ross Smith with his Award Certificate



Karen presenting Suzie with her Award Certificate

Beyond that, Suzie is passionate about the patient voice being heard and patients having an active role in decision-making. She enthusiastically supports PNDU's work and shares PNDU's information with HPN patients and professionals, as well as answer dietetic questions from our private email forum, and has written at least one dietetic article for Dripline.

To top it off, Suzie is a very caring healthcare worker, genuinely concerned about the welfare of her patients. She has contacted me in her own time when concerned I was not coping well, as well as helping me out-of-hours with medical concerns on several occasions.

Merran Spargo is a Clinical Nurse Consultant at the Children's Hospital, Westmead in Sydney. Merran is honestly and whole heartedly adored by her HPN families. She is knowledgeable, professional, trusting, humble, nurturing and above all else someone that HPN families depend on when they are at their most

vulnerable time in their lives, going home with their child on HPN. Merran's preparation and organisation of literature, training sessions and one on one focus sessions, ensured that I had been expertly trained to commence HPN management. Merran also took the time, mostly in her personal time, to come to our family home to ensure my husband was accredited. During my training and post discharge Merran often coordinated several case study meetings with my daughter's key medical team, she also represented us with impeccable poise if we had some often very difficult questions to be answered, which alleviated a lot of our anxiety.

She ensures that all community and hospital resources are made available to HPN families and often facilitates HPN coordination when we travel interstate, ensuring that the local hospitals are informed we will be in town. Sitting with my son at 6pm on a Friday evening in ED, ensuring that all his medical needs were being met and that my own emotional needs were being comforted, she made sure that I had gone to get some dinner before the cafeteria closed. These type of gestures make Merran who she is.



Merran (centre) receiving her Award Certificate from one of her nominators, Sonya (right) and daughter Milla

Dimi Chrisafis is a contract PN courier for Baxter Healthcare, Sydney Pharmacy. Dimi doesn't just deliver PN to patients – she cares about them and gets to know them, always asking after their welfare. She laughs with patients, but also cries with them. It's not unusual to find Dimi teary on discovering that one of 'her patients' has passed away.



Karen presenting Dimi with her Award Certificate

Dimi is also very diligent, knowing how vital HPN is for patients. If patients have concerns or problems, she has tried to find solutions or to find someone else who can assist, and if something about a delivery doesn't seem right, she will always check.

Dimi is also very passionate about support for patients and has been a wonderful advocate for PNDU, doing whatever she is able within the regulations she works, to connect patients to support. She also supported PNDU by attending our Sydney symposium in 2011.

Dimi's highest priority is the welfare of the patients she delivers to. This dedication and care over so many years has made a difference in the lives of many HPN patients

Congratulations and thank you to all our PNDU Award winners – it's people like you who make a real difference in the lives of Aussies and Kiwis living with HPN and it's a privilege to be able to honour your hard

work and dedication. Thank you to our Professional Award judges - Prof Gil Hardy and Prof Patrick Ball, and thank you too to all those who submitted nominations. We look forward to acknowledging the great work of PNDU volunteers as well as HPN professionals again in 2016.

Brr, it's Cold!

WORDS BY GILLIAN

One of our recent chats on PNDU's Google Chat Forum for Aussie and Kiwi HPNers and carers has been about something that has never been mentioned by anyone before: having a cold line against your body whilst infusing in winter. Here are some of the comments and possible solutions suggested by some of our members. It all began when one member asked if people had any special techniques for changing clothes while hooked up to PN (Parenteral Nutrition).

- I like to hang the tube outside the neck hole so there isn't a cold tube against my skin, but then can't get my shirt off without disconnecting and reconnecting. Sometimes I try to feed the bag through a hole and end up in a big knot that needs to be untangled. Quite funny!
- Sometimes I leave my top or dress still attached to the line until I disconnect in the morning.
- I know what you mean about not liking a cold tube against your skin. I have a little cover similar to the Gusgear line covers <http://www.gusgear.net/line.html> I made it with soft fabric and a bit of Velcro. Works well.
- I wear a singlet in winter underneath the line. I can 'climb' into the singlet and out for showering. The line can be over the singlet, but under my top.
- In winter, room temperature can be less than 20 degrees C, which is very different to body temperature, and the line doesn't warm up like clothes do because the PN keeps being pumped through. I hate a cold line next to my skin, as well as the awkward clamps that dig into my skin.
- Like most of you, a cold line next to my skin is a no-go and I hate winter because of the threading in and out of clothes!
- When I had my Hickmans line I had it coming down and out under my top. I always wrapped my smart site connections in the sterile towel from dressing pack so that reduced the amount of line/skin contact.
- I like jackets instead of jumpers when connected.

I'll finish with one last member comment that sums up one aspect of life on HPN (Home Parenteral Nutrition): "How quick is it to change when you're not connected?! Or walk upstairs or across the room without picking up backpack first? It's the little things you appreciate big time."

HPNers Socialising and Learning in Brisbane

WORDS BY LARA

When the Brisbane AuSPEN HPN Consumer Workshop and PNDU social gathering was first mentioned in the PNDU email group, I immediately dismissed the events without a second thought. Not because I wasn't interested in attending; quite the opposite. But Ballarat is a long way from Queensland, and the time, energy and money required to get there would be, I thought, beyond me.

When it was announced that there would be two travel grants allocated to members to attend, I still didn't think much of it, but from that point on a seed was planted in my mind. Perhaps it would be possible? With money to cover all or part of our accommodation, maybe I could con my sister into coming to be my wheelchair pusher, heavy lifter and general assistant? I applied for a grant, thinking that unless I was actually successful, there was no need to worry about it anyway and I may as well throw my hat in the ring. When the email came saying I and two other members had been awarded grants, I read it with equal parts excitement and extreme nervousness, bordering on dread.

It had been over two years since I had been anywhere on a plane, and that was a holiday with, and completely organised by, my parents. Although I used to jet set around the world with only a backpack for months on end (the normal kind for clothes, not the bulky infuser ones we all know and love), travelling somewhere for more than one night with PN is still a relatively new concept for me. I often visit my parents, but they have a house that was designed with me in mind and a supply of all my equipment is kept in stock there at all times. Brisbane was another ballgame altogether.

My relief was overwhelming when we arrived at our accommodation on the Saturday night to find both PN and saline waiting in the unit's fridge. Being a weekend, and my clinical nutrition nurse also in Brisbane for the big Gastro2015 conference for medicos and clinicians, if something had gone wrong we really had no backup plan. I was also pleased

to find that I had no trouble coming through the airports with a wheelchair, pump and stoma; I clearly remember the perplexed look on the security guards face when I put my blue IMED pump (remember them, the ones the size and weight of a cinder block?) through the x-ray machine many years ago.

Sunday morning was beautiful and sunny, a welcome change after a long, cold Ballarat winter. My sister Sian and I headed for the Gallery of Modern Art meeting point (the upside-down elephant), a little later than schedule but not hideously so. There I finally got to put some faces to the familiar names I know from the forum, as well as meet those finding out about PNDU for the first time. With just under 30 HPNers, carers and families there, it was a great turnout. I have to admit, I did hang back and people watch a bit (hopefully not in a creepy way). I found it fascinating to watch the different participants interact and eat (or not), and almost startling to see other people with the pumps and equipment that I'm used to only seeing in my home. My sister said she also found it disconcerting to hear a PN pump, but have someone other than me attached to the end of it. It's not something that either of us experience often.

Chris, Tanya, Brooke and oldest son, Dylan were there, having travelled to Brisbane from NSW for the events, leaving HPN brothers, Jordan and Logan back home with their dad and auntie. Fay (HPNer) and Lindsay also from NSW and staying with sister and brother-in-law, Alison and Tony were also already there by the time we arrived. Carolyn (HPNer and PINNT UK Chair) was very jet-lagged, having just arrived from England early hours that morning, but was dragged along by Karen (HPNer) ☺. Poor Jane (HPNer) and Neil, more New South Welshmen, had been on a bit of a goose chase around the city before eventually locating and joining us. For Queenslanders, Sarah and daughters, Lourdess, Madeline and Lara (HPNer), it was their first introduction to the PNDU family, having come with good friends Tracey and Sophie (on Home Enteral Nutrition). Locals, Robyne (HPNer) and Tom, also new to PNDU, were welcomed, and it was lovely to also meet local and PNDU member, Celena (HPNer). Queenslanders Eileen and granddaughter, Mayana (HPNer) who had only been home from hospital for 2 weeks, came with daughter Zoe and her daughter Tegan. Mayana had everyone amazed with her energy levels, as she raced here and there around the gathering. Although locals Melinda, Gerard and Molly (HPNer) came towards the end of the gathering, it was still great to meet them too and put another face to a name.

In all, a wonderful opportunity for HPNers and carers to meet, share stories and know that we're not the only ones living with this unusual life support therapy.

After leaving the picnic, we had grand plans to wander along Southbank and explore; Sian had never been to Brisbane before and I had only spent one long-weekend there BI (Before Illness) but instead the sky decided to unleash armageddon, also known as a tropical storm. In the end we retreated to a cab, looking like drowned rats, to get back to the city, buy groceries and rest.

By Monday my energy reserves were running low after two huge days, but I told myself to harden up, ran an extra saline and made it to the venue for the AuSPEN HPN consumer workshop with about 30 seconds to spare before starting time. What followed was a fascinating mix of presenters on topics of all kinds, from the advocacy work of our sister organisation in the UK, to the benefits of various venous access devices, to the breakdown and explanation of the different kinds of lipid mixtures available, the importance of eating for kids on HPN, what AuSPEN does, and the important role PNDU plays, as well as a great presentation from Carmel, telling us her HPN story. All things that would mean nothing to people who are not immersed in the worlds of HPN and medical nutrition the way that we and our families are, but to us are vital information.

I'd like to thank AuSPEN for all their work to put this fantastic workshop together for the benefit of those of us living with HPN. The knowledge of both the presenters and the other participants in the room was invaluable, and I have a list of queries and comments to take back to my team. During the final open session, it was refreshing just to ask questions about various line locking methods and pumps and have people understand what I'm talking about, let alone be able to give me an answer! It was also great to hear what people are achieving whilst living with a drip, but also some of the struggles and hardships people have been through. Sometimes I read the emails from our group and think I must be doing something wrong; people are working, raising kids, travelling and getting on with life, whilst I still count a good day as being one when I shower, dress and leave the house without issue. Meeting people in person helped me to realise that everyone is going through similar ups and downs, and facing many and varied challenges. I would never wish these difficulties on anyone, of course, but it was nice to hear that I'm not the only one facing them.

By the end of the day I was completely exhausted and dragged myself back to our unit to collapse in a heap. I DID manage to rally enough to go out for dinner with my sister... Seafood is one of the few things that really agrees with me, and I was determined to make the most of being in a city with a plentiful supply.

With the social gathering and workshop over, we had two full days in Brisbane to spend in whichever way we chose. Dodging another crazy storm, we managed to fit in a respectable amount of shopping, sightseeing and eventually we even made it back to Southbank to ride the Brisbane Wheel (yes, we acted like tourists unashamedly). I did get rather a shock when I heard my name being shouted as we passed the artificial beach section of the riverbank; my clinical nutrition nurse and dietician were there dangling their feet in the water to cool off during the Gastro2015 conference lunchbreak.

We returned home on Thursday, which was both a relief and a bit sad as the end of holidays often are. Travelling with PN definitely has its benefits; the amount of empty space in your suitcase after using the various dressing packs and lines etc. means shopping is positively *required*; but more importantly, it is achievable with the right planning and support. This is probably not news to most of you, but I certainly received a huge confidence boost from this trip and will not be as hesitant about travel in the future.

Rumour has it that the AuSPEN HPN consumer workshop and PNDU social gathering next year will be in Melbourne, and if so I will definitely be attending both events. I would encourage everyone who is able to do the same. I want to thank PNDU sincerely for the opportunity the grant gave me to participate this year, and the encouragement and support I have received from everyone involved.



Sian (left) and Lara (HPNer) on the Brisbane Wheel



Tony at our meeting point – the upside-down elephant



Tony, Alison, Fay (HPNer), Carolyn (HPNer), Sophie, Tracey, Lara (HPNer), Sarah, Lourdess, Madeline, Chris, Neil, Celena (HPNer), Eileen, Mayana (HPNer), Jane (HPNer), Sian, Lara (HPNer), Zoe, Robyne (HPNer), Tegan, Tom



Fay (HPNer), Jane (HPNer), Celena (HPNer), Lourdess, Sarah, Tracey, Sophie



Lara (HPNer) and Lourdess



Lara (HPNer) and Sian



A very jet-lagged Carolyn (HPNer)



Tracey, Brooke

Celena (HPNer), Tanya, Chris



Dylan



Eileen, Mayana (HPNer), Zoe





Tom, Neil, Gerard, Molly (HPNer), Melinda, Jane (HPNer), Celena (HPNer), Robyne (HPNer)



AuSPEN HPN Consumer Workshop

Infusions at Infuzions – Confusion?

Editor's note: Is this a place for HPNers only? You must be infusing before you can enter? Karen (PNDU's convenor) and Carolyn (UK's PINNT [HPNer support group] president) found this restaurant whilst infusing and out on the town in Sydney recently. It's an Asian restaurant and they had very yummy Asian tapas. 2 HPNers + 1 restaurant = 3 infusions!



What's the point?

WORDS BY KAREN

For 4½ days in the last week of September, I exhibited for PNDU at Gastro2015 in Brisbane. Gastro2015 was a big conference combining the annual conferences of the Gastroenterological Society of Australia, the World Gastroenterological Organisation, plus various smaller medical groups, including AuSPEN (Australasian Society of Parenteral and Enteral Nutrition). It was aimed at medical professionals and clinicians with nearly 2,000 delegates in attendance.

The exhibition hall was huge with some 63 trade exhibitors (pharmaceutical companies and all things 'gastro', including a Micrel stand for an HPN pump!). They were long days and to be honest I was very tired by the end. Who would think that standing at an exhibition booth talking to people could be so tiring!

So why bother? What's the point of PNDU exhibiting at a conference like that, especially when it cost money for PNDU to exhibit this time? Well, let me explain...

Gastro2015, because it was combined with AuSPEN's Annual Scientific Meeting (they don't combine every year), was a really important event in PNDU's calendar for a number of reasons:

- there was great opportunity to meet up informally with our Baxter Healthcare and Fresenius Kabi friends;
- as well as opportunity to network with other patient support groups like IBD Group, ausEE, Crohn's & Colitis Australia. Because of the crazy cost to exhibit this year, we were fortunate to be able to share an exhibit with our



Karen (right) and PINNT Chair, Carolyn, at the entrance to the Exhibition Hall

friends at ausEE, which worked really well.

- Alongside the conference, Chris and I formally met with AuSPEN Council members to discuss our activities and other matters of mutual interest or concern.
- And a last really important reason was to continue efforts to reach all the Aussie and Kiwi clinicians caring for those on HPN, and let them know that PNDU exists and what we offer HPNers and carers!

There are still many HPNers and carers, doing it tough on their own, unaware of PNDU's existence and the support we offer by sharing life with others travelling the same road. And it's primarily through our clinicians (or accidentally stumbling across us on the internet!) that HPNers and carers find out about PNDU. Not everyone needs a support group, however the value and need for patient support groups are recognised worldwide, including in AuSPEN's HPN guidelines: "patient support groups... provide assistance, encouragement, moral support, and social interactions". Every Aussie and Kiwi HPNer and carer should have access to information about PNDU and we continue to strive for this.

Apart from meeting HPN clinicians who didn't already know about PNDU, and sharing our information and resources with them, it was also great to make contact again with those HPN clinicians we already know and who are great supporters of PNDU's work.

So yes, it was a long and very tiring week, but so worthwhile for PNDU!



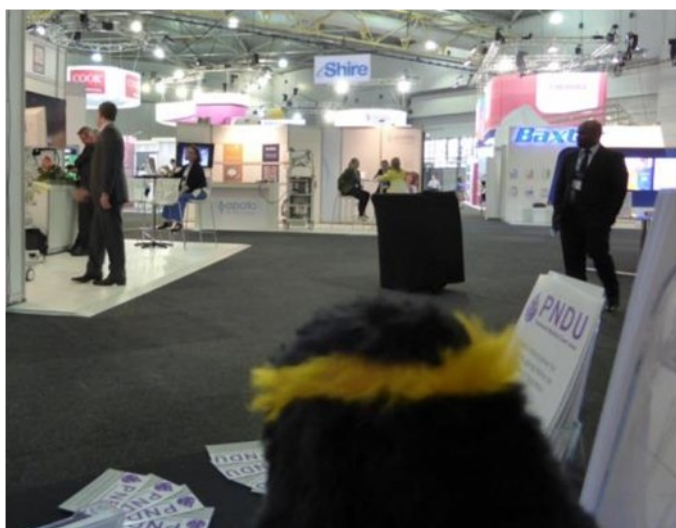
Karen and ausEE's President, Sarah, at the joint exhibit for PNDU/ausEE



Our friends at Baxter Healthcare...



...and Fresenius Kabi



Pendoo's view of the exhibition hall during session time



Micrel's exhibit for their Home PN pump and backpack



The exhibition hall during session break (photo courtesy of Gastroenterological Society of Australia (GESA))

Easing the trauma of the Emergency Department

WORDS BY CHRIS

In light of some recent discussion on the PNDU Google Chat Forum, PNDU decided to get a quick idea of how many members have a letter to present when they arrive at the Emergency Department (ED); if any members don't, have they had trouble obtaining one; and for those who have one, what is included in the letter.

Here is a summary of responses to this short survey:

- Just over half of the respondents (9 out of 17) don't have an ED letter. Of that number, most (7 out of 9) haven't asked their hospital team for one.
- Two out of the 9 respondents asked for a letter for ED but were declined by their hospital team. One of these has received a letter for travelling.
- The two who have been declined were told that their hospital knows how to deal with their situations/care, so a letter isn't necessary.
- There are quite wide variances in what is contained in the ED letters of those who do have one.

Those members who hadn't asked for an ED letter (or had an out-of-date letter) and who believed a letter may assist them, were encouraged to talk to their hospital team about the possibility of them providing one, giving the reasons how they believed it may assist, particularly if they are away from their hospital when an emergency happens. It was suggested, if possible, they discuss what they believe would be good to include in the letter, including the suggestion in AuSPEN's 2008 HPN guidelines (below), all the while recognising that our hospital teams are responsible for our clinical care, and make decisions based on what they believe is best for us.

Paragraph 3.4 of AuSPEN's 2008 HPN guidelines says:

"3.4. The patient and carer should receive an individualized care plan that includes overall aims and monitoring plan.

Patients and their families/carers should know all people who have significant roles in their care (with a written record of their names, positions, and contact details). *The patient may be provided with an open admission letter and/or written pathway for emergency/ambulance services. The patient may also be provided with a summary document of his/her condition.*" [Italics added by PNDU]

Following on from this Google Chat Forum discussion and survey, I was asked to write about my family's own

experiences with and without a letter to present on arrival at the ED in an HPN emergency. I and my family are carers of my 2 grandsons on HPN, and also spent 10 years caring for my adult brother-in-law on HPN. We have had many experiences in ED! Below are some of my experiences and observations.

Life with Intestinal Failure (IF) requiring HPN can at times be difficult, complications from the underlying disease or occasionally associated with the HPN, can necessitate frequent trips to hospital. But most people on HPN, can achieve a relatively good quality of life. Eventually we all become somewhat comfortable with our daily routines and treatment schedules. Attending regular hospital appointments, we are surrounded by the familiar faces of our specialist PN team. But what happens in an emergency trip to ED?

The reality is when things go wrong, they will most often go wrong outside of normal hours! Presenting at the ED can be a traumatic experience at any time, the experience can be even more traumatic if you encounter ED staff who are unfamiliar with your condition and central line care. If you are travelling you might find yourself in a non PN treating hospital, many miles from home. You may not be well enough to explain your condition to the ED staff. Will your carer/companion be able to explain your condition?

Over the years we have had to present at the ED for various reasons including, blocked/occluded, cracked, broken or migrating central lines. Once we have been assessed by the triage nurse as not immediately life threatening, we take a number and wait in line for treatment. This is understandable in the very busy and highly stressful environment of the ED. For us, one of the most frustrating and misunderstood reasons for presenting at the ED, has been complications with central line infections (sepsis).

Just as our treatments vary between hospitals, so too, we have found, do the emergency departments vary in how they respond to; and deal with the situation of central line emergencies, particularly when we haven't had a letter from hospital team to show ED. Some of our worst experiences have been:

- Extended waiting time because there isn't anyone trained in paediatric CVL access in the ED. As parents or carers once inside ED at our hospital, we are not allowed to access the CVL either, just adding to the frustration and waiting times, for blood cultures and antibiotics, while ED staff track down a trained hospital staff member.
- ED staff, for one reason or another can't or won't contact your treating PN team or specialist, after hours.
- Presenting with high temperature and rigors then being told, you just have a cold or flu bug and discharged home without blood cultures being taken, only to return within 24 hours with septic shock, admitted to ICU.
- Explaining the situation to the triple zero operator can also be very time consuming and extremely frustrating also, eg "if they're shivering put another blanket on them".
- Confusion as to whether or not to pull the central line is a common call. When a young intern hops on the bed and wants to pull the CVL, you realise there is lots of confusion and little understanding of the HPNer's condition.

All HPN patients and carers have been taught the seriousness of central line infections and the signs to look for. From our experience the first signs of central line infection, will occur soon after connecting the PN (we connect around 6pm). Body temperature may at first drop below 35 degrees then suddenly spike to 40 plus, shivering with rigor may occur.

If any symptoms occur, our first step is to stop the PN and clamp the line. Then head for the hospital or dial triple zero.

Over the years, after each difficult ED episode, we discussed the problems with the PN team. At first we were given a simple letter of introduction without any contact details for our PN team or explanation of likely reason for presenting at ED. We found this early version of the ED letter wasn't very effective.

In consultation with us, our grandsons' hospital has now provided us with an emergency action plan in line with what is suggested in paragraph 3.4 of AuSPEN's 2008 guidelines (above). So we now have in place:

1. a letter of introduction and ED management plan, detailing assessment and initial management of a presentation with possible sepsis, including contact details for our HPN team.
2. any hospital staff entering the details into the hospital computer will open a Clinical Applications Portal (CAP) Alert on the hospital computer system. This alert explains the medical condition, triage procedure, ED management plan and contact details for our treating specialist.
3. The CAP alert will then appear on the ED central touchscreen.

This emergency action plan is actually yet to be trialled, and we hope we will never have to use it! After a succession of bad experiences however, there is some comfort knowing we have a plan in place should the occasion arise when we need to use it. We have also been advised to carry a copy of the hospital's central line care procedures and make hospital staff aware of this procedure.

Dave at Oley, 2015

WORDS BY DAVE

Editor's Note: Not long before existing and new PNDU members enjoyed AuSPEN's recent HPN consumer workshop and PNDU social gathering in Brisbane (see "HPNers Socialising and Learning in Brisbane", above), Dave was across the seas at a similar conference event in the USA, just on a much bigger scale!

This July I attended the Oley conference held this year in Albany, New York USA. It was the second time I attended the conference and an experience which was informative and inspiring.

For those who are not familiar with the Oley Conference, it is the largest conference focussing on enteral and parenteral nutrition open not only to consumers but clinicians and health care providers working in the field as well. The unique mix of delegates means there are many opportunities to engage personally with people who might normally be on the other side of the phone in either the day to day management of one's own medical care routine or for professionals, at work.

Having first attended the conference in 2013, I had the advantage of already knowing many of the staff and attendees and received a warm welcome from the friends I met two years prior. Most of the attendees are American but there were also other international delegates. Many of the consumer delegates return to the annual conference every year not only to learn more about the latest in treatment and research but also to network with others that face similar issues and challenges, and who over the years, become fast friends.

The conference program for the 3 day event covers a range of lifestyle and medical topics. Interestingly, as many consumer delegates attend with their families, special separate sessions were also run to offer families (and specifically, spouses) opportunities to share and learn from each other in dealing with relationships, financial management and effective advocacy.

Medical sessions were offered in the mornings on topics ranging from *Recognising Signs of Bloodstream Infections* and *Overcoming Vascular Access Challenges*. In the afternoons the conference offered interactive workshop programs led by clinical and industry professionals which were conducted in small groups to give everyone an opportunity to direct practical questions to the workshop trainer. Workshop topics ranged from highly specialised subjects such as *Recognising and Treating Bacterial Overgrowth* to broader topics such as *Short Bowel Syndrome: Management and the Best Outcomes*. The conference also included an awards ceremony, industry recognitions and lots of well-attended social activities.

I found that although I was already aware of many of the subjects and points raised in the conference program, the open discussion and integration of hearing clinical experiences with personal consumer stories led to a deeper learning experience of and also was a trigger for queries and topics of discussions with my daughter's medical team at home in Sydney. On my return, our team at home were very interested in hearing about the live issues in enteral and parenteral nutrition for EN and HPNers in the States and receptive to re-examination of Ariel's treatment program in light of things I'd learned and which we subsequently discussed.

In all a trip to Oley is well worth the logistical effort. It is something that our family will continue to participate in as part of our mission to stay abreast of new research and to maintain access to relevant peer experiences and connections to a very responsive and well rounded group of medical experts. One day we hope to bring Ariel with us to meet the families attending Oley so that she knows that she not only has an extended family of HPN friends in PNDU but also a warm, inclusive community across the ocean who are different, just like her.

- Dave, father of Ariel (4yrs)



A Funny Thing Happened...

WORDS BY GILLIAN

Recently we had two pet related posts on our Google Chat Forum...

- We have four large dogs and they all love the PN. I've been on PN for a loooooong time and it's never done any harm to the dogs. ☺
 - My cat loves to lick up any of my PN that drips on to the floor. I hope it won't kill her! She's been doing it for years though. ☺
-

A Brief History of (parenteral) Time

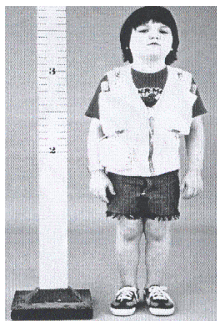
PERSONAL RECOLLECTIONS BY G/L

Sir Christopher Wren (1632-1723), the famous architect of St Paul's Cathedral in London, is generally considered the father of intravenous (i.v) therapy, when a student at the University of Oxford. He designed the first working infusion device using a pig's bladder as container and a goose quill needle to infuse milk, ale, oil and opium to dogs. Over the next 150 years these experiments led to the first blood transfusions between animals, animals to humans and eventually after the elucidation of the circulation system, blood groupings and sterility, successful blood transfusions to humans.



However it wasn't until the Korean war in the 1950's that i.v therapy began to be widely used by the American forces and the first attempts at intravenous feeding were made, with sterile solutions of amino acids, such as Amigen (Baxter) and Aminosol (Abbott and Vitrum), produced by hydrolysing casein (milk) protein.

Credit for the early attempts at 'hyperalimentation', with combinations of amino acids and high strength glucose is usually given (especially in USA) to the pioneering papers of Dr Stanley Dudrick in 1968 that demonstrated adequate growth of premature babies by this life-saving therapy, and later enabled his patients to become ambulatory and then administer their alimentation at home using small containers in the pockets of a waistcoat (vest). I was fortunate to spend time with Dr Dudrick and colleagues in the mid 1970's at his centre in Texas and have remained friends ever since.



Early ambulatory Hyperalimentation.



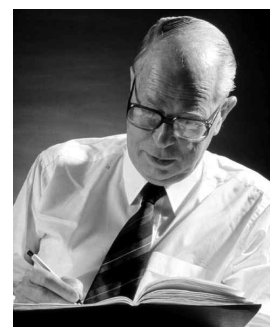
Hardy and Dudrick: 1976 Thin Friends; and 2010 Fat Friends

However the Americans were constrained by not having a safe and effective i.v lipid emulsion (IVLE) as a concentrated source of energy and for the supply of essential fatty acids (EFA). Early American patients had lard rubbed over their skin to avoid EFA deficiencies!

Professors Arvid Wretling and Oscar Schuberth, working in Stockholm, are considered by many in Europe as the fathers of Total Parenteral Nutrition (TPN), i.e. the i.v administration of complete nutrient mixtures, including lipids.

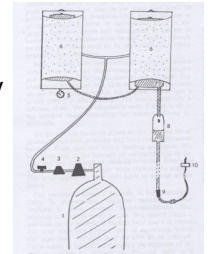
Intralipid, an IVLE based on soyabean oil was developed by Wretling when working for the Swedish company Vitrum and the product was registered in Sweden and UK in 1961. In the next few years the British Medical Journal published several papers describing use of PN with IVLE. Hydrolysates were eventually replaced in the 1970's by more precise pharmaceutical mixtures of pure synthetic amino acids, such as Synthamin (Baxter) and Vamin (Vitrum), which over time by a series of mergers and take-overs, became KabiVitrum, KabiPharmacia, Pharmacia Upjohn and finally FreseniusKabi.

Serendipitously the crude protein hydrolysates also contained significant amounts of trace elements, so that in the early days there were no reports of micronutrient deficiencies. Unfortunately, as the purer synthetic amino acid solutions gained in popularity, trace element deficiencies became inevitable and the very first paper describing zinc deficiency in long term



Arvid Wretling

PN was published by a group at Auckland City Hospital, New Zealand in 1976. The first evidence of PN 'down under' is an anecdotal report by a Dr D.A. Coates from Australia, published in 1966, followed by another in 1972, describing the benefits of including alcohol (Fosters xxxx?) as an energy source in the PN regimen!!



New Zealand

We have no precise records of early HPN in Australia but Dr Jack Havill, a pioneer who, for many years managed our founder Brenda, until he retired, published an account in 1977 of a novel PN infusion apparatus [see right] used by his first Kiwi HPNer. There is still some argument about where the first HPNer lived. In early 1973 Dr Khursheed Jeejeebhoy in Toronto Canada, described a patient who had been on HPN for 23 months, and pictured is a Brazilian HPNer with a crude 'backpack/ bottle carrier' from 1971 [see below, A], but the earliest published record is from a very dedicated but modest pair of Gastroenterologists, Drs Stig Jarnum and Karen Ladeforged in Copenhagen Denmark in 1970.



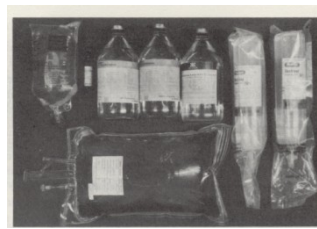
Brazil, A



USA, B



France, C



UK, D



UK, E

In the early 1970's, all PN in UK and Australasia was a complicated therapy with multiple glass bottles [see above B], but French pharmacists were transferring their PN solutions into an expensive 'sausage shaped' silicone rubber container, worn by the patient [see above, C], that was washed out and 're-sterilised' before being re-used.

Together with colleagues at St Marks Hospital, London in 1975, I designed and developed the first low cost disposable sterile 3 litre plastic bag for PN that was clinically evaluated then manufactured by Baxter UK. PN was compounded into this single container from all the separate glass bottles in the hospital pharmacy [see above, D and E]. This allowed PN to become an ambulatory therapy and for the first UK HPNer to go home in 1977.

Subsequently, in the late 1980's the need for an HPN support organisation became apparent and eventually, over 25 years ago, PINNT (UK's HPN support group) was born. The history and evolution of PINNT is another story, but my early involvement with the UK support group was a tremendous experience for me that proved invaluable when Brenda and Jacqueline asked me to help form PNDU in 2009. The past 6 years have been very exciting and it is extremely gratifying to see how our Down Under group has grown and matured.

But now, with much regret I have decided to take myself off the PNDU Google Chat and Face Book forums. I have recently been elected Chairman of the newly created International Clinical Nutrition Section (ICNS) of A.S.P.E.N. (the American Society of Parenteral & Enteral Nutrition) and have also been invited to join the Faculty Advisory Board (FAB) of the international Conference for Advancing Nutrition (iCAN).

In these roles I have already been invited to make a video recording of my *Micronutrients in PN* lecture at the ESPEN congress in Portugal, and have other lecture invitations in UK, China, Poland and Turkey over the next few months. So I shall be extremely busy and I'm not getting any younger!

However, I must stress that **I am not leaving PNDU** and, at the request of the Management Committee, will remain a member of the MC for the time being, excluding myself and declaring any possible conflict of interest, when any agenda items could conceivably relate to the industry. I will also continue to contribute to, and assist with, Dripline, whenever required.

I shall be more than happy to stay in touch with you all. You can send a message to me anytime, via contactpndu@gmail.com, and I will respond to you independently from PNDU.

With best wishes to you all for a healthy and happy parenteral future.

Thank you Gil!

WORDS BY KAREN

As the horizons of his work career widen, Gil has sadly had to step aside from our private PNDU forums (Google Chat Forum and closed Facebook group). As our resident clinical nutritionist, we will certainly miss Gil's informed

contributions to various discussions on the private forums. Having someone able to give information about studies or findings on various aspects of PN; the history of HPN (including his own involvement in making HPN possible); or information on what's happening overseas, Gil's input has been greatly appreciated since PNDU began.

Gil is a founding member of PNDU and last year, alongside Brenda and Jacqueline, received PNDU's inaugural Lifetime Membership Award in recognition of his encouragement and contribution to PNDU's establishment back in January 2009. Thankfully we aren't losing Gil altogether, and he will remain in PNDU's Management Committee as Assistant Treasurer, as well as continue to contribute to Dripline.

Thank you Gil for your ongoing interest, involvement and desire to have the patient perspective taken into account at all levels of our care. We appreciate all your work on behalf of PNDU and wish you the very best for the future.



PN Gardening Tips

WORDS BY GILLIAN

Some HPNers on our Google Chat Forum recently revealed some PN (Parenteral Nutrition) related gardening tips.

- For the last 16yrs I've fed the outside plants, especially man ferns, but also camellias, rhododendrums and other acid loving plants with left-over PN. Also, I've given well- watered down PN to indoor plants such as ferns and plectranthus. I never thought about the lipids.....maybe that's why they all died!...only joking, they all seem to do well.
- Not much of a gardener myself, but I would have thought any form of PN would make a good fertilizer. Omegevan® and SMOFlipid® both include fish emulsions, which are great fertilizers. Carbohydrates (sugar) and lipids/fats are essential in fertilizer - both Aquasol and Nitrosol contain a mix of above. Maybe we have a new market for HPNsol, because believe it or not, ground up soy beans make great lawn fertilizer!
- I put PN, watered down, on veggies, but the gardenias don't like it!

I've known several HPNers who diluted their unused PN and used it to feed tomato plants with great success, but can't remember dilution ratio.

So no excuses for sad, neglected plants, or for throwing away the last dregs of PN!

Supplying Life Changing Solutions

WORDS BY JESSICA GORDON OF BIOMED, NZ

Hi, my name is Jessica Gordon and I am the Product Group Manager for Biomed Ltd, which is one of the two suppliers of HPN in New Zealand. The company was originally developed as the offsite compounding unit for the three Auckland public hospitals. Today, Biomed is a privately owned and operated company that supplies a number of life changing solutions around New Zealand and Australia. Biomed Ltd supplies HPN to a number of pediatric patients in New Zealand.

A very rewarding part of my job is to provide support to the hospital and families of HPNers. Many of the HPNers we look after have long term conditions that require them to be on HPN for a long period of time. For new HPNers, I liaise with the hospital and ensure the family has a smooth transition from the hospital system to the HPN system. For families who have a family member on HPN and have been discharged, I provide support for any queries around their HPN and service when they are at home and/or in hospital. This support is available to the families 24/7 so they are always able to get hold of someone when they need help with their HPN.

I came to know of PNDU when I first started at Biomed Ltd and was learning about the world of HPN. Since then, I have been in touch with the team and have told many of our patients' families about this support group. I finally met Gillian and Karen at the HPN Symposium in November last year and it



was such a pleasure to finally put names to faces. PNDU always keeps me up to date about other HPNers around New Zealand and Australia [via Dripline articles].

At Biomed Ltd we are passionate about our patients. Being able to see the impact we have on patients and their families is very satisfying. We have come to know the HPNers and their families very well over the years, which has encouraged us to ensure they receive the best HPN service possible.



Jessica with Gillian at PNDU's GastroNZ exhibit in Auckland 2014

Oops! Ostomy Accidents

EDITED BY GILLIAN

Editor's Note: *Since a common outcome of Intestinal Failure (IF), the reason we are all on Home Parenteral Nutrition (HPN), is to have an ostomy, I felt it was appropriate to share some of these comments from our Google Chat Forum. I think it shows the resilience that people develop when dealing with chronic illness and its associated problems.*

Has anyone else had some bad stoma bag mishaps? I just had one this afternoon and it amazes me how far and wide a bag full of liquid poo can fly!! Thankfully a bathroom is easily cleanable and disinfectant-able, I was at home and not expected to be anywhere soon, and it's a sunny day for a load of washing. ☺

I had [my HPN child with stoma] with his sisters at their piano practise - a rather fancy teacher in a posh part of the city with WHITE carpet.... Who has white carpet??? Well his bag leaked and stained drips for a few metres before I figured what was happening. All of us were horrified and it was so hard to get out. The girls have a new piano teacher since then... The criteria was she had to have dark carpet with optional piano qualifications! ☺

Trampolines are also fun when the stoma bag goes pop at a birthday party ... And then [my child] wondered why he was the only one left on! All part of the fun of stoma bags right? ☺

I would imagine most of the kids have had a few exciting stoma mishaps! [My HPN with stoma daughter] has had heaps! I agree that trampolines are not good for stomas! Neither is gymnastics or dance lessons! A few weeks ago she was running around a friend's house with a whole heap of kids and left a trail behind her. It was so embarrassing at the time but thankfully after a few litres of disinfectant, a change of clothes for all the kids and a bottle of wine for the adults, we all laughed about it. I think sometimes you have to just laugh and not focus on how abnormal our lives are at times! No matter what stoma appliance we use (and we have tried heaps) there will always be a few mishaps with active kids! I would rather she live her life as much as possible than live in fear of her bag exploding! ☺

We have had so much trouble with [our HPN with stoma son's] bags lately. He's starting to sit up and trying to roll over...just leads to leaks. Physiotherapist's appointments aren't great for bags either. We went through 6 bags in 2 days last week! We are trialling some new bags but they're not looking that promising. To think I'm finding his stoma care harder and more frustrating than his PN care! ☺

I find it really hard being a young women with a permanent stoma. I am always terrified of getting leaks. Luckily I haven't had any when I've been out. I've had a few when I've been asleep - it is not nice to wake up in the middle of the night to that mess!! I wish I could be like a kid and not so self-conscious!

The longer I've had my stoma the worse it has become. Thanks for sharing your stories, your humour and unending positivity ☺

I have woken up in the night in a brown mess and have had to turf my husband out of bed to change the sheets etc...it doesn't make for a good night's sleep, does it? ☺

We were visiting relatives and staying at a nearby B&B for a change and a treat. I changed my two-piece system bag, had breakfast, and bent over and the bag fell off – quite full because of breakfast!!! Yellowy-brown mess everywhere on the lovely cream carpet. We cleaned it up as well as we could, leaving a large stain. It was also check

-out morning, so I had to explain this all to the lady – very embarrassing for me, but she was lovely. We moved a rug over the stain for her next guests due that day, and of course we paid for the cleaning. 😊

Keeping a Record

WORDS BY GILLIAN

Being on HPN (Home Parenteral Nutrition) means that various aspects of our health are regularly monitored through a variety of tests and checks, such as blood tests or scans. When visiting clinicians, either our regular hospital team or another specialist, it helps to be as precise as possible with the information that we give them. Recently on our Google Chat Forum some ideas were posted on preparation for visiting your doctor, including record keeping.

- Have a reliable person with you for important appointments, as a support person and in case you forget the outcomes of the discussion.
- Have a list of what you want to discuss at the appointment so that nothing is forgotten.
- Keep a diary between appointments of what's happening with your body - weight, food and fluid intake, hours of sleep, energy levels, gut symptoms, etc. If you have 'facts', it holds a lot more weight (excuse the pun) with medical professionals. These can be kept on a spreadsheet.
- Send this information to your specialist, together with a few bullet points of what you want to discuss/propose at your appointment, a week before your appointment to give him/her time to digest, discuss with other team members, etc. Recent blood results should be attached if available.

Having this information to hand helps you feel more in control of what might be discussed and decided at the meeting, and also shows the doctor that you are actively involved in monitoring your health.

International Alliance

WORDS BY KAREN

As a founding member of PACIFHAN (International Alliance of Patient Organisations for Chronic Intestinal Failure and Home Artificial Nutrition), PNDU continues to play an active role in the establishment of this alliance with the aim to hopefully soon be able to start projects and work towards our goals. PACIFHAN meetings are held by Skype every 4-8 weeks for 90 minutes with founding patient organisation representatives from UK, Poland, Sweden, USA, Czech Republic, Italy and Australia/New Zealand. In the southern winter months, this has meant 5.30am Skype meetings for PNDU's President and 9.30pm for the European members! Bring on daylight savings when the time zone alignment is a little more favourable!

With an agreed name, logo and goals, 4 member organisations exhibited on behalf of PACIFHAN at ESPEN 2015 Congress in Lisbon in September in order to proclaim our existence to the medical world. (ESPEN is the big European equivalent of our AuSPEN and it was on the sidelines of ESPEN Congress 2014 in Geneva where we all met to start working towards an alliance.) PNDU didn't have a representative involved in this year's exhibit, but another PACIFHAN member has written the following report.

PNDU looks forward to when the set-up processes for PACIFHAN will be complete and we can work together with other member patient organisations to promote international sharing of information and resources to improve the quality of life of patients on HPN.

Words by Darlene, Oley Foundation

We were introduced to the beautiful city of Lisbon as we flew over the Atlantic, circling over the Tejo River to the airport. WOW! That sentiment continued over the ESPEN 2015 Congress!

The 'work day' started with the Skype call around the world with member organisations who weren't able to attend, and afterwards there was a bit of fun! Together we set up the PACIFHAN exhibit, starting with a blank slate. Thanks to those who were willing to balance cautiously (or not!) on chairs to put up our name, our lovely logo, a set of photos featuring one patient from each member organisation along with the slideshow, our new brochure that arrived at the hotel in plenty of time, balloons to provide additional color, and candies to lure in those delegates who might not have visited us. This was overseen by seven enthusiastic PACIFHAN members!

We were visited by attendees from six continents, including several clinicians from countries that do not provide Home Parenteral Nutrition for a variety of reasons (notably some South American countries and Romania). During the exhibit hours (6 hours on Saturday, 9 hours on Sunday and Monday and 3 hours on Tuesday) we had about 48 people sign up

requesting information. Many of these were so amazed by our slideshow that demonstrated an excellent, adventuresome lifestyle of those on Home Artificial Nutrition. Other exhibit visitors were from countries with persons on PN and enteral therapies at home, but with no patient organisations. Several of these were impressed with the role of such groups that are important to quality of life from the patient's point of view. I think they were impressed that this outlook for patients may be somewhat different than the clinicians' viewpoints!

Monika, from Czech Republic, presented an outstanding discussion of PACIFHAN at the Open Meeting of ESPEN's HAN and CIF Workgroup (Home Artificial Nutrition and Chronic Intestinal Failure Workgroup) on Sunday morning (7:30 am!) and our group was well received! Additionally, I think that the enthusiasm of not only our group but also of the HAN workgroup will be important to the PACIFHAN longevity.

All in all, I believe that all of us who represented PACIFHAN were impressed with the success of the exhibit. It really validated the importance of our association for the betterment of life on Home Artificial Nutrition.



Sydney's latest gathering

WORDS BY MEL

On Saturday October 10th, a number of Sydney members of PNDU met for a social gathering at Jane and Neil's house on the Upper North Shore. Whilst a few of our beloved regular members were noticeably absent (Gillian and Ray, and Renee and Mervyn!), the remaining patients and carers revelled in the chance to catch up. It was also wonderful to see a few new members joining us for the first time. These catch ups provide a rare opportunity for us all to meet with others who really understand the journey we are on.

We were blessed to have Carolyn (Chair of PINNT [support group]) from the United Kingdom, and Emily from Missouri, USA, share their experiences. I think we were all quite stunned at the wonderful services offered by homecare companies in the United Kingdom in particular. The personal, temperature controlled fridges specifically designed for patients and the insulated large boxes for delivery where ice bricks could not touch the PN, were some aspects which we all thought wonderful. However, we are always reminded that, amongst other challenges, the patient numbers in Australia are so vastly different from the U.K. and USA. Perhaps one of the most exciting elements of homecare in the UK is the delivery by a registered driver in a temperature controlled vehicle (if not using the insulated boxes) who has a key to access the patient's fridge, unpacks the boxes and sends a message to the patient when their PN has been delivered. So there is no need as we have here in Australia of often having to wait at home most of the day for it!

Many of those of us who care for children on HPN were thrilled to meet Emily, who has been on HPN since 6 months of age. It was wonderful to see her now living as normal a life as possible! She is a delightfully articulate young lady who was only too happy to share her personal experiences of growing up with HPN. Emily attends college in Boston, a long way from her family and often travels nationally and sometimes internationally. She has kindly left her contact details and is keen to answer any questions you may have about her journey. Please contact Karen at contactpndu@gmail.com if you would like Emily's details.

In tandem with Carolyn and Emily, Karen also shared the homecare overview and PN provision we have in Australia. It was so interesting to compare the three countries and we were all encouraged by what we heard and the reminder of how fortunate we are to live in countries that provide HPN and where travel dreams can often become a reality. We were also encouraged to discuss with our hospital teams any questions or ideas and suggestions.

There were a record number of children on HPN at this Sydney gathering! Jordan(brother Logan was sadly ill and unable to come), Daniel, Milla, Ariel and Emily all bounded through Jane's beautiful garden with their siblings in tow. It was just such an amazing blessing to hear the sound of laughter and know that despite all their medical challenges, the children were behaving just like any other group of kids. They even had to be told to slow down a few times! We are hoping to have further play dates with the children over the next few months. It is so isolating for these children and parents, so for them to play with someone who also has 'bits and bobs' and who understands when one of them has to sit down as they are a bit hot and dehydrated, is wonderful. We encourage any other parents of little ones in the wider Sydney area who would also like to catch up to please let us know so we can inform you of dates and times! Email us at contactpndu@gmail.com

Many many thanks to Jane and Neil who have once more opened their home to us all, and graciously didn't kick us out when we stayed long past the 3pm finishing time.

Many thanks to Karen, Emily and Carolyn who provided such an interesting comparison on HPN homecare.

Many thanks to all the members of PNDU in Sydney and beyond, as we continue to support and encourage each other on this most challenging journey set before us.



Chris, Carolyn (HPNer), Dylan, Miranda with Eadie, David with Ariel (HPNer), Jane (HPNer), Josh, Sonya with Milla (HPNer), Mel, Emily (HPNer), Karen (HPNer), Ann-Marie with Daniel (HPNer), Emily (HPNer), Neil, Mal (in front)



David, Karen (HPNer), Ariel (HPNer), Eadie, Miranda, Emily (HPNer), Jordan (HPNer), Brooke, Dylan, Jane (HPNer), Carolyn (HPNer), Chris, Tanya, Sal (HPNer)



All on HPN – Karen, Ariel, Jane, Milla, Carolyn (UK), Emily, Daniel, Emily (USA) [Sal and Jordan are missing]



Wonderful hosts – Neil and Jane (HPNer)



Carolyn (HPNer) (UK) experiencing some of the native birdlife at Jane's

Left: Emily (USA), Sal, Carolyn (UK), Jane, all on HPN



Mal, Jane (HPNer), Carolyn (HPNer), Ann-Marie, Mel and Sonya (at back) enjoying great conversation



Dylan, Ariel (HPNer), Jordan (HPNer), Brooke and Eadie having fun with Jane and Neil's kids' treasures



Carolyn (PINNT Chair), Karen (PNDU President), Emily on HPN from USA presenting a fascinating comparison of HPN in the UK, Australia/New Zealand and USA. All on HPN.



Left: Carolyn (PINNT Chair), Emily on HPN from USA, Karen (PNDU President), all on HPN – a multi-national gathering!

HPN Kids and Eating

Editor's comment: Below are four families' experiences with children on HPN (Home Parenteral Nutrition) who are allowed to eat, but can't or won't. As with all medical information, if you have questions or concerns, these need to be raised with your medical team.

Family 1

I thought I would give you my experience with getting my child B [child on HPN] to eat. I think the key point in getting B to eat was that she needed to say that she wanted to learn to eat and be like other kids. Of course the team at [our hospital] tried to get her to eat over the years, but she just dug her boots in and wouldn't try. B didn't start eating until one day she told me she wanted to learn to eat. She was 10. So I looked around for a private Speech Pathologist. I found one who mainly dealt with adults who had had strokes and needed to learn how to eat again. It was amazing to see the simple techniques that were used. Yes B was scared at times and there were a few tears, but she was determined and within around 6 weeks she was eating and hasn't looked back. I used to sit and watch her eat and just couldn't believe she was doing it! It was that exciting! Of course word got around to the other HPN families about how B was now eating. One Mum, whose daughter was 6, wanted to go to the Speech Pathologist that I had taken B to. She ended up taking her daughter, but because the little girl just wasn't interested, it didn't work, so she stopped taking her.

B has always had either an NG tube, and still has, a peg, for overnight feeds, when not on PN. These kids are very clever when it comes to food. B would always take a lunch box to kinder and primary school and you would swear she was eating - going through all the motions but not actually eating. So don't be hard on yourself if your child is not eating. For our children, eating is a learned thing, not natural. Hopefully one day they will tell you that they want to learn to eat. And then it will happen!!

I suppose B would have been diagnosed with Oral Hypersensitivity, but I personally don't like labels. Our kids didn't have a normal baby life. B was not breast/bottle fed, so missed out on all the milestones that come with eating. Then all of a sudden, I'm trying to get her to eat. It just didn't happen. When I took her to the Speech Therapist, it was one stage at the time. We don't think about what our mouth is doing when we eat and it's quite a complicated process. Step 1 with B was strengthening her jaw muscles. Step 2 was turning her brain reaction off so she wouldn't gag. Step 3 was putting a soft food in her mouth and teaching her to move it around with her tongue. She had no idea what to do with her tongue. There would have been at least another 5 steps before she would swallow. My advice is to get professional help because I honestly believe that you can't do it on your own. B saw hospital Speech Therapists all the time but they didn't manage to help her.

Family 2

Getting A to eat has been an incredibly frustrating exercise for us with no results so far. I've often times blamed our decision to have an NG and then the PEG for A's disinterest and lack of skills with food intake, but we will never know. Hopefully she will turn a corner on that front soon. It seems to be one of the very important, but least controllable treatments. We've been to scores of Speech Pathology sessions, so it's lucky that A hasn't got oral aversion as such, but for all the show that she puts on for us sometimes, very little actually makes it into her tummy. We've backed off lately for lack of energy on our part, but it's a challenge that stares us in the face every day. We're hoping that structured recess and lunch schedule with the kids at school next year will make a difference. A is 4.5yrs now and pretty confident socially (in fact a real busybody and party animal). Physically though, she is not the most stable or coordinated and falls over a lot. I will ask our OT about the hypersensitivity assessment and what to do. We have been doing Magic 123 (which is an emotion coaching program that helps parents encourage positive behaviour and deal with anti-social behaviour. The program manages behaviour by identifying emotional triggers and works by disrupting patterns) which worked for a while, but lately the counting is drowned by her wailing.

Family 3

The paediatrician diagnosed D [the child of an HPNer] with oral hypersensitivity. It's likely a result of the severe reflux he suffered as a wee thing, the GI tube and the vomiting (they thought he had motility issues in his oesophagus at one point). D is a highly anxious child. He has sensory defensiveness in other areas - in new environments, around new people, loud noises etc etc. He doesn't like being out of his comfort zone. Having said that, we challenge him (in small, reasonable measures) and he has slowly become more confident and less clingy. We're trying to toilet train D and that in turn, can affect the success of his eating and other issues. It's difficult to work on everything they need help with! I guess that's why small steps are good - for both parents and child! D was on HPN as a preemie baby, but not for long. He was tube fed breast milk for a long time. This has led to his aversion to textures at 3yo. Prior to that, we had trouble even getting him onto solids. He still won't chew food and dislikes anything in his mouth. With his eating, we haven't progressed a lot. He is still on puree and hasn't learnt how to chew. He was never a baby who put everything in his mouth. I wish he had been, for it would have helped with his eating. I like the book, *Loving Your Kids On Purpose*, by Danny Silk. It's a Christian book, but I think it would be useful for everyone! And 1 2 3 Magic was a good book too, I think they go hand in hand, but 1 2 3 Magic was a bit more simple.

Family 4

We have tried not to label E with anything else. She has enough labels as it is!!! We have always treated meals as if there is nothing wrong with her. She is served a smaller dinner exactly the same as the other children and often just plays, but sometimes will pick at things. She also helps me cook all the time and packs her lunch for school. She actually eats maybe a teaspoon of food every couple of days. I think just being around food and letting her sample lots of food, even if it is just smelling it, has helped.

Supporting our Non-HPN Children

Editor's Note: *Three of our Google Chat Forum members shared the following with us, and may be of interest to others who feel that they, also, have a child who could benefit from having HPN home issues used as a basis for consideration in the HSC and university admission.*

One parent wrote:

My eldest son is doing the HSC this year and we are not sure if he will get the marks for the course he wants to do. He is very able, but seems to have lost his focus and is quite stressed. The school has said he should apply for the educational access scheme, which is for those who have life circumstances that are beyond their control affecting their education. One of these is having a severe illness or death from an immediate member of the family. So this would be me. For one child, early on in my illness, he developed sleep issues which we have since dealt with and managed. Another child had severe meltdowns and self-esteem issues, which the psychologist has said could have been through all we have been through. My eldest at one point told someone at church that he felt he had to be the strong one in the family. This was back when I had long spells in hospital. [My husband] developed depression as well and I think for my son, he felt he had to be the one that did everything and the person to be relied on. I think this is now manifesting itself in his inability to focus and study and at times overwhelming fears of the future.

I have asked my various teams for reports supporting my condition etc and the impact on family life. I just thought that for my kids all the HPN care is normal for them by now and wouldn't impact them. I never stopped to think from an outsider's point of view, it's not normal and therefore to expect an impact on my children emotionally.

The reason why I share this, is just to raise the point of the importance of considering the impact emotionally on our close family members who are journeying with us, particularly children.

I am hoping this is accepted by the university admission centre and helps him get into a course.

Another parent wrote:

Both our teens qualified for this program due to [my daughter's] illness and it lead to [one child] being accepted into a university course that she probably wouldn't have been able to otherwise. We had a good relationship with the school counsellor and hospital social workers.

Unfortunately our kids don't qualify for so many support programs as their needs are so rare and specific. That is so hard for them and their siblings when they have Canteen and Starlight etc so obvious at hospital.

Our older kids all were offered places on Crusader Camps by the hospital chaplain, which gave them some good old fashion fun away from the stresses at home and hospital.

Westmead also has a program for families who don't "fit the mould" to access holiday cottages on the south coast for much needed breaks.

Another parent wrote:

Carers NSW run a young carers program, your children can access this program until age 25.

Please follow this link - it may be of help: <http://www.youngcarersnsw.org.au/the-yc-program/>

Also attached are flyers for the young carer bursary program - a bursary of \$3000 would certainly help at university. [Email PNDU at contactpndu@gmail.com if you would like us to send you the flyers.]

Pampered Pooches

Editor's Comment: In a previous issue we discussed uses for our silver bubble wrap. Below are pictures of Karen's sister's outdoor dog's bed. Tamworth at night in winter can be cold!



A Day in the Life of an HPNer

WORDS BY GILLIAN

I decided to make toilets the subject of this issue's 'day in the life'. Most HPNers have an ostomy of some kind, and this makes daily life an extra challenge when away from home...or even sometimes at home.

In my case, I have a high out-put ileostomy, which is usually predicable only due to its unpredictability. I know certain things will go to the bag with amazing speed, such as coffee, soft drinks or wine, but apart from that, nothing is certain.

I would pit myself against any non-ostomate for being the first to find a public toilet in a shopping centre, new town, or travelling around the country. The toilet symbol is like a magnet which draws my eyes, and provides a reassurance that, if needed, there is a toilet nearby.

I try to do the sensible thing and refrain from eating and drinking much if I am out, or about to go out. Ray and I enjoy a coffee and cake for morning or afternoon tea, but I am now used to having water instead, and sharing the slice with him – they are usually big enough for two, anyway.

Sometimes, despite being careful, I get caught out. A couple of times over the years we have had to exit a freeway to a suburb or town and hunt down a public toilet. This is made easier with a toilet app on my phone – I use ‘Show the Loo’, a free app. [Australia and New Zealand also have public toilet websites – www.toiletmap.gov.au and www.toiletmap.co.nz.] The app isn’t always perfect or easy to find, but it helps if no sign is around. A couple of times I’ve had to ‘go bush’ beside the road and hope the snakes slither away before I arrive. The most awkward time was on a drive to the dog (dingo) fence out of Coober Pedy with two friends. If you’ve been there, you’ll know there is no cover, no convenient tree or bush around, only small sandy hills. So I had to excuse myself and duck down as much as possible behind one of these.

It’s also a nuisance when dining out at a restaurant. I’m sure that if anyone notices me visiting the toilet at least three times over dinner, they must think I’m bulimic, especially since my weight had dropped to a low level about a year ago and I looked too thin. However, if you worry about what people think, especially total strangers who have no place in your life, then you’d miss out on doing a lot of enjoyable things.

Although not directly associated with HPN, most HPNers would be able to identify with my scenarios, and it is just one aspect of Intestinal Failure which can affect our quality of life.



No place to hide - Dog fence, near Coober Pedy

Thank You

We wish to thank the following for their generous donations which totalled \$3,475:

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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

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