



DRIPLINE



PNDU

Parenteral Nutrition Down Under

In this issue we say farewell to Karen, PNDU's Convenor, then President, for nearly 10 years, and find out her plans for the next stage in her life; we sadly add another name to our 'In Memoriam' roll; we celebrate an HPNer member becoming a teenager; Jodie completes her series of 3 articles on coping with life with a chronic illness; we gain insight into a mother's feelings when her child is in hospital; we go on another bus trip with Sal and her family; we find out about a new drug that may be of benefit to some SBS-IF sufferers; we find out what PNDU MC has been up to at AVAS conference in Sydney and otherwise; and more, so relax and put aside some time to read, learn and empathise,

Gillian
Editor

CONTENT

- [Farewell to Karen \(PNDU's President\), including an interview](#)
- [A Child's Journey in Hospital Life \(OR, Our Brave Littlies #1\)](#)
- [Home Parenteral Nutrition \(HPN\) Awareness Week 13th-19th October 2019](#)
- [Sal's First Adventure Trip in a Flexible Clipper](#)
- [New PNDU Supporter T-Shirts](#)
- [Revestive® Recommended for Listing on PBS in Australia \(and PNDU's Role\)](#)
- [AuSPEN re Revestive®](#)
- [Birthday Corner](#)
- [PNDU at the AVAS Conference 2019, Sydney](#)
- [PNDU's Latest Member Study – Retraining of HPNers in HPN Procedures](#)
- [Back in Hospital \(OR, Our Brave Littlies #2\)](#)
- [Adelaide Consumer Workshop and Social Gathering](#)
- [Preparing your HPN Child for School](#)
- [Coping with a Life of IF on HPN, Part 3](#)
- [Three Memories – health related - Emily](#)
- [How is NZNIFS Helping HPNers?](#)
- [PACIFHAN Registers in Brussels](#)
- [Packing HPN Needs for a Holiday](#)
- [PNDU Annual Awards](#)
- [In Memoriam](#)
- [Upcoming Events](#)
- [Planning Overseas Travel](#)
- [Thank You](#)
- [PNDU Information: Membership, Donations and Contact Information](#)

ISSUE 28
MAY-JULY
2019





Farewell to Karen

Words by Gillian

As well as being PNDU's 10th anniversary, 2009 is also the year PNDU's first President, who has been with PNDU almost from the beginning, steps down from her role and from the Management Committee. It is with sadness that PNDU says farewell.

For over ten years, from infancy to its currently well-established organisation, PNDU has benefited from Karen's leadership. With a definite vision of where we should be heading and how we should go about it, since late 2011 as Convenor and then PNDU's first President, Karen has led the Management Committee with absolute integrity and commitment to best practice. With the solid support and assistance of the MC members, Karen has increased awareness and credibility of PNDU among Australian and New Zealand clinicians in order for them to be able to refer their HPN patients for support, as well as developing and cementing relations between PNDU and AuSPEN (Australasian Society for Parenteral and Enteral Nutrition), AVAS (Australian Vascular Access Society), IVNNZ (Intravenous Nursing New Zealand), NIFS (New Zealand Intestinal Failure Service), the various pharmaceutical companies involved in HPN, and with PNDU's international counterparts through PACIFHAN (the international alliance of support groups like PNDU). Karen will be missed, but since she generously gave the MC nearly two years' notice so that our new President, Chris, could shadow her and learn all that she does, the transition should go smoothly. Karen has set the bar high for PNDU standards and I know she will be wishing us well. Take a well-deserved break, Karen!

An Interview with Karen:

How did you become aware that PNDU existed?

My ever-supportive pharmacist, Declan Gibney, saw a notice in a clinical magazine soon after PNDU had formed, and let me know. I quickly joined. Little did either of us know what lay ahead!

Why did you decide to become involved in the Management Committee?

Almost as soon as I joined, PNDU's founders, Brenda and Gil, roped me in to helping behind the scenes of this newly formed group. My health was stable and I had skills that could assist. The President's role however was furthest from my mind back then, and I consider myself PNDU's 'accidental' President.

Are you able to choose a few highlights of this decade that particularly stand out?

- All our PNDU social gatherings! Meeting and connecting with our amazing members, and being part of the very special PNDU culture of acceptance, care and support!
- HPN Awareness Week! From humble beginnings in 2011, it's an amazing celebration of this crazy HPN life we live.
- Seeing PNDU's credibility increase amongst clinicians, clinical bodies and industry players to produce strong working relationships.
- PACIFHAN! Representing PNDU on the international level and on an equal footing with our overseas counterparts. Plus finally seeing PACIFHAN registered in Brussels in April this year.
- Having a PNDU member survey accepted for publication in a medical journal!
- Our 10th Birthday party which was a celebration of it all!

Why are you standing down as President and leaving PNDU's Management Committee?

A variety of reasons, including surprise that I'm still alive and consequently wanting to plan for my unexpected future; a desire for less busyness and more time for family and friends; a belief it's healthy for an organisation to change leaders from time to time; and thus, with PNDU having reached this good place, a desire to see someone else to take PNDU forward into its next phase.

What are your plans for the future?

My big plan is to move to Newcastle next year (north of Sydney and closer to family), so lots of sorting and cleaning before then. I'm looking forward to a quieter and far less exciting future, including more SLEEP!, reading, gardening, knitting, and lots of catching up with family and friends.

Being part of PNDU and its first President has been an amazing experience and beyond my wildest imagination. I'm incredibly grateful to all who have supported, encouraged, and helped with their time and skills. I'm very proud of how far PNDU has come in 10 years, but it's definitely a team effort. So thank you to all PNDU members, and especially past and present members of the MC. I wish Chris and the team only the very best for the future, and look forward to even better things to come for PNDU.

A Child's Journey in Hospital Life. (Our Brave Littlies, #1)



Words by mum, Sonya

It has been a while... And we truly celebrate the immense joy of life free from consistent hospitalisation.

So many emotions all rolled into two photos!

We are now home from our admission this week and I sit here this Friday evening, deep in thought of the past week, over a glass of wine. Only three short days as an in-patient after a six months reprieve. Yet, it was the most incredibly exhausting three days for us all.

I should have gone for a long run, or a swim to release this natural emotion that sits heavily with me on this Mother's Day weekend. I chose the wine of course! Winter is coming.

After a lengthy six hours in negotiation strategies, medical therapy play and countless attempts in regaining Milla's trust, we finally had successful entry into a theatre bay to be anaesthetised for surgery. Tough. And what we also witnessed and endured post-operative, literally BROKE ME!

This is the hidden side of long-term hospitalisation in special needs children that resurfaces without warning.

Frequently, episodes of care such as preventive clinic visits, acute care, medical procedures, and hospitalisation can be emotionally threatening and psychologically traumatising for long term hospital kids.

Our kids are often subject to psychological trauma, demonstrated by anxiety, aggression, anger, and similar expressions of emotion, because they lack control of their environment.

This sense of helplessness, coupled with fear and pain, can cause our kids to feel powerless in a hospital or healthcare setting. These emotional responses can delay important medical treatment, which is what happened in Milla's case this week. Induced trauma and induced anxiety that had surfaced was a defining moment.

So many attempts in medical role-playing with her Child Life Therapist and anaesthetist's team. (something not included in an anaesthetist's job role) Demonstrating positive language around her pending procedure is very important. (I also work on this at home prior to her admissions.)

What I witness and endure with my beautiful girl, mostly on my own, no parent should have to do, countless times. Calmly begging her to keep still, telling her it's going to be okay, and we understand how this is difficult for her. All while the 'amazing anaesthetists' manually attempt to mask, without success, then inject a syringe of inhaling anaesthetic stench countless times, all whilst pinning her tiny body down with four other medical peers in a blood-curdling attempt to anaesthetise her...I wouldn't wish any of these moments on anyone. However, we share this journey with so many families.

There are really few words to truly capture the essence of what this journey of special needs parenting really is.

The sudden realisation of the sheer enormity of psychology that is now required to assist our beautiful soul with her countless ongoing surgeries still ahead of her, all whilst keeping her overall wellbeing at its highest form came crashing down.

This, of course, followed by many meetings in strategy planning with her most respected and valuable team in Milla's ongoing surgical future.

We press restart ... we celebrate everyday she's able to rejoin the normality of life. We celebrate every milestone that she's been able to achieve that has bought her/us to this point. Especially of this past six months. She's earned it. We've earned it. We rejoice in it. Because our beautiful, loving, highly spirited, effervescent, brave and courageous little girl knows exactly what's going on now she is older; she is very aware of what lies ahead. And she very much communicated this deeply this week.

Everything shifts, expands and changes daily, weekly, monthly and yearly along this complex and intense journey.

As always, our heartfelt thanks to Milla's incredible medical team, the unwavering support during this admission was truly felt. We are ever so grateful.

Thanks to you all who continue to support Milla's journey.



Photos:
Pre surgery—Medical role play • 'Dr Milla'
Day two post Op—Pure creative joy
• 'Warrior Girl'

Home Parenteral Nutrition (HPN) Awareness Week 13th-19th October 2019



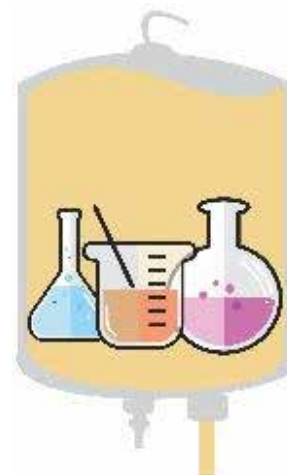
Words by Chris

HPN – A Rare Diet

PNDU's Management Committee has started preparations for our 9th Awareness Week. 'A celebration of life' for approximately 280 adults and children across Australia and New Zealand, living with the rare and complex condition, Intestinal Failure, requiring the complex life support therapy, Home Parenteral Nutrition (HPN). A Rare Diet.

Life on HPN can often be a very difficult and isolating experience. Awareness Week, as the name suggests, is a wonderful opportunity to raise awareness and understanding of what life is like, living with HPN for Intestinal Failure.

PNDU extends an invitation to all HPNers, family, carers, HPN hospital clinicians and our industry friends to join in the HPN Awareness Week celebrations, and help make Awareness Week 2019 the biggest and best yet.



Resources

PNDU will again provide a great range of resources to help you become involved in Awareness Week celebrations, help spread the word and raise awareness and understanding of life with HPN. Resources for our member HPNers, family and carers will include a video to share, stickers, social media profile and twibbon, and an example newspaper article, so you can write and share your own story with your local newspaper.

For hospitals and industry friends, PNDU will again provide an HPN AW 'Resource Pack' with wonderful ideas on how to help celebrate and information on the available PNDU resources. (stickers, flyers, posters, crossword and video).

PN Pharmacy Tours

PNDU is again making arrangements with our industry friends, Baxter – Australia and New Zealand, and Biomed – Auckland, for guided tours of their PN compounding facilities. A wonderful opportunity to see how our PN is manufactured and a chance for HPNers and carers to share their story with pharmacy staff.

Tours are open to all HPNers, family, carers and HPN clinicians.

Biomed Auckland offers tours any day during Awareness Week.

Baxter has the following tour dates:

Tuesday 15th October:

- Perth Tour: 11:30AM start at 46 Vinnicombe Dr, Canning Vale, WA

Friday 18th October:

- Auckland: 11:30AM start at 33 Vestey Dr, Mt Wellington, Auckland
- Christchurch: 10AM start at 98 Treffers Rd, Wigram, Christchurch
- Sydney: 11:00AM start at 1 Baxter Dr, Old Toongabbie, NSW
- Victoria: 11:30AM start at 9-29 Syme St Brunswick, VIC
- Brisbane: 10AM start at Unit 2/1115 Stanley St, Coorparoo, QLD
- South Australia: 11AM start at Tennyson Centre 520 South Rd, Kurrulta Park, SA

For more information or to book a place on a Pharmacy tour, email PNDU today contactpndu@gmail.com

Sal's First Adventure Trip in a Flxible Clipper



Words by Sal

To appreciate the significance of this story, some background information will help to give you some context. My amazing husband and carer Matt has always loved old vehicles, and has restored or assisted in the restoration of about 10 vehicles from the 1950's and '60's, including our first bus/motorhome, a 1967 old Pioneer Coach Ansair Scenicruiser, that has featured in previous adventure stories of mine shared in the Dripline newsletters. Anyway, Matt first saw a Flxible Clipper when he was about 12 years old, and it was love at first sight, and his dream for having one to tour Australia in was born.

Fast forward to 2 years ago, when we had the opportunity to buy a wreck of a 1956 Flxible Clipper, Matt the eternal optimist, could see it was actually salvageable, and thanks to a mate who offered to house it on his property in the Southern Highlands, 150km away from our home in Sydney, Matt's dream was looking slightly possible. We had to sell his almost completed and restored 1957 Morris Commercial Truck, but it meant having his dream bus!

So, the plan was to keep driving and using the Scenicruiser and save up to fund the restoration in the meantime. But in March last year, a bus collector offered to buy the Scenicruiser, to add to his collection of ex Pioneer coaches, and as we never thought we would be able to sell the Scenicruiser, due to the high

maintenance and level of skill to manage the frequent breakdowns, it was a gift. The trade-off was that we couldn't get away until the Clipper was on the road. In late May 2018, the restoration project began, with about 20 members from our bus club (the Fxible Clipper Club of Australia) travelling from across Australia to pull apart the bus over a weekend. Sadly, we also discovered that the engine was no good and was also removed, as were all the mechanical components and suspension, and we were left with a rusty misshaped frame. Matt would travel every weekend to work on the bus, despite the chilly highlands weather and lonely nights. Sometimes I would go for a day, or our sons or a mate would help, but essentially Matt did all the work, including the reshaping of the front and rear that had been butchered by a previous owner. I would paint his repairs, our 15 year-old son learned how to fibreglass and he made new panels for the front and rear. In August, a few members of the club came and put a brand new engine and gearbox (that had been generously donated to us by some members of the club,) in. Matt continued to restore the axles, frame and more. My daughter, her bestie and I, cleaned up and painted the underside of the bus during the October long weekend, a most necessary but pretty messy and awful job than no one else offered to do - go girl power!! In early November, about 25 bus club members came together to put new sides on, the remaining mechanics and running gear in and by the end of the 4 days, Matt drove the bus out of the shed (minus windows and some panels). In mid-December, it was complete enough to get a permit and drive it home to Sydney!!

Matt continued to work tirelessly every weekend and many week nights too, to get the bus ready for registration, with the goal of making it ready to drive to the bus club annual rally at Easter. A month out from Easter, it was ready to be engineered, but the first engineer took one look and refused to assess it. Then we had to find and wait for another engineer and time was ticking. Two weeks out from Easter we had it assessed and it needed a few minor adjustments, which Matt knocked out quickly but then we had to wait for the engineer to be free again. It passed at last, but then we had to wait for the bus to get the roadworthy inspections. Fortunately, despite running out of fuel on the way, and having a police lights escort to a fuel station, whilst being towed by a 1980's Mazda ute that kindly pulled over to help, the bus passed the roadworthy inspection first go, on the Monday of the week of Easter. But then we had to battle insurance companies for a green slip and then later it took several visits to the Roads & Maritime Services (RMS) to finally get the bus registered on the Tuesday before Easter. So, 2 days later on the Thursday evening, the number plates were screwed on, bus was packed and we left for Crows' Nest, north of Toowoomba QLD, for the annual bus club rally!!

The bus is affectionately named "Bridget", named after the working bee weekends which the club had named 'Bridge' Weekends, an acronym for 'Busting Rust, Inhaling Dust, Garage Engineering' and we added the 'T' for transformation or triumph, as that is what she is.

So, Bridget was behaving perfectly on her inaugural trip as we headed north via Newcastle, collecting our daughter Juliet on the way. We stopped for the night at Burning Mountain, near Scone, NSW- with a mattress on the floor for Matt and me and a mattress for Juliet. Our son Bradden and his girlfriend had both already crashed on the coach seats, so we left them there. We left the next morning on Good Friday at about 7am, after disconnecting my HPN, and arrived at Crows' Nest QLD at about 5pm. On entering the caravan park, our bus club came and surrounded the bus applauding us as we drove in. 10 ½ months to take a rusty, holey, moss-covered wreck with a broken engine that hadn't been on the road for over 35 years, to being a fully engineered, registered bus with completely new engine, gearbox, diff, brake system, power steering, new sides and more, was definitely a club record. Sure, Bridget needs to be painted and the interior needs to be fitted out (everything in there currently is just temporary), but we were at the rally and Matt was living out his dream at last!! He had put in temporary power so we could charge my pump and for lighting. He had installed a toilet that had a curtain of old sheets for privacy, a sink and running water for washing hands, a fridge for food and a fridge for PN running off a solar panel and batteries, a BBQ for cooking, a tent for the kids to sleep in, what else do you need for glam camping?!

We had dinner provided by the club that first night, where we could catch up with friends and chill after all the excitement of the long drive. There was intermittent rain on Saturday morning, but that didn't dampen the locals' spirits who came to the caravan park to check out the 18 Fxible Clippers on display and our club got to check out Matt's hard work as well. The club headed to the local bowling green in the afternoon for

some barefoot bowls, where I had some winning shots. Saturday night was a 'Rock N Roll' themed dinner and dance night. We all dressed up and Juliet, our family dancer, had a ball doing the jive and other dances during the night, stealing the floor a bit! Bradden and Ainsley danced under the moonlight in between showers of rain, and I even got to dance with Matt, with my Baxter backpack complimenting my Rock N Roll costume! Easter Sunday, a group of us went to the local Uniting church, where we were thoroughly welcomed and embraced. The club loves to do convoys, so most of the buses headed for a short scenic drive to an apparently 'oldest pub in QLD' for lunch. It is quite a sight to see that many old buses, and although most are able to reach the speed limit, pity the car trying to overtake us all!! Sunday night was a club meeting and future rally locations were discussed. One of the members is an amateur filmmaker, and he always puts together some fun movies of club outings and fictional fun stories. This time we featured with the bus resto and a reflection of how we are there for each other as friends and a club. Sadly, Monday morning we had to head home and back to work for Tuesday, so we said our goodbyes early and made the long trek home, arriving very late that night. Bridget behaved perfectly and her maiden trip went without a hitch, so refreshing compared to the Scenicruiser treks, where if you didn't breakdown on the way, you would on the way home!!

Matt continues to work on Bridget most weekends and has started on the interior fitout. At least now she is at home in our driveway, as a landmark feature of our street, and Matt can work on her as time permits without having to drive 150km each way. I feel so incredibly blessed to have Matt work so hard to enable me to travel in such style and comfort and to enable my HPN needs and have such wonderful family adventures. Our bus club members are equally amazing in their generosity for all the parts and time they gave us to be able to make it all possible in that time frame. We can't wait for our next trip away to Bunyip Victoria, in June, to collect wheels for a son's 1957 Holden panel van being restored in our back shed (yes, our place is a classic vehicle carpark!)

PS Bridget has already done a private charter for a 1950's themed 18th birthday party since Easter, and once painted will make an excellent character limousine!!



'Bridget' when first bought



'Bridget', still being restored



Sal (HPNer) and her cap



The inside, still under restoration



Rock and Roll night –
Bradden, Ainsley and Matt



Go Juliet (daughter) and Sal!



New for PNDU supporters – Supporter T-shirts

Words by Karen

Share the PNDU love and help raise awareness of HPN at the same time.

We're excited to announce: we've extended our merchandise range to now include supporter t-shirts! Now everyone can join in the t-shirt fun.

T-shirts are just \$17 each (cost price) + plus postage within/from Australia. Women's and men's sizes available. Go to our [Merchandise page](#) for more information and to order your supporter t-shirt today.



Revestive® (teduglutide) is recommended for listing on the PBS in Australia – the role PNDU played as the HPN consumer voice



Words by Karen

While PNDU doesn't promote any specific drug, therapy or pharmaceutical company, PNDU does support access to medications/therapies for all HPNers. Revestive® [see article below for a medical explanation of the drug] is already approved for use by the Therapeutic Goods Administration (TGA) in Australia and Medsafe in NZ for adults with surgical Short Bowel Syndrome-Intestinal Failure (SBS-IF) reliant on HPN, but is extremely expensive. Consequently, PNDU members and the Management Committee (MC) have been involved in the Revestive® submission process in Australia over the past nearly 3 years by giving the consumer perspective of what it's like living with SBS-IF and HPN.



Early on, members completed surveys and interviews and contributed their thoughts. Meanwhile, the MC provided three written submissions to the Pharmaceutical Benefits Advisory Committee (PBAC); and on behalf of members, I was invited to present the consumer experience at an initial PBAC stakeholder meeting, as well as answer questions at a later PBAC consumer hearing.

We were delighted to hear from the PBAC consumer representative in late April this year that it is expected Revestiv[®] will be available on the PBS in Australia for adults with surgical SBS-IF by the end of this year. A more detailed summary of the PBAC's summary is available here: <http://www.pbs.gov.au/info/industry/listing/elements/pbac-meetings/psd>

While sadly not all PNDU HPNers will be eligible for this drug (and anyone who is eligible needs to carefully discuss the pros and cons with their treating team), PNDU is proud of the role it has played as the HPN consumer voice in this important development for HPNers in Australasia. We're also hopeful of more options for all 'down under' HPNers – adults and kids. To this end, PNDU provided a written submission to Pharmac in New Zealand last year, however the sponsor's initial submission was rejected. PNDU will continue to support this and access to other medications/therapies for adults and children across Australia and New Zealand living with HPN.

Through this process, PNDU has been very grateful for the encouragement and work of the PBAC, including consumer representative, Jo Watson, the many clinicians involved, and the drug sponsor, Takeda.

Introducing Teduglutide (Revestiv[®]) for Intestinal Adaption



Words by Peter Lim

Medical Director of Intestinal Failure / Gastroenterology Staff Specialist at Royal Prince Alfred Hospital, Sydney

Editor's Note: Although PNDU doesn't promote any particular drug/treatment for Intestinal Failure, we support educating our members in the latest developments which can then be discussed with their hospital team.

Intestinal Failure is a rare but significant medical condition, most commonly caused by removal of part of the intestine due to disease, resulting in an individual's inability to maintain their own nutritional requirements through absorption of food and fluid from the intestine. The main treatment for this is nutritional supplementation with parenteral nutrition (PN). The amount of PN required depends on the residual gut function and a process called intestinal adaptation.

Intestinal Adaptation

When part of the intestine is removed, the body's natural reaction is to make some physical and functional changes to the intestine to compensate for the loss of gut function. This process is called intestinal adaptation. There are a number of changes that occur:

- Reduction of gut motility
- Elongation, thickening and dilatation of the remaining bowel
- Increase in the height and width of villi, the finger-like projections on the inside of the intestinal lining or mucosa. (Villi increase the surface area of the mucosa, therefore increasing the absorption of the bowel).

These changes allow the remaining bowel to increase its absorptive ability to try and replace the lost gut function. In other words, it makes the remaining bowel work overtime!

This process is highly variable in terms of how much adaptation occurs and how long it takes. It is generally thought that this process can take anywhere from 6-24 months. The amount of adaptation determines the final absorptive capacity and therefore will affect the amount PN required.

Introducing Teduglutide

Glucagon Like Peptide-2 (GLP-2) is a hormone in the gut that helps maintain intestinal growth and health. It is also the hormone responsible for intestinal adaptation. When GLP-2 binds to receptors in the intestine, the adaptive changes occur to promote absorption.

Recently, a new medication called teduglutide, a synthetic version GLP-2, has been developed to promote adaptation. Teduglutide is administered as a daily injection under the skin. Patients need to have been stable on home PN for at least 12 months. Close monitoring by an experienced intestinal failure team is required whilst on treatment, and adjustments are made to parenteral support, according to changes in urine output.

Teduglutide has been shown to increase absorption such that home parenteral nutrition patients can reduce their PN requirement. In the pivotal STEPS study, 63% of patients on teduglutide achieved a $\geq 20\%$ reduction in PN or IV fluid requirement after 6 months of treatment. On average, patients reduced their parenteral requirements by 4L, which meant at least 1 day off PN for 54% of patients. In longer term studies, some patients were even able to wean off parenteral support altogether.

Teduglutide seems generally well tolerated, with the main side effects reported in the trials being abdominal pain/cramping and distension, nausea and injection site reactions. Occasionally, swelling of the stoma site can occur. Patients need to be monitored closely while on treatment, as the expected increase in absorption means more fluid uptake and therefore can lead to weight gain, shortness of breath and fluid

Birthday Corner



This year, James turned 13! His day wasn't that exciting and the weather was very wet and cold yesterday. We went out for breakfast with extended family before school. He went to school. Then we finished the day off with some friends and family at our house for dinner and cake.

James really enjoyed the extra company we had around...lots of laughs which was really nice. He was spoilt with lots of gifts and messages of love and birthday wishes. He went to bed a very happy teenager!

We are planning on having some of his mates around on the week end for more birthday celebrations.



Words by Karen

The 2019 AVAS Scientific Meeting was held in Sydney in May, with the theme 'Walk the Line', and over 150 delegates attending. Chris and I attended on behalf of PNDU and were very encouraged by the value placed on the consumer perspective. For this we are incredibly grateful to AVAS and the vascular access community.

As well as touching base in person with our AVAS and AVATAR friends, IVNNZ friends who made it across the ditch, and many passionate clinicians, other encouraging PNDU opportunities were:

- being able to once again exhibit for PNDU free of charge
- being invited to give a ½ hour presentation on the consumer perspective of vascular access
- presenting PNDU's scientific poster on our most recent member survey – retraining in HPN procedures [see article below]
- having a snippet from Tina & Andy's 'Taking Hebe Home' video on connecting up to PN in the home environment shown during the conference Film Festival, with opportunity to give a short introduction
- being invited to be part of an expert panel discussing the topic 'whose line is it anyway?'
- and lastly, being asked some questions for a film record of the conference, including what does the conference theme 'walk the line' mean to the consumer?

Thank you AVAS for all these opportunities and for putting consumer interests front and centre! PNDU looks forward to continuing our relationship with AVAS and AVATAR.

Below: a collage of PNDU at AVAS conference 2019



PNDU's latest member study – Retraining of HPNers in HPN Procedures



Words by Karen

BREAKING NEWS: With minor changes, this latest study is the first PNDU study to be accepted for publication in a medical journal! It will be appearing soon in the peer-reviewed multidisciplinary official journal of the Australian Vascular Access Society, *Vascular Access*! Woohoo!

Research provides hope for now, and for the future of all HPNers. That's why PNDU has always been involved in, as well as conducted our own, pilot observational and consumer audit studies of the small HPN population 'down under'. We are very proud of this important and valuable activity, especially given PNDU's size and resources, and very grateful for the assistance from both talented members, as well as research professionals, willing to lend their expertise.

Below is the abstract of PNDU's latest member study: Retraining of Home Parenteral Nutrition (HPN) Users in Australasia – A Consumer Audit Study. The full analysis, abstract and poster of the study are on [PNDU's Surveys & Studies website page](#), where all PNDU's studies can be found.



We were thrilled to have had opportunity to present the poster at AVAS conference in Sydney in May. At scientific and medical conferences, delegates can present research information in the form of a large poster (a bit like a school assignment!). The posters are all displayed, with opportunity for the authors to explain the research at a dedicated poster session during the conference.

[Retraining of Home Parenteral Nutrition \(HPN\) users in Australasia – a consumer audit study](#)

Introduction

Published guidelines recommend patients and carers are trained and meet competency in certain criteria of connecting and disconnecting procedures before going home with HPN. Despite many HPN users requiring HPN indefinitely, PNDU was not aware of retraining of HPN users unless the user had recurring central line-associated blood-stream infection (CLABSI).

Objectives

To survey PNDU members on their experiences of formal retraining in HPN procedures, and how members perform one aspect of these procedures: withdraw back (into syringe), for comparison with latest expert opinion.

Methods

An anonymous on-line questionnaire was circulated to all Australasian HPN members in November 2018.

Results

There were 40 responders representing 30 adult and 10 child HPN users. Thirty-two (80.0%) responders had been on HPN for 2 or more years, receiving initial training before discharge. Just over half (57.9%) had received retraining with most (81.0%) retraining prompted by a specific event, commonly related to a suspected or confirmed CLABSI or change of medical equipment/item used to perform the procedure. Overall, 34 (85.0%) responders withdrew back into the syringe before connecting to PN, 25 (73.5%) discarded the aspirate, and 9 pushed the fluid back into the central line.

Conclusions

Few HPN users receive regular retraining as part of HPN management. Considering possible benefits in complication prevention, consequentially maintaining quality of life and reducing healthcare costs, we recommend discussion and further research into regular retraining. Additionally, more research is needed to determine best practice for withdrawal of blood, and, if required, how much drawback is sufficient and safe.



Evelyn (an HPNer) is back in hospital with another tricky line infection. Part of her mum, Amy's, post this morning said "Picture of her crazy cheese face because she is adorable." We have to agree!



Adelaide Consumer Workshop and Social Gathering, November 22nd – 23rd Not To Be Missed!



Words by Chris

We hope to welcome as many HPNers and their carers as possible at these two wonderful 'Free of Charge' events.

PNDU Social Gathering: - Friday November 22nd

Venue to be confirmed

PNDU invites all our HPN members, family and carers who are able to join us in Adelaide, to come along to a social gathering, meet with other HPNers and carers in a relaxed friendly atmosphere, exchange stories of life on HPN with other HPNers who really understand your journey. Learn more about PNDU and what we do for you.

For more information and to register email contactpndu@gmail.com

AuSPEN HPN Consumer Workshop. 12:30 – 4:30 Saturday November 23rd

Adelaide Biomed City – Royal Adelaide Hospital – Port Road Adelaide SA 5000

We are very grateful that AuSPEN has organised another HPN Consumer Workshop, specifically for HPNers and their carers.

The AuSPEN HPN Consumer Workshop is a unique opportunity to learn more about your HPN from expert clinicians working in the field. This event is open to all adult HPNers, their carers and adult carers of children on HPN only.

How to register will be advised at a later date.

PNDU Travel Sponsorship to attend these two events in Adelaide

PNDU is offering two Travel Sponsorships, to the value of \$600 each, to assist HPNers and carers attend these events. Priority will be given to PNDU members who haven't before attended an AuSPEN HPN Consumer Workshop plus the PNDU Annual Social Gathering. If you have attended past events, you can still apply again. If you're not yet a PNDU member, complete the membership form on our [website](#) today.

To apply for a Travel Sponsorship, simply write two paragraphs describing why you would like to attend these events and what benefit attending will have for you. Send your email to contactpndu@gmail.com

(One sponsorship per family, travel must be completed and receipts forwarded to PNDU before reimbursement can be made).

Closing Date for applications is 16th August.

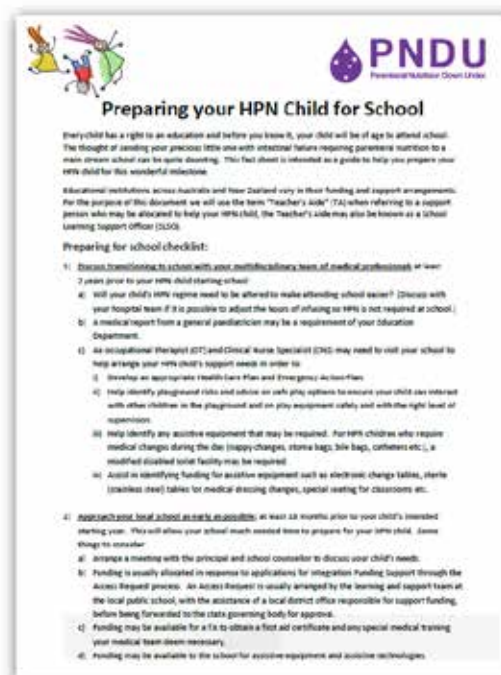
Winners announced 1st September.

New Fact Sheet "Preparing your HPN Child for School"



Words by Miranda

For a parent with an HPN child, your child starting school may be an exciting, but also overwhelming time. As with most families, it will be the first time that a child will be regularly spending extended periods of time apart from their parents and carers. For an HPN child who has a central line, and often stoma bags, feeding tubes, special feeding, toileting and other medical requirements, this time can frankly be terrifying for a parent! What information do you need to share with the school? How can you ensure that they will be safe at school? And how can you help your child fit in? Based on the experience of member parents, PNDU has released a new Fact Sheet 'Preparing your HPN Child for School' to assist members with little ones who are transitioning to school. The Fact Sheet contains lots of practical tips, ideas and also links to other helpful resources to help you prepare your child and your child's school so that the first few weeks will be a positive, happy and safe experience. To find the Fact Sheet, please log onto the Member's section of the PNDU Website (www.pndu.org), you will find it in the "Kiddies Korner". Thank you to Chris, Karen, Gillian, Shirley, Miranda and other wonderful contributors for generously sharing their experience and time in helping us put this together.





Words by Jodie

Coping with a life of chronic illness and long-term parental nutrition is difficult. It has taken me many years to learn how to cope in healthy ways.

Living in a sick body is never easy. Here are some tools I've adopted to accept intestinal failure and its long-term treatments. I hope this list will give you ideas and in turn, help you cope too.

1. I try to think kindly about myself, as if I am my own best friend. This means pushing out a huge self-critical voice. I try to remember that the critical voice speaks opinions, not fact, so I'm not obliged to believe it.
2. I don't expect myself to just 'get over' whatever I'm feeling. 'Toughen up Princess' people don't have a place in my life because they invalidate my suffering. The difficulties we endure as IF-HPNers are always valid.
3. I don't let myself camp out in the victim mentality zone for too long. That place gets me depressed and angry, fast.
4. I ride out uncomfortable emotions, knowing they won't last. Emotions constantly change and knowing this gives me great hope that my heart won't feel awful forever.
5. I listen to TED talks (Editor: Inspirational Technology, Entertainment and Design talks) and read inspiring stories. These give me some emotional fuel to keep going.
6. I acknowledge not coping and seek support at these times. I give myself permission to not have it all together, all the time. It's okay to be scared and weak – we're only human.
7. I self-advocate when my needs aren't being met by medical professionals. If I'm feeling too emotional, which is often the case, I ask for someone to advocate on my behalf.
8. When my bodily capacity decreases, I increase my brain and heart engagement. This often involves learning something new or extending thoughtfulness by contacting a friend that I haven't checked up on for a while.
9. I believe I'll lose only if I give up. Every inch forward is a win in our world.
10. I try to remember that I'm much tougher than my mind tells me. I've lived through so much already. I have a dependable track record of making it through hard times...and so do you

Three Memories...health related



Words by Emily

Editor's Note: Emily is a young American HPNer who regularly contributes articles to Dripline about aspects of her life on HPN. Emily spent a semester studying in Sydney and met up with some of our PNDU members.

This is the story that my dad loves to tell. It goes like this. He was walking to the entrance of my day-care centre to pick me up for the day when he saw me on the playground being followed by a young boy. I was about five years old at the time and had a broviac on my right chest. My mom would usually send me to day-care in a turtle neck to hide it, but I always found them constricting and protested. That was a day I won and as a result, the broviac was pretty visible. There was a little boy who couldn't have been much other than three years old asking me over and over again "what's that?" and gesturing to my chest. My dad watched for a bit as I avoided the boy's questions, simply playing dumb with "oh, it's nothing" and redirecting my body from him. This did not deter the boy, as it wouldn't for any three-year old without the ability to take a hint, and he insisted, "no, no, I see it, it's right there" placing himself back in my line of sight. I, being a scrappy child who commonly got "doesn't play well with others" on my record card, apparently got right in the boy's face, not an inch from my nose touching his and said bluntly and lowly, "it's NOTHING." This frightened him and he quickly fled the scene. In my defense on my report card, I didn't want to get along with those kids.

My favourite story is when I was 16. I was getting an ultrasound at a teaching hospital and working with a self-confessed new tech. Before he began, he asked me to share my medical history. Because it's so long with so many subplots, I chose to brief him. Short gut, PN dependent, open-heart surgery in '96, multiple line infections, the same old song. The tech began his work and I zoned out. I spent my time as I do most in these situations, wondering who painted the ceiling tiles with fish and how long ago they were done. When the hospital opened? Are these kids still kids? Imagine painting one of these tiles as a kid and then seeing them decades later during your ultrasound. Did I paint these tiles? How old am I? After a solid 45 minutes, I noticed that the tech had gone from relatively relaxed to the furrowed brow. He asked me if I still had my appendix, noting that he was having trouble finding it. I replied confidently "sure do". After about 10 more minutes he left, brought in a more seasoned co-worker who after ten minutes left for a supervisor. I had three individuals looking for any sign of an appendix for another twenty minutes until a fourth person came popped his head in casually to say "oh, I talked to the dad, it was removed in '96" in perfect unison three heads snapped right back at with looks that accused me of playing a dirty trick. First, if you can't find an appendix perhaps it is your job as an ultrasound tech to deduct that there isn't one. I mean, how many places can an appendix hide? In that moment the only thing I could say is "I'm just as surprised as you are." Before being subjected to the 'you have to reveal your entire medical history' lecture. To set the record straight, I was actually just as surprised and angry in that moment. I was angry that I wasn't aware that I didn't have an appendix or my parents never bothered to tell me, but also that three years ago I read the play *Our Town* in English class. For anyone that doesn't know that play, a character dies because his appendix bursts during a camping trip and he dies of an infection. Never mind that the play is literally set in the early 20th century when medicine as much more touch and go and yeah, we didn't even have the technology to detect an appendix that's about to burst we kind of just waited for it to happen and hoped you're in the right place at the right time so maybe we could control all the bile that will seep into your system. Never mind that here I am in the 21st century where you can get your appendix removed in a same day surgery because here we are in the 21st century with the technology to get a surgery in a shorter amount of time it takes for a plumber to finally arrive to your house to fix that leaking faucet that you've been putting off fixing because the plumber takes so long just to arrive that you have to take the day off from work. Forget that, because here I was in the 21st century, at 13 years old, a full one hundred years from when this character died, convinced that when I die it will be a ruptured appendix. Of all the things I've survived, a ruptured appendix will be the death of me. As ironic as dying from a splinter. And now, here I am, realizing I had spent the last three years of my life fearing an organ that was removed from my body, that is surely gone, gone, gone, decayed and turned to carbon. I asked my dad why he never bothered to tell me, his response? "Your gall bladder was removed in '99."

The last story is about someone I care deeply about. The only person I'd still want to visit me when I'm in the hospital. I've never been one for hospital visitors. If we're close, I'll notify you that I've been admitted and maybe when I've been discharged. I keep visits with my parents to a minimum. I think it's because when I'm in the hospital I don't look well and I don't feel well. Of course I don't feel well because if I did I wouldn't be there, but what I mean is that I get very anxious. I get easily triggered and easily snap. I get emotional and depressed. I cry a lot and all the worst kinds of thought sneak in. I prefer to keep all my loved ones at a distance and handle it by myself. After discharge it usually takes me a couple of days to re-adapt to regular life as the depression symptoms ease off. Being in the hospital is a reminder of how little control I feel over my life because of my illness, but also because of how all-encompassing the system can be. He only visited me once. I was only hospitalized once. He admitted to hating hospitals but offered and I said yes. He didn't know how to cook at the time but I loved how engaged he was over *Cook Off* with Bobby Flay because I love that show. He shh'ed me to watch it and I loved it. He asked me when I would be freed, alluding to hospitals being a prison, and I loved that too. He had new glasses and visited me despite having an exam later in the day. He was sick and brought tea. He asked me why chicken eggs don't hatch in the fridge then shortly after he left, called me convinced he was trapped in the elevator. He left his name badge in my room, listing out his birth name. Thinking he'd need to scan it to take the elevators back downstairs, as you do to get to the patient floors, he tried to open the doors but they were already closed. He called me panicked. The nurse told him to press the down button. And I loved it. They spelled his name wrong on the badge. I remembered being bothered by that. It was his birthname, and sounded the same, and in no way impacted its ability to reach patient floors, but not spelled his way. It was not his name. He was going to come back the next day but he didn't. He didn't call to cancel, he just never showed up. I suspected he

was depressed too, he would briefly talk about struggling to make a decision about something until it was too late and the moment passed. He looked grey. I could guess the guilt would soon follow and it would be easier to hope they never missed you in the first place, so you'd never have to disappoint. Or at least that's how it'd go with me. That was the last time I saw him. I'll admit that I wondered as I watched him leave. That was three years ago. I've learned now that you can be mad at someone and still love them. You cannot see someone for so long and still love them too. Some people never leave you. And that's ok. It's all ok.

How is NZNIFS helping Kiwi HPNers?



Words by Cate

Background; the [New Zealand National Intestinal Failure Service](#) (NZNIFS) was established 4 years ago, with the purpose of working towards improved service provision for patients living with Intestinal Failure (IF). The team were tasked with the following:

1. Data collection to begin to understand prevalence, and identify trends
2. The development of a clinical network to support practice, workforce development and care provision close to home
3. The development of standards of care and clinical guidelines
4. Advocacy re: care provision for patients with IF.



In day to day practice this means that we are notified of patients who receive Intravenous Nutrition (IVN) [Editor: another term for Parenteral Nutrition] for greater than 20 days; in partnership with the local teams we collect outcome data, such as time on IVN, rates of rehabilitation - measured by recording nights on IVN, number of central lines and rates of infection. To date we have observed that most patients are successfully rehabilitated off IVN. The team's focus is on supporting patients to remain in their home centre where possible - to achieve this the NIFS team meet regularly with local care teams by video conference or phone to develop management plans to support ongoing rehabilitation.

Much of our day to day activity is dedicated to the provision of in-hospital acute care, and the provision of telehealth as described above. It is however hoped that we will be in a position later this year to circulate draft clinical guidelines for review and endorsement by the clinical network. This is slow and important work; through having dedicated time to focus on the IF patient group we have already seen improved rates of rehabilitation, with a number of patients coming off IVN who it was thought would not.



Intestinal Rehabilitation & Transplant
ASSOCIATION

CIRTA - The congress of [Intestinal Rehabilitation and Transplant Association](#) (IRTA) is the 'must attend' biannual international conference for those working with patients with Intestinal Failure. The 2019 meeting was held in Paris the week of 3/7/19 - 6/7/19. A strong delegation attended from New Zealand, with colleagues from Melbourne and Sydney in attendance.

Paris was glorious, if not a little overwhelming as we arrived during a heat wave. Over the last decade we have observed a shifting trend in focus for the IF patient group, with the focus shifting from transplant towards rehabilitation with more people particularly children surviving long term on IVN and transitioning to adult care. There is great debate re: how best to achieve optimal rehabilitation; the Paris group particularly focus on normalising diet and oral skills where absolutely possible with IVN provided to support nutrition. Whereas most other international groups use a mix of tube feeding, oral diet and IVN with a focus on the patients being on the least number of nights possible. The outcomes are equally similar; at the end of the day it is about preserving or improving function.

NZ NIFS (paediatric team) is a pilot site, for the newly established International Intestinal Failure Registry which collects detailed data of patients who have been on IVN for greater than 60 days; one of the team will be in touch to seek consent if this relates to you or one of your family members. It is expected that all centres will have the opportunity to submit data prospectively from mid-2020. This is an exciting development and it will provide the foundation for a much needed evidence base in a range of areas, and may ultimately lead to the development of new classifications and processes.

NZ NIFS presented 4 posters at CIRTA. Kim Herbison (Clinical Dietitian) was awarded a travel award for best abstract (First 3 years of NIFS comparing baseline data in Starship with NZ NIFS all consumer data), and Amy Andrews (Clinical Dietitian) was awarded poster of distinction for the emerging disparity in socioeconomic status for patients with IF. Cate Fraser-Irwin (Co-ordinator Paediatric NIFS) presented 2 posters; the first related to the ongoing burden of care after achieving enteral autonomy, and second, the outcomes of a survey completed by NIFS to understand the availability of psychology and psychiatry services for patients with IF in New Zealand.

Much of our time was dedicated to promoting CIRTA 2021 which will be hosted in Auckland. The scientific committee will include colleagues from Australia making for what we hope will be an innovative and exciting meeting. We sold attendees with the offer of fabulous NZ Wine (raffle) and sampling New Zealand Chocolate. While we ruthlessly promoted all that New Zealand has to offer, we all participated in workshops which we hope will be the beginning of genuine international collaboration. It is hoped that IRTA will generate standards of care in relation to transition for young people, psychological assessment and nutritional management and other printed materials that we can all access and use.



Helen Evans and Amin Roberts of Starship Hospital at CIRTA



Cate Fraser-Irwin, Kim Herbison, Amy Andrews, Starship clinicians and poster presenters

PACIFHAN registers in Brussels!



Words by Karen

Exciting news: on 13 April 2019 **PACIFHAN** (the International Alliance of Patient Organisations for Chronic Intestinal Failure and Home Artificial Nutrition) was registered as an international non-profit association in Brussels (the usual place for international registration). You can see the Media Release on our website [here](#).

As a founding member of PACIFHAN, PNDU has been involved since its beginnings in 2014 when representatives from 6 national Home Artificial Nutrition (HAN) support groups (us, Czech Republic, Italy, Poland, United Kingdom and USA) met in Geneva and agreed to work together.



It's been a long challenging road to get to this point of legal registration (including all documents needing to be in French or Flemish!). Now, finally, all 9 current members (Sweden, Denmark and France also joined), and new members waiting in the wings, look forward to the opportunities that lie ahead to work together as the trusted international reference on HAN from the consumer perspective, and to fulfilling PACIFHAN's mission 'to promote the international sharing of information and resources to improve the quality of life of HAN patients'.

Along the way, while registration had been slowly progressing, much was already being gained for PNDU's benefit through sharing information and learning from the experiences of other support group leaders; not to mention the invaluable contacts made. As PNDU President, I've had the privilege to date to represent PNDU in PACIFHAN, including at the two face-to-face meetings in Geneva (2014) and London (2016), and am PACIFHAN's inaugural Secretary. (As PNDU's next President, Chris is set to take over from me in August as a PACIFHAN Director.)

It has been no small feat for a bunch of mostly volunteer national support group leaders, navigating multiple time zones (PACIFHAN meetings are at 5.30am in winter for me, 9.30pm in Europe!), language challenges, and heavy workloads with our own national groups, to work together. But we're excited to have now reached this important milestone!

PNDU looks forward to PACIFHAN's future, and not so far off, celebrating the second World HAN Day alongside our PACIFHAN colleagues on 15th October 2019 (during our HPN Awareness Week).

Packing HPN Needs for a Holiday



Words by Gillian

Over the past 13 years on HPN, I've gone on many holidays, but I have to be just as careful nowadays as I was on the first holiday to not be blasé about packing my HPN and other medical supplies, or I'll potentially be unable to connect up to my PN.

- My approach is to count the number of days I'll be away and add a couple on, then work out how many of each item of ancillary equipment I'll need. For some items I need one per day, but for others I need 2 per day. If your mental maths is a bit iffy, use a calculator.
- For packing, I've used 2 methods. Method 1 is to simply count out all that I need and put them into my medical suitcase. This means that every day I'll need to get all the items I need; or every week I need to find a week's worth and store in another place.
- Method 2, pictured below, involves putting out each day's needs in a pile and bagging them (I used

disposable nappy bags from the supermarket. I then used the empty bag to dispose of my used ileostomy bag).

- Remember all your items and add a few extra in case of loss of sterility when setting up, or an item not working properly, or any other 'in case' possibility.
- Also remember your backpack and pump. If you infuse for a long time and need your pump in the charger plugged into the electricity while infusing, you might need an extension lead to reach the power socket.
- If flying, remember that you must have your pump and charger in your hand luggage, as you tick off having no batteries in your cargo luggage, PLUS it guarantees that you will have it at the end of the journey. Also have 1 night's PN and ancillaries so that it doesn't go astray with lost luggage.
- If flying, don't take the brown bottle of chlorhexidine as it's flammable and classed as a prohibited item. Ask your medical team if wipes with chlorhexidine can be substituted. I use about 6 wipes when connecting up.
- Remember your medications.
- Pack all you need for other medical treatments.

Below is my packing for 19 days away. My 'medical' case just fits it all in, including backpack.



Laid out, 1 pile per day



Packaged in nappy bags



In a largish case, 750x500x-250mm

PNDU Awards – not in 2019...



Words by Karen

PNDU Awards are a way of recognising the great work of members in their efforts for PNDU, as well as health professionals and industry in their dedication to providing high quality care for those living with Home Parenteral Nutrition in Australia and New Zealand.

The Awards are held during the middle of the year, with winners announced at PNDU's Annual General Meeting in mid-August... EXCEPT THIS YEAR!...

In view of PNDU's 10th Birthday celebrations early this year, and as part of that, the recognition of the great work of HPN hospital care teams of all PNDU HPN members by way of Certificates of Appreciation, PNDU Awards will not be held in 2019.



We look forward to holding PNDU Awards again in 2020. At any time, feel free to view on [our website](#) the Roll of Honour of all winners over the last 5 years.



Editor's Note: Sadly, we add another name, Ross, to our list of PNDU HPNers who are no longer with us. They will be remembered with love by our caring support group members.

PNDU remembers past HPNers

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

Ross – 23 January 2019, aged 67 years

Celena – 27th November, 2017, aged 43

Emma – 9 April 2017, aged 35 years

Lara – 16 February 2017, aged 7 years

Teresa – 15 February 2017 aged 58 years

Natalie – 18 September 2016, aged 27 years

Sam – 13 September 2016, aged 14 years

Carol – 2 September 2016, aged 67 years

Jessica – 24 January 2014, aged 20 years

Tynasha Rose – 29 October 2012, aged 5 years

Aria – 20 June 2011, aged 5 years

Pauline – 29 April 2011, aged 38 years

Hebe – 3 January 2008, aged 2½ years



*May the cherished memories of these dear ones
never fade.*

Upcoming Events



16 August	Applications close for Travel Sponsorships
19 August	PNDU's Annual General Meeting
1 September	Travel Sponsorship winners announced
13-19 October	HPN Awareness Week
15 October	World HAN Day
22 November	PNDU's Annual Social Gathering – Adelaide (open to all HPNers and families)
23 November	AuSPEN HPN Consumer Workshop – Adelaide (open to all HPNers and carers)
23-25 November	AuSPEN 2019 Clinical Conference – Adelaide (PNDU will be attending)
27-28 March 2020	IVNNZ Conference – Christchurch (PNDU will be attending)
3 April 2020	NIFS Education & Network Day – Wellington (PNDU will be attending)

Planning Overseas Travel



As a founding member of **PACIFHAN** (International Alliance of Patient Organisations for Chronic Intestinal Failure & Home Artificial Nutrition), PNDU can put you in contact with sister organisations in various countries overseas (UK, USA, Czech Republic, Denmark, Italy, France, Poland and Sweden) which may be able to assist with any HPN travel questions in those countries. Just ask us at contactpndu@gmail.com.



Thank You



PNDU wishes to thank the following people and companies for their generous donations totalling \$4576.60.

Facebook Birthday Fundraiser: PNDU member Renée E. recently set up a Facebook Birthday Fundraiser on her social media page, a wonderfully generous idea and very simple to do. Renée has raised over \$1000. Simply log into your Facebook page, click fundraiser from the left-hand column, click non-profit and type in Parenteral Nutrition Down Under. All donations received by Facebook are processed, a tax-deductible receipt given, then passed on via the PayPal Giving Fund linked to PNDU.

- R Eastwood [Birthday fundraiser]
- A Atkins
- M Einstein
- K Winterbourn
- The Book Depository [thanks to the many who purchase books through The Book Depository link on PNDU's [homepage!](#)]
- Baxter Healthcare Pty Ltd



Membership for Aussie and Kiwi HPNers and carers:

We welcome all Aussie and Kiwi HPNers (ie those living at home on Home Parenteral Nutrition) and carers to become PNDU members. To become a member, we invite you to go to our [website Membership page](#).

Benefits:

- Access to all areas of our website, including Members Only pages (Travel, Kiddies Korner, Pharmacy Scripts, Hints & Tips, Clinical Info and more ...).
- Access to one or both of our private on-line groups (email and Facebook), connecting you with a wonderful network of support from other HPNers and carers.
- Receive news/information on HPN-related issues.
- Opportunity to contribute to PNDU Inc.'s work in raising awareness of HPN and supporting HPN research.



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



We also welcome others to join PNDU as members, giving you access to all pages of our website, receipt of our newsletter Dripline and other HPN-related news, as well as opportunity to contribute to PNDU Inc.'s work in raising awareness of HPN and supporting HPN research. To join, please go to our [website Membership page](#).

Donations



If you would like to support the work of PNDU, we would welcome your donation, no matter how big or small. Please go to the [Donate page](#) on our website for [PayPal](#) and [Direct Deposit](#) details.

All donations over \$2 made to PNDU in Australia are tax deductible!

For our New Zealand supporters, PNDU has partnered with IPANEMA, to make supporting PNDU from NZ easy! Tax deductible donations to PNDU can be made by NZ based companies to IPANEMA, while individuals in NZ making a donation to PNDU through IPANEMA may claim a tax credit for their donations*. IPANEMA will pass on to PNDU 100% of such funds. (*This is general information only, please see your accountant for specific advice about your financial rights and obligations.)

Donating via direct deposit

Please provide your name as a reference. If you require an acknowledgment/receipt of your donation, please email us at contactpndu@gmail.com.



<p>Australia (\$AUD) Bank: Westpac Account Name: PNDU Inc. BSB: 032 056 A/C No.: 482 738</p>	<p>NEW ZEALAND: (\$NZD): Bank: ANZ Account name: IPANEMA A/c No: 06 0273 0308799 00 Please include reference "PNDU" IPANEMA (Charities Commission Registration CC21178) is a NZ charity</p>
--	---

Management Committee Members

President - Karen

Vice-President - Chris

Secretary/Public Officer - Miranda

Treasurer - Chris

Editor - Gillian

Committee Member - Fay

Contact Us

Parenteral Nutrition Down Under Inc. ABN 49742201085

contactpndu@gmail.com | www.pndu.org

Registered address: [128 Rainbow Street, Randwick NSW 2031, AUSTRALIA](#)

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

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

Designer: MBE Hurstville