DRIPLINE

PNDU
Parenteral Nutrition Down Under

ISSUE 29
AUG-OCT
2019

This is a very busy time for PNDU's Management Committee and HPNers, as it includes both PNDU's AGM and Awareness Week, the time that we are able to consciously try to inform the general public about living life on HPN (Home Parenteral Nutrition). This issue introduces the new MC members; provides a summary of Awareness Week activities; includes 2 young adult HPNers' stories; members' comments about their HPNer children and sport; how to access a new PNDU hints and tips sheet on applying for NDIS support; A Day in the Life of an HPNer on the topic of Fatigue; members' comments about HPN and Anxiety; discovering the importance of Vitamin C; as well as farewelling our past president, Karen. I hope you find the issue informative and an enjoyable read as we share aspects of life on HPN with you,

Gillian
Dripline Editor

CONTENT

- PNDU's New Management Committee, including an excerpt from Karen's final President's Report – 19th August 2019
- Karen's Farewell Lunch
- Fighting for a Change and a Cure – Ebony's Story
- The Week that was...Awareness Week 2019, day by day
- Haylee's Story
- HPN Children and Sport
- Freedom for 'Pumpkin' – (helping a baby to get around the house)
- Anxiety and HPNers
- Navigating NDIS Applications – PNDU's 'Tips' Sheet
- Introducing Teduglutide (Revestive®) for Intestinal Adaption (a reprint with apology)
- Vitamin C, the 'Limey's' Nutrient
- Birthday Corner
- A Day in the Life of an HPNer – Fatigue
- HPNers and the Work Force: HPN and Employment – A Call for Requests
- A Handy Storage Unit
- Japanese Public Toilets for Ostomates
- Upcoming Events
- Planning an Overseas Holiday
- Thank You
- PNDU Information: Membership, Donations and Contact Information

PNDU's New Management Committee (MC)

Words by Gillian

This year's AGM on Monday 19th August was an especially significant one, as it heralded a major change in the MC membership. For the past eight and a half years, Karen has been, initially, our Convenor, then after Registration, President, and the committee has had the same members for several years. However, 2 years ago, Karen very kindly gave notice of her intentions to resign at this AGM, so that Chris, our new President, could learn the ropes and shadow her, so his learning curve isn't as steep as it could have been.

It is difficult to explain to non-MC members the impact that Karen's leadership has had in the development of PNDU, from its beginnings with 5 members and almost no credibility with professionals, to being recognised as having an important role as a support group for HPNers in Australia and New Zealand, as well as being a voice for HPNers, invited to present, as well as exhibit, at professional conferences, such as AuSPEN (Australasian Society for Parenteral and Enteral Nutrition), AVAS (Australian Vascular Access Society), and IVNNZ (Intravenous Nursing New Zealand) and NIFS (National Intestinal Failure Service in NZ). The MC members thank Karen for her dedication and professionalism in guiding us to where PNDU is now.

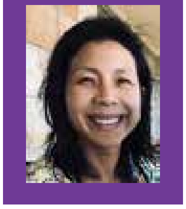
On a personal level, I will greatly miss Karen's 'eagle eye' in helping to get Dripline ready for publication – she always proof-read it and, no matter how carefully I had checked it, she always managed to find several errors. I'll have to lift my game now!

Part of Karen's Annual Report, presented at the AGM, is included after the introduction to the new MC members.

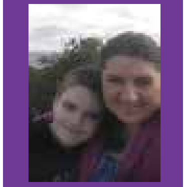
Our new MC consists of:

President,
Chris, carer for 2 grandsons, both on HPN

Vice President and Editor of Dripline,
Gillian, HPNer

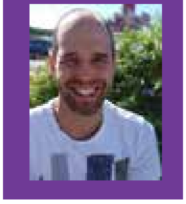


Secretary and Public Officer,
Miranda, carer for HPNer daughter, plus 2 other children



Treasurer, new member,
Belinda, carer for HPNer son

Member,
Fay, HPNer



Member, new member,
Ryan, carer for HPNer wife.

An excerpt from Karen's final President's Report – 19th August 2019

PNDU has truly come of age, turning 10 years old in January this year, and well-accepted and known by consumers and carers, clinical groups, hospitals and industry, locally and internationally as the go-to organisation 'down under' for Home Parenteral Nutrition (HPN) consumer and carer support and representation.

This President's Report is a perfect opportunity to recap the past year, ready for the year, and future, ahead. For me personally, this Report is especially significant as it marks 10½ years of involvement in PNDU (almost 8 of those as Convenor/President), and my last. It's from a place of incredible gratitude and appreciation that I step down as President and out of the Management Committee (MC) to allow PNDU's next President, Chris, to lead PNDU forward and into its next chapter. I am so proud of our little organisation and how far it has come in 10 years, and humbled to have had the privilege to lead a great MC, our members and PNDU to this place of growth and success.

PNDU's MC is its engine room. With all MC volunteers – me, Miranda, Chris, Gillian and Fay – living with Intestinal Failure (IF) and HPN either as consumers or carers, teamwork is crucial, and I'm grateful for the generous involvement, skills and contributions of all MC members. Our MC Skype meetings have continued every 6-8 weeks, and with this AGM, we welcome 2 new MC volunteers – Belinda and Ryan. A wonderful blessing to PNDU...

Lastly, thank you to our MC, volunteers who assist in other capacities (Renee, Sharyn, Gil, Sharon), and to all our members who make this amazing PNDU organisation and community what it is – vibrant, caring, and effective in its mission to 'support, research and inform consumers, carers and providers of Parenteral Nutrition for Intestinal Failure'. I wish Chris, the whole MC and PNDU nothing but continued success into the future."

Click here to read Karen's full final President's Report, or find it on our website on the **Corporate Info page** (Annual Report 2019)

Karen's Farewell Lunch

Words by Gillian

When someone who is hard-working and is a good example of honesty, integrity and goodwill to those around them retires, they deserve a very special farewell. A 5-course meal at a top-flight restaurant with an expensive gift at the very least. Yes, Karen deserves all that and more for her dedication to PNDU over the past 10 years. There are 2 problems with that scenario: firstly, Karen is too humble to accept such a farewell, and secondly, she would be horrified if PNDU money was spent in this way! (rest assured, the MC agrees entirely with her re mis-spending precious funds!)

So, Karen's farewell was held at a café local to her, with Chris, Miranda and Gillian travelling to join her. Unfortunately, Fay was out of the state and couldn't be there. Karen even insisted on paying for her own meal rather than accepting it from the MC members! However, as a garden lover, she accepted a gift of a plant from PNDU, as well as a PNDU Lifetime Achievement Award.

Enjoy a well-earned rest, Karen!

Chris, Karen, Gillian and Miranda

Karen, with her plant and certificate

Fighting for Change and a Cure

Words by Ebony

My name is Ebony and I suffer from Intestinal Failure and require Home Parenteral Nutrition (HPN).

I was born in 1997, after a very traumatising birth, with a healthy weight of 6 pounds 4 ½ ounces. For the first few years of my life, no one noticed anything unusual apart from severe reflux; I also had a very low immune system and caught everything that was going around, which would take me weeks to recover from.

However, from the age of 11, for whatever reason, my health has been nothing short of a struggle. I went from being a normal active, healthy child, larger than life, to becoming ill overnight with what we thought was a simple Gastro- virus. This consumed me until the age of 13 and I had to repeat Year 6 as a result. I had a 2-year reprieve, but unfortunately after the trauma of being so ill, I suffered from post – traumatic stress, anxiety and depression and was unable to attend High School so studied via correspondence. Although I was not 100%, I was still able to continue dancing and singing until once again I became unwell at age 15, after a fall, with the same Gastro symptoms and struggling to eat due to significant pain and nausea. This is when my frustrating and painstaking journey began with trying to make me well again.

I was diagnosed with Superior Mesenteric Artery Syndrome at age 16 and declined considerably. SMAS is a very rare and life-threatening digestive system disorder that occurs when the duodenum (the first part of the small intestine) is compressed between two arteries (the aorta and the superior mesenteric artery). SMAS typically is due to loss of the mesenteric fat pad (fatty tissue that surrounds the superior mesenteric artery). This compression causes partial or complete blockage of the duodenum. Symptoms vary based on severity, but can be severely debilitating.

SMA Syndrome can be treated conservatively, but due to the severity of my illness I had my first major abdominal reconstructive surgery at the age of 17, in 2015, followed by 6 more major abdominal surgeries, after which my health declined considerably and rapidly, after each and every surgery was unsuccessful.

Rare was big in my childhood. I looked like an anorexic girl. I was significantly underweight and emaciated with a white pale face and dark rings under my eyes, my growth was stunted, and my bone density was delayed resulting in osteoporosis.

Gaining weight became the biggest focus of my young life. Fattening me up became everyone's main goal. But with a digestive system that didn't work and absorb nutrients properly, this only resulted in increased suffering and pain.

During the six hard years from the ages 16 to 21, I depended on a combination of naso-jejunal tube feeds and PEJ tube feeds and ate as much real food as my body could manage. Having nutrition constantly pumping into my body became unbearable with all the pain and grief that it caused, including sleepless nights, blockages, aspirations, leakages and granulation tissue formation. It did not add any substance to my skeletal frame.

My new illness was mysterious to even the most renowned doctors and surgeons and there was no evidence of anyone else suffering from the same combination of symptoms or why my body had rejected every surgical procedure that was performed. I was unique in the medical world, as far as they could tell.

My diagnosis of SMA syndrome has required Home Parenteral Nutrition to be commenced. This is a life supportive therapy that is carried out in the home setting and it can be a very physically tiring and psychological affecting therapy that involves myself directly, as well as all those immediately connected to me in the home. Home parenteral nutrition (HPN) is a very complex type of life support where artificial nutrition is administered to patients via an intravenous infusion. Each infusion of nutrition is tailored to the individual.

Long term Parenteral Nutrition can be associated with significant morbidity and mortality and due to the invasive and serious nature of the treatment, the gastrointestinal illness and multiple surgeries prior to commencing HPN, living with HPN has posed psychological challenges for me.

Food, eating and drinking fulfil multiple social functions. Meals are often eaten together with family and friends and represent one of the most social aspects of the day. Special meals are planned for important occasions, where a large emphasis is placed on the use of food and drink as a celebration. A large proportion of socializing revolves around eating or drinking, and the ability to share this pleasure with family and friends is an important social experience. But unfortunately, many people living with HPN, including myself, take little or no food and fluids orally, therefore, I often miss out on this experience and feel a sense of social exclusion, especially around festive times of the year including Easter, birthdays and Christmas.

Also, incorporating HPN into my and my family's everyday lifestyle has involved changes in our daily routine. HPN is associated with repetitive and long-running intravenous infusions, often between 12-16 hours overnight, and the constant need for care and supervision is restrictive on both my mum's and my ability to socialise. In addition, my mum and I are also restricted in our ability to travel and to maintain a job, because of the high demands of time management that are needed for careful attention to satisfactory aseptic HPN care.

In addition, I often feel self-conscious about the way the CVC (central venous catheter) is perceived by others. Sometimes I worry that the bulge of the site will be visible under clothes and I feel apprehensive about how people react and stare when my dressing is visible. Psychologically, the presence of HPN and a CVC serves as a constant reminder of being unhealthy, often making me feel resentful and fearful.

I am now a young 21 year-old adult and have been on HPN as life support for 1 year now. It gives me a much better quality and perspective of life, but it isn't a cure for my rare disease. Even though I often look much healthier than I feel, it is important to understand that HPN is an expert at disguising the brutality of Intestinal Failure. Ultimately what has developed between me and Home Parenteral Nutrition is a complicated relationship. HPN has given me more independence and freedom, and a new outlook on life and its possibilities. However, it's also exhausting and comes with its own life-threatening complications which have landed me in the intensive care unit on several occasions. But most importantly it has given me the ability to survive.

I am also a member of Parenteral Nutrition Down Under. Since HPN is a very complex and highly specialised life supportive therapy, not knowing anyone on HPN can be very isolating and challenging. However, being a part of PNDU's email group and closed Facebook group helps me to connect with people just like myself and to feel supported.

Those who are suffering intestinal failure and require Home Parenteral Nutrition are all strong in spirit and in heart. We have all learned to smile over frowns and hold back tears until they recycle back into the background of our eyes; living life and blending into a world that is clueless about the life of those living with a rare disease, the stares and blank face looks when they hear.

Intestinal Failure is rare and misunderstood. IF and HPN patients are in a minority and do not hold the same mass appeal and familiarity of diseases such as cancer and diabetes. But even so, we each deserve world class care, therapies, treatment, research and support services so we to can have extended and improved lives.

The Week that was...HPN Awareness Week 2019, Day by Day

Words by Chris

Home Parenteral Nutrition Awareness Week is the biggest event of the year for PNDU, the opportunity for everyone to come together; not only to raise awareness, but to provide a better understanding of what life is really like living with Intestinal Failure and Home Parenteral Nutrition. PNDU does this by providing resources to our members, hospitals and industry friends. Sharing resources with family, friends and the wider community helps PNDU achieve our mission to Support, Research and Inform Consumers, Carers and Providers of Home Parenteral Nutrition for Intestinal Failure across Australia and New Zealand. PNDU would like to thank everyone for their support and generosity shown during HPN Awareness Week 2019. What an amazing week it was!

Sunday: HPN AW2019 started with the release of the PNDU AW Video, a light-hearted look at dining out. PNDU presents "Home Parenteral Nutrition Degustation" https://www.youtube.com/watch?v=GHYv5VWV8MU

PNDU
presents
Home
Parenteral Nutrition
Degustation

PNDU would like to thank Miranda and Dave for producing and starring in the AW Video; from the wonderful reviews the video has received, I think a new career awaits these two amazing PNDU members.

Monday: A big shout out for everyone to "Show us your Stickers" with 2000 stickers posted to PNDU members and supporters, it was great to see the photos and hear the stories of how everyone was becoming involved in HPN AW2019.

Tuesday: Marked World Home Artificial Nutrition Awareness Day. PNDU, a founding member of the International Alliance of Patient Organisations, PACIFHAN. It was wonderful to join in World HAN Day and share stories from "HAN's Around the World" http://pacifhan.org/world-han-day/

Wednesday: Industry friends Fresenius Kabi and Slade health opened their doors to welcome HPNers and carers for a tour of their HPN compounding facility in Sydney.

Touring Fresenius Kabi's compounding facility at Slade Health

Words by Gillian

Fresenius Kabi/Slade Health opened their doors to HPNers to tour their PN compounding facility at Mt Kuring-gai. It was a wonderful opportunity to see their very modern facility and to meet the dedicated and very welcoming staff members.

Chris, and his wife, Tanya, Karen, Jane and Gillian were met by Jane Yanco, and after filling in a visitor's sheet, we were introduced to Michelle Stevenson, who hosted us in the FK part of the tour. We waited for some of FK's staff members, who hadn't previously done the tour of the compounding facility, to join us. We then travelled to another floor of the building to where Slade Health runs the facility where PN is compounded, as well as other medical supplies and drugs.

We were met by Anita, Slade's production manager, who conducted the very interesting tour. We began in 'receiving', where the 'ingredients' for PN are unpacked and put in the correct tub into a refrigerated cabinet until needed. Another section held ancillary equipment needed by the technicians for their work. We then watched one of the technicians unpacking the 'ingredients' for compounding a PN formula. It was very encouraging to see how important sterility is, as we watched him wiping the stainless-steel bench with large alcohol wipes, then each side of the packets to be used, then the plastic sleeve containing the formula to be compounded. Anita pointed out that the glass in the windows actually looked a bit dirty – as though they had been sprayed, but not wiped dry. She explained that they are sprayed with a sporicide, which needs to be left to dry itself in order for it to do its work. She then explained that 6,000 - 8,000!!! Agar plates are used DAILY to collect samples from technician's clothes and body, as well as surfaces. These are kept for at least a week to see if 'bugs' are grown, and if they are, what they are and where the sample was from, for following up.

We then saw the dispatch section where the PN is sent to customers, before returning to Fresenius Kabi premises for a talk by an HPNer – me in fact.

While waiting for everyone to arrive, we HPNers noticed the trouble FK had gone to in keeping with our 2019 slogan 'HPN, A Rare Diet'. Someone had filled different sized PN and other bags with different types of nutrition: a bag of fruit, of vegetables, of eggs, of jellybeans, etc. A fun touch, representing the different nutrition provided in our PN bags. In all, there were about 25 Fresenius Kabi and Slade Health workers present. Chris spoke first as PNDU president, a bit about PNDU, then introduced me. I had been asked to speak about life on HPN, so I tried to make it representative of all HPNers as much as I could, by explaining that as HPN is nutrition, not medicine, we have very differing wellness. I then spoke about the things we mostly have in common, such as adjusting the routines of our lives around HPN, including delivery, setting up and the need for absolute aseptic technique, about issues of storage of our PN and ancillaries, disposal of rubbish, fatigue, etc.

We concluded by playing the PNDU-developed HPN Bingo game, using a 'real' bingo ball mixer to obtain the numbers, then me reading aloud the corresponding HPN related issue. It was a bit of fun to finish a very worthwhile tour.

Thursday: PNDU President Chris, Visits Parliament House in Canberra.

PNDU as a partner organisation with Rare Voices Australia, was invited to attend Parliament House in Canberra for the release of the McKell Institute report - Disability and Rare Disease: Towards Person Centred Care for Australians with Rare Diseases.

https://mckellinstitute.org.au/research/reports/disability-rare-disease/

PNDU President Chris, is a staunch advocate for equitable access to health and disability services, including the NDIS. Chris's grandchildren Jordan and Logan's story appears in the McKell Institute report.
PNDU is very grateful and would like to thank Rare Voices Australia, for this opportunity to represent PNDU in the Nation's Capital and speak directly with politicians about our rare disease Intestinal Failure, Parenteral Nutrition and the work we do for PNDU.

Trent Zimmerman, Dr Mike Freelander, Bill Shorten and John Alexander were among the ministers Chris had the chance to speak with.

Chris Talking to Trent Zimmerman MP Bill Shorten MP Nicole Millis CEO RVA Dr Mike Freelander MP

Friday: Baxter opened the doors to their HPN compounding facilities across Australia (Brisbane, Sydney, Melbourne, Adelaide and Perth) and New Zealand (Christchurch, Auckland) thus providing an opportunity to not only see how our Parenteral Nutrition is manufactured, but to also meet the dedicated staff and share personal stories of life on HPN. It's not always easy to share our HPN journeys in front of a crowd of people we don't know. PNDU would like to thank our brave HPNers, Haylee (VIC), Mariann (NSW) Roseanne (NSW), Barbara (SA) and Georgie (NZ)

Touring Baxter (NSW)

A few words from Chris.

We were warmly welcomed by Steven Flynn, General Manager of Baxter ANZ.

Watching how our PN is made, we gained a better appreciation of the dedication and attention to detail that is required to ensure the finished product, our HPN, is of the highest standard. Maintaining a clean environment is of the utmost importance. To wrap up the tours, so to speak, a demonstration of how to gown up in protective clothing was organised with a Baxter staff member and a volunteer from our tours, Philip (VIC) and Peter (NSW)

Touring Baxter (VIC)

A few words from Philip.

Another tour of pharmacy meets very modern technology; I'm always reassured that Baxter runs to the highest standards, and aim above, not a lackadaisical "it should be enough". There was a larger patient group this year, and it's always good to hang out with others with varied medical reasons for being on HPN.

And what would the tour be without dress ups? I was part of the tomfoolery, baking slowly in disposables, which I found are very difficult to put on in a professional way without very good balance.
Thanks once again to Baxter and the PNDU team for organising this.
PNDU would like to thank Local Member for Brunswick, Tim Read MP for joining the tour, it's always wonderful to have the support of our politicians.

Touring Baxter (Auckland)

A few words from Georgie.

I just wanted to thank PNDU for organising for my friend Emma and I to tour the Auckland Pharmacy and to share my story with the staff this morning. I thoroughly enjoyed it, and loved seeing the behind the scenes of it all. It is truly mind blowing to see the staff so dedicated to their work in helping so many of us New Zealanders with these life-saving therapies.

PNDU would like to thank Baxter for organising these pharmacy tours. Katie Barovs, Product Manager – Home Nutrition, Baxter Healthcare, sums up the value of interactions between Baxter staff and HPNers:

Hi Chris and Team,

WHAT A WEEK. All of Baxter was still buzzing today.
I can officially report that the Baxter teams all thoroughly enjoyed celebrating and advocating for HPN throughout the week.

I am so full or words of gratitude that I don't know where to begin.
The patient and carer story-sharing was a powerful demonstration of strength and determination to live life to the fullest. I really do believe that the two-way sharing between staff and families is the best way to understand each other's experiences.

Thanks for all that you do.

Cheers,
Katie

Saturday: To close out Awareness Week and to help people understand what life is like on HPN, PNDU shared a Personal Story from a very brave member, Ebony. With the support of Rare Voices Australia's social media channels, Ebony's story was able to be shared with the wider community, as well as the PNDU forums.

https://www.fairforrare.com.au/news/51/ebonys-story

PNDU would like to thank the following Hospitals for their support

Words by Chris

14 HPN Hospitals across Australia and New Zealand received HPN AW2019 Resources.
PNDU received some very positive feedback with regard to how the resources and information helped bring about a better understanding of life on HPN during AW2019

Royal Brisbane and Women's Hospital and the Specialist Nutrition Support Team.

In terms of the feedback, it was really great to hear how the crossword helped clinicians who don't have a lot of exposure to PN understand some of the aspects that become part and parcel of life on HPN.
'The quiz highlighted that there is a lot of extra organising and hassle that an HPNer (and their families) have to do to try to have a semblance of normalcy in their lives and do things we all take for granted, eg travel. The crossword was a great idea – got a lot of info across in a fun way.'

Others who commented said they never realized how an IV infusion would affect the urine output overnight, or had ever considered aspects around mobility and that a backpack was an option!

Thanks again for all your great resources and the wonderful work PNDU does to help make HPN more visible and understood from a patient/carer/family support perspective.
Emma

Royal Prince Alfred Hospital.

Just letting you know the nutrition teams on the ward are running in-services for the staff for HPN Awareness Week!! They're running bingo, quizzes and education sessions! We've got all your posters up, so it's looking great! Cheers, Sophie.

Other hospitals involved in HPN AW activities were:

- **John Hunter Hospital**
- **John Hunter Children's Hospital and HNE Kids Health**
- **Auckland Hospital**
- **Gold Coast University Hospital**
- **Queensland Children's Hospital**
- **North Shore Hospital (Waitemata DHB NZ)**
- **Princess Alexandra Hospital**
- **Royal Prince Alfred Hospital**
- **Starship NZ**
- **Sydney Children's Hospital**
- **Children's Hospital Westmead**
- **Waikato Hospital NZ**
- **Takeda (Shire) (Industry friend)**

Industry friend Biomed:
'We had a lovely week celebrating HPN awareness week.
We celebrated with a talk from one of our home patient's mother, so the staff could learn more about HPN. The sales team organised a competition where staff could learn to connect TPN in an aseptic manner and then we ran time trials for each team.
The resources you sent me were distributed through the week throughout the company, which was great.

Kind Regards, Jessica

A PNDU founding Member, Professor Gil Hardy, and his dining club friends hosted a fundraiser for PNDU

We had a very successful HPN AW fund-raising dinner with Dining Club Friends and neighbours last night, with over NZD250 raised for PNDU.
Hope the week was also successful for you all.

Best wishes Gil

Gil's Dining Club Friends and neighbours in Auckland, NZ

Haylee's Story

Words by Haylee

My chronic illness is called Gastoschisis, which means my bowel was outside of my stomach when I was born. I now only have 20% of my bowel left, which resulted in my new diagnosis: Short Bowel Syndrome (SBS). I've never been able to eat properly as I could never hold anything down. This resulted in HPN and peg feeds for the rest of my life.

Of course, this was a challenge, especially during my childhood. I suffered quite a lot of complications, with over 100 surgeries and some very long hospital stays. Due to my HPN, I also had countless line infections caused by switching from ports to central lines. This resulted in my veins getting blocked, which was eventually fixed by getting a stent inserted into one of my main veins.

During all of this, it was very hard to keep up with school and keep friendships. By the time I came back home from a long admission, we had drifted apart. However, the hospital was my second family and I have made a lot of lifelong friendships from that. Personally, I gave up trying to be good at my schoolwork until high school.

During my teen years at high school I had a carer. It was hard to interact with other people as they knew I had a disability. Because of my short height, I also got stared at and was always mistaken to be in year 7 instead of year 10. To keep up with my friends, I sometimes had to take my HPN with me to parties in a backpack. This made me feel quite insecure, but I've tried to learn to embrace it.

I've always been anxious when I leave the house with my HPN. Until the past couple of years, I never used to leave the house once I got connected onto my lines every night from 7pm to 7am in case of infection. But recently I've realised I just want to live my life, because HPN will always be a risk no matter what I do. When I left the children's hospital and entered the adult world, there wasn't a lot of guidance. We lost a lot of our support and funding and weren't shown how to do everything. However, with time, a new routine is slowly building, and I am learning new things every day.

HPN has made my life quite difficult and can sometimes be a burden, but I am forever grateful that it has given me the chance to live.

I find PNDU such a great and helpful community and so relatable, as we are all going through the same thing.

HPN Children and Sport

Editor's Note: One member's post triggered an interested response from other members, who want their children to be able to participate in physical activities and sport, but are unsure of the suitability.

Mel's Post: This amazing lady is Jess!
Jess and the team at Evolve gymnastics have been beyond remarkable! Due to her brittle bones, and all the medical bits and bobs beneath that shirt, Emily has never been able to participate in a gymnastics program, despite really wanting to. When I approached Evolve, they went above and beyond! Once a week, Em works with Jess on a modified gymnastics program. Em adores this time and it has been just beautiful to watch the special relationship develop between Jess and Em!
Thank you Jess and the team! It is wonderful to see a local company focusing on inclusion and supporting the mental health of kids, as well as their physical development!!!

Some comments from PNDU FB:

- My young son has had both a central line and a gastrostomy button for the past 2 years and plays sport. He plays goal keeper for his soccer team. He trains 4 nights a week for an hour, and then the game on Saturday. We have sourced a padded goal keeper's vest from overseas that keeps everything firm and tucked away under his jersey. It is what he lives for and is super passionate about. We are lucky he is having a good run at the moment and is able to do it. He is not a happy boy when his body doesn't allow him to train.

- It's a really tough situation to be in as parents. Our kids are high risk no matter what they are doing. Our son's mental health was a big deciding factor in allowing him to participate in sport. Ideally goal keeper is the last place we would like him to play but it's something he is super passionate about. We do what we can to minimise the risk, but know he will never be 100% safe. It is scary and a decision every parent in this situation needs to weigh up for themselves. He also plays Oztag in summer, but with a tight vest under his shirt so the cords can't be accidentally grabbed.

- My daughter participates in general PE at school each week - something we thought she wasn't going to be able to join in. We tape her central line with Hyperfix™ and she wears a vest. We then coil her GG, JJ and ILE inside a Tubifast™ around her tummy. We also use onesies to keep everything tucked away and secure. In 2 terms we've not had a single issue - it's wonderful!! She has also just started SIAS gymnastics and basic dance this term, (all school programs). She's monitored and the activity is modified if it poses any risk – it's terrific!

- We have grappled with this issue - we have erred on the side of caution on this one. Our daughter does participate in sport, but no regular contact sport/games. She kicks a soccer ball around with friends after school, but we haven't let her play club soccer, nor judo nor anything where the risk of line dislodgement is high. She has done dancing, though, which she loves! It is hard sometimes for her to have to sit out and miss an activity she'd like to do, but we have decided to be reasonably strict about it so that we wouldn't regret anything, as she is likely to be PN dependent for life. When she is older and more responsible (and sensible), we might ease up a bit and let her make some of those decisions on risk.

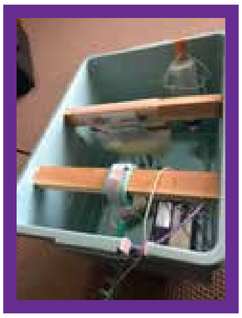
Freedom for 'Pumpkin'

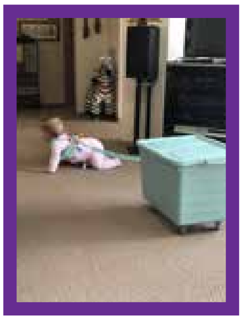
Words by Julia

How to let my daughter, affectionately known as 'Pumpkin', try out her new crawling skills while attached to pumps, feeds and an IV pole for 20 hours every day? Here's how we've achieved a little more freedom at home.

The crate and castors are from Ikea. I bought the walking harness online from a website called AliExpress (the spiral cord makes it easy to fit tubes inside for protection) and a couple of pieces of wood cut to size at Bunnings and glued. I lined the hole for tubes with irrigation tubing from Bunnings which I split and glued in place, to ensure there was no risk of tubes rubbing against sharp plastic.

This should work just as effectively when she's toddling and still too little for a backpack.





Anxiety and HPNers

***Editor's Note:* Anxiety became the topic on PNDU's private chat forum, and it was such a common problem for many members that I thought it worthwhile to put the many practical suggestions together in an article, hoping that some of the ideas might helpful to others. The ideas are from some of PNDU's members who suffer from anxiety, who have found these activities to help them. As one of our witty members put it...'And now, FREE with your chronic illness you get extras: anxiety and depression!'**

If anxiety is ongoing and worsening then it's important to speak to your doctor about having professional help from a counsellor or psychologist. It would be helpful if this person was familiar with treating those suffering from the debilitating effects of chronic illness.

Members' Suggestions:

- Weekly meditation class, then practicing it at home as well. This has helped me to relax and take it day by day.
- Daily meditation.
- Good friends to talk to when life is tough; those who get you and will walk this journey with you. Community is everything- you cannot do this alone.
- Daily exercise - within your limitations. But movement is critical to physical and mental health.
- Being in nature, the beach, the bush or whatever you love.
- Creativity in any form - baking, knitting, art, etc
- Listening to uplifting music.
- Be kind and gentle to yourself. Don't berate yourself. You are doing the best you can with difficult circumstances.
- Yoga and the yoga breathing techniques help me enormously, both with anxiety and with pain management.
- Making artwork or drawing helps a lot.
- Inspiring (or simply enjoyable) reading.
- Volunteering for a cause you believe in - if you have the energy.
- I listen to a lot of music.
- I ride a recumbent bike.
- Walking is always good for the soul.
- Having good friends helps.
- I used to paint, which I loved, so I should probably get back into that.
- I've accepted my health isn't ever going to get better; I feel that in accepting my symptoms and just wanting to best manage and cope with them, that I have a certain degree of control, and that has reduced my anxiety by not having false hopes of getting better with new treatments.
- My faith and prayer are important to me.
- Colouring in books.

Navigating NDIS Applications – PNDU's 'Tips' Sheet

Words by Chris

***Editor's Note:* Accessing NDIS funding has proved to be a very complex and frustrating process for many members. Our president, Chris, has had much experience with the process when trying to access funds for his two HPN dependent grandsons, and has very patiently shared helpful ideas to individual members on PNDU's private chat forum. It was decided by the MC, under Karen's leadership, that it would be very helpful for Chris to write a hints and tips sheet for anyone starting the process to refer to, whether it be HPNer, carer or clinician. Many thanks, Chris, for this document.**

The National Disability Insurance Scheme (NDIS) is a wonderful initiative that has been rolled out by the Australian government. The NDIS is designed to help people get the support they need so their skills and independence improve over time.

In Australia, Home Parenteral Nutrition (HPN) for Intestinal Failure (IF) is funded by the health system. Sometimes however, those living with HPN may require disability support services such as occupational therapy, physiotherapy, speech pathology, dysphagia therapy, psychology, self-care and domestic support. Unless eligible for aged care assistance, in order to receive government assistance for these support services, an HPNer/carer needs to apply to access the National Disability Insurance Scheme (NDIS).

Unfortunately, applying for access to the National Disability Insurance Scheme (NDIS) can be a complicated and often frustrating experience for people living with HPN for Intestinal Failure. This is a topic which often comes up for discussion in our PNDU forums, among our Australian members.

To help our members navigate the NDIS, PNDU has created a "Tips Sheet" of helpful information to assist Australian members needing to access the NDIS to fund support services for Intestinal Failure requiring HPN. The information and tips have been gathered from members who have already travelled the NDIS access journey.

The PNDU NDIS Tips Sheet can be found by logging into the PNDU website, members only information section, **"Hints and Tips" + "Kiddies Korner"**

Editor's Apology:

The following article was published in the last issue of Dripline #28, but an unusual formatting error, made at the designer's, went unnoticed – a mistake whereby a paragraph from the article on Revestive and PNDU's role, written by PNDU's President, Karen, was added to the end of Dr Peter Lim's article. As well as apologising, I decided to reprint the article.

Dr Lim's article in its correct form is already on our website's Clinical Information members-only page (**https://pndu.org/dashboard/clinical-info/**).

In an update, the Health Minister announced on 1st October, 2019, that Revestive is now available on the PBS in Australia for adults with surgical SBS/IF: **https://www.health.gov.au/ministers/the-hon-greg-hunt-mp/media/new-and-amended-pbs-listing-to-counter-short-bowel-syndrome-upper-limb-spasticity**

Introducing Teduglutide (Revestive®) 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 ≥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 overload.

Teduglutide in Australia

Teduglutide has recently been recommended to be available on the Pharmaceutical Benefits Scheme (PBS). It is hoped that it will be available on the PBS within the next 6 months. This represents an exciting development in the treatment of intestinal failure due to short bowel syndrome, and one of the first medications to be available in the treatment of this condition.

Vitamin C: The 'Limey's' Nutrient

Professor Gil Hardy PhD FRSC FASPEN

Editor's Note:* *Professor Hardy is a Life Member and one of the founders of PNDU. As a Professor of Clinical Nutrition, he has been involved in various aspects of PN since the early days of its development. Gil very kindly offered to write this article for Dripline about the importance of Vitamin C and how HPNers might be lacking in it, and I thank him for the time he has put into it.

Vitamin C (Ascorbic acid) is an essential micronutrient that functions as a strong antioxidant, controlling iron metabolism and working with various enzymes that manage many of our energy and metabolic processes. Since the vitamin is water soluble, it is not retained by the body which needs daily replenishment, usually from fresh fruits and vegetables, the richest source of micronutrients.

Severe Vitamin C deficiency is known as scurvy and can arise from as little as four weeks without replenishment. Dr **James Lind**, a British naval surgeon, identified that citrus fruits prevented the disease of scurvy in 1747. One hundred years later, lime juice from the West Indies, providing higher amounts of vitamin C, was used throughout the Royal Navy, giving rise to the American use of the nickname "**limey**" for the British. **Captain James Cook** had previously demonstrated the advantages of carrying Vitamin C-rich "**Sour krout**" on board for his explorations 'Down Under',

Symptoms of scurvy include weakness, fatigue, bleeding gums, impaired wound healing, and arthralgia. Some of the symptoms are non-specific, and deficiency can be masked by other diseases. Although scurvy is now rare in western societies, many people, who do not include fruit and vegetables in their diet, may be at risk of micronutrient deficiency (1). Females deplete faster than males and have an increased requirement during pregnancy. Cigarette smokers have lower levels than non-smokers, partially because of increased oxidative stress (2).

Individuals with malabsorption issues or those on long-term haemodialysis may also be at risk. Ascorbic acid is absorbed in the small intestine, with bioavailability dependent on the amount ingested. Various gastrointestinal conditions may increase the risk of vitamin deficiency due to dietary restrictions for malabsorption, surgery or the increased physiological needs imposed by certain medications such as steroids. Lower levels of vitamins A and C have been found in Crohn's Disease (CD). Up to 75% of CD patients following curative surgical resections have malabsorption, potentially requiring micronutrient supplementation (3).

Vitamin C has a key role in collagen synthesis, a protein found in skin, bones, tendons and cartilage. Many signs and symptoms of vitamin C deficiency, such as frequent bruising, poor wound healing, loose teeth and easy fractures, are the result of inadequate collagen production. Scar tissue involved in wound healing requires vitamin C for its development and maintenance, so wounds that do not heal after surgery may be related to vitamin C deficiency. HPNers of an advancing age, in which bones can become thinner and more brittle, are susceptible to osteoporosis and the risk of bone fracture increases. Vit C is important for bone health, because the collagen that helps to keep bones strong requires the vitamin for its production. There is a positive association between higher Vit C intake and greater bone density, which indicates stronger bones and reduced fracture risk.

Good Vitamin C status is important for maintenance of heart health. It is involved in metabolism of cholesterol. Low vitamin C correlates with high total blood cholesterol which may increase the risk of heart disease, whereas a high Vitamin C has been associated with lower blood pressure and higher HDL, the good form of cholesterol.

Stress depletes Vitamin C and other micronutrients, which can have a knock-on effect on other bodily functions and general wellbeing. Hospitalised patients with acute stresses such as major burns or trauma and critically ill patients display reduced levels and should be assessed for possible supplementation (4). Many clinicians have recommended Vitamin C and zinc supplementation for prevention or treatment of pressure ulcers. However, there is little good quality published evidence and current guidelines do not advocate this practice (5). More importantly, supplementation with a range of micronutrients, including vitamins A, C, E, zinc and iron have been linked to an improvement in wound care management (6).

People with a urostomy can be more at risk of urinary tract infections (UTIs). Vit C can help acidify the urine and create an unfriendly environment for bacteria to grow. However, very high supplementation doses may be necessary. It has been suggested that prolonged ingestion of high Vitamin C doses may cause kidney stones, however there is little evidence to support this. Ascorbic acid has relatively low toxicity. The upper limit set for adults in Australasia is 1000mg per day.

Scurvy is usually the result of complete Vitamin C depletion, but a low vitamin status could have other ramifications. Blood testing is relatively expensive and may take some time, but a plasma ascorbate concentration of less than 20μmol/L indicates inadequate Vitamin C status (7) which should be confirmed most easily from diet history and a detailed assessment of clinical signs and symptoms.

Daily oral doses for Vitamin C of 45mg in adults with an increase to 60mg during pregnancy and 85mg during lactation are recommended to prevent the development of scurvy (8). **For those on short or long term PN, AuSPEN recommends the routine provision of 110 to 150mg per day, including during pregnancy/lactation (9) For premature and term infants up to 12 months, ESPEN/ESPGHAN guidelines recommend 15-25mg/kg/day and for older children 80mg/day (10). All international guidelines stress the importance of including Vitamin C and all other micronutrients in daily PN bags for adults and infants.**

Key points:

- Vitamin C is an essential nutrient that defends the body against illness and infection
- Vitamin C is not produced by humans and must be supplied in the diet
- It is difficult for most HPNers to consume enough dietary Vitamin C from fruit and vegetables to meet daily needs
- The potential for developing a vitamin C deficiency is quite high amongst many hospitalised patients.
- A daily dose of 110 to 150mg vitamin C is recommended for adults on PN
- A dose of 15-25mg/kg/day is recommended for premature and term infants, and a dose of 80mg/day for older children on PN.

References

1. NHMRC, NZ Ministry of Health. Nutrient Reference Values for Australia and New Zealand. 2006.
2. Blanchard J. J Nutr 1991;121; 170
3. Fillipi J et al. Inflammatory Bowel Diseases 2012:12;185
4. Berger MM. Gastroenterology 2009;137(5 Suppl): S70-78
5. EPUAP Clinical Practice Guidelines. Washington DC. 2014
6. Vas PRJ et al. Int J for Lower Extremity Wounds.2017:16:226
7. Levine M, et al. Jama 1999;281: 1415
8. Osland E et al. Asia Pac J Clin Nutr. 2016;25:636
9. Bronsky J et al. Clin Nutr 2018:37;230
10. Institute of Medicine. National Academy Press: Washington DC, 2000.

The idea for this article was stimulated by a review on the importance of Vitamin C by Margaret Allan in the June 2019 issue of New Zealand Osteomate Magazine.

Birthday Corner

HAPPY BIRTHDAY

Cataleya has had the most amazing day ever.
She was spoilt lots and did so much and had an amazing cake.

A Day in the Life of an HPNer – Fatigue

Editor's Note: I opened this issue's Day in the Life ... topic to the members on both of our forums to comment on. The first section is from adult HPNers and the second from adult carers of paediatric HPNers.

Adult HPNers

Jodie

I've reduced my TPN from 7 nights to 6 and more recently, to 5 per week. Whilst this gives me more freedom (unattached!) and has improved the health of my liver to a large degree, I'm having to pay for the reduced number of nights with less energy. The day after no TPN, I struggle. I often wonder if it's worth the sacrifice as less energy means more lethargy, malaise and ultimately, less quality of life. But liver health is more important and I'm getting enough calories in 5 bags per week so I'm taking the energy hit as part of the package.

It'd be so much simpler if we could just plug into a power socket for a few hours each day to recharge!

Anne

In the mornings, I am very slow and cannot make any appointments before 10.30am or 11am. I have to go to bed at 8.30pm and cannot stay awake beyond 9pm... then of course I am up several times in the night going to the toilet!

Three weeks ago, I started an exercise program, once a week, with homework. It is early days, but I think it is helping to deal with fatigue.

Jacqueline

I need naps daily as well. Sometimes I feel exhausted and I haven't even done anything!

What I notice too, after I wake up, I feel very disorientated. I need at least an hour to feel "normal" again. Maybe this has got to do with my TPN, which runs during the night.

Sal

I'm finding that I'm getting tired more easily at the moment and really have to pace myself. I have a power nana nap in the afternoon where I might rest for up to an hour, but only sleep for about 10-15 minutes, which I somehow naturally do. The odd occasion when I sleep for longer, I find it harder to wake up afterwards. Some days I'm at work and naturally no chance for a rest.

My muscles fatigue really quickly as well and become painful by the end of the day and I'm hanging out to connect up. But I do push myself and probably do far too much, but I find it's better for my headspace to not be idle.

Daniel

Yes, fatigue is a killer. Some days I'm full of beans and others I just don't have any energy at all.

I seem to force myself more when I'm on holiday. Which means it takes longer to recover.

T (No longer on PN)

I just thought I'd chip in too - thinking back, I would definitely get fatigue too - but for me it was mainly from lack of sleep through the night; I found it would catch up on me. After about a week or two of TPN interrupted sleep, I would find myself falling asleep on the train home and need to be in bed by 8.30pm (with my normal bedtime more around 10.30 - 11pm)! But then it would be okay for a while. I would also need long naps on the weekend, usually around the middle of the day, when I wasn't connected - I'd have such a deep sleep that I'd feel more rested as a result! Energy levels for me were overall pretty good after going on HPN, it was just the lack of good sleep that affected me.

Lisa

I experience fatigue every day. I usually don't dress or shower until I have the energy and I am gentle on myself about housework. I do online grocery shopping and try to delegate things like dishes, washing etc. I tend to relax and watch TV or study online when I can and find that now, if I don't have the energy, that's okay and it's alright to just veg out. A day or so of frozen meals for the family won't kill them, the housework can wait, the food can be bought online and bills can be paid online; so really, I just focus on what my body wants that day and what I can and can't manage. I also go to bed by 8:30 every night and wake around 7 am. Sleep is important too.

Carers of Paediatric HPNers

Belinda

Not so much from a PN patient but as a parent for a child on HPN, I find that I tire quickly during the day after taking care of him overnight. I have noticed though that Aidan doesn't have the same energy as the other kids his age. He would often come home from school (when he was doing half days) and he would just need an hour or two to recover. Aidan doesn't empty his own bladder, so we have to do that for him every 4 hours on PN nights - thankfully he only has PN every 2nd night.

Miranda

It's really interesting to hear about some of your experiences in the morning!! Ariel wakes up extremely cranky every morning (always has) and is very slow moving. I'm not sure if it has anything to do with PN, or whether she just isn't a morning person. It is always a difficult time of the day for us, as I am always in a whirlwind rush in the mornings, trying to get through the myriad of medical things as well as normal routines of getting 3 kids dressed, packing bags, getting to work and school on time etc. It definitely doesn't help that everyone in the house has had broken sleep in the night...for the last 8 years!!!

Melanie

Emily definitely fatigues much more than our other kids. She needs a lot more down time and isn't as active. She will often push herself to the point of exhaustion and end up vomiting and we have to force her to slow down and rest. It's hard when all she wants to do is keep up with her friends and siblings. This exhaustion is definitely more apparent in the afternoons and on hot days.

Chris

This is a problem for both Jordan and Logan (aged 10 and 7 years respectively) Mornings can be a mixed bag to deal with, depending on the amount of disruption during the night, both boys are incontinent, (bladder and bowel), which can result in changing nappies, clothes and bedding overnight, leaking abdominal drainage tubes can also result in changes of clothes, bedding and dressings around the leaking tubes. Add to this pump alarms, recently compounded with the new colour bodyguard pumps, and a goodnight's sleep is something we can only dream about.

Not the ideal way to start the day, grumpy children and tired carers.

Increased activities, such as playing games in the park or walking any distance and both Jordan and Logan tire easily. After 15 - 20 minutes, the boys both show signs of fatigue; after an hour of play, both are usually spent and need to sit and rest. Again, we encounter problems trying to get the boys to drink enough fluid to stay hydrated or to sit and rest. Dealing with ADHD and moderate intellectual handicaps, it is almost impossible to get the boys to stop and rest; the excitement of being out and about, especially playing in the park or riding scooters, is the only focus for the boys and they will both continue to play until totally exhausted. With exhaustion/fatigue also come heightened behavioural issues; the more fatigued, the worse the behaviour.

Jordan is the first to crash at night. By 7:30, it's like someone has taken the batteries out of him and he falls asleep almost on time every night.

Logan takes a little longer; the more fatigued, the more he will fight the need to go to sleep.

HPNers and the Work Force: HPN and Employment – A Call for Requests

Words by Emily

Editor's Note: ***Emily (young HPNer) is a regular Dripline contributor, who lives in the USA, but has spent a semester at university in Sydney, and has met with some Sydney HPNers at a social event.***

In the States I work full time as a supported employment specialist for adults with persistent mental illness. This means that I support my clients in all job searching activities, such as building a resume, submitting applications, following up with employers, and going on interviews. Once they secure employment, I help them maintain it while continuing to maintain their mental health. This is my first "big girl" job since graduating college and I've just passed my one-year anniversary.

Since diving into the world of patient advocacy and meeting more people on PN, I've realized that not everyone works full time. Growing up my parents emphasized the importance of going to school and working and I'm simply lucky enough to have been able to do both while on PN. At the recent Oley Foundation Annual Conference in Chicago, I was part of a panel of young adults discussing common socioeconomic barriers they've faced as a PN patient. Topics including dating, self-image, and mental health. A BIG topic that I did not foresee was employment. I was surprised to be able to bring my expertise as a vocational specialist into this community.

Since then, I've been racking my brain and drafting articles tackling PN and employment with little success. What do people want to know? What are their specific concerns? I've been working or going to school my whole life so it all seems second nature to me. Then it hit me, instead of guessing what people want to know, simply ask them! So, I'd like to ask you, what are your employment related questions? What do you want to know? Do you have questions on how to disclose your condition to an employer? How to juggle work and medical appointments? Please let share with me your questions at **emilyprk@bu.edu**! I will compile the questions and answer them in the next issue of Dripline!

A Handy Storage Unit

Words by Belinda

Editor's Note: ***Although PNDU doesn't promote companies or items of furniture as such, I felt that as storage of all our supplies is a common problem, it was worth sharing Belinda's 'find', since it works very well for her and may be just what some of our members need.***

My son is now back to needing lots of medical supplies after having his central line reinserted.

I did struggle though with the extra supplies that come with a central line, as I had previously changed his room around to better help him cope and have more space, and had removed a lot of the medical storage which we had, as it was no longer needed! Since I absolutely freak out with mess and head into a minor breakdown when the house is untidy, I can be found cleaning at all hours if it bugs me enough, I had to do something fast that would work when it came to storage.

So, I spent a few hours scratching my head before I went down and checked out the local Fantastic Furniture store and found an interesting unit that has a number of different adaptations available: you can add square storage boxes, drawers, and drop-down cupboards. It's a very handy little unit that we now use to hold the billions of items my son seems to have now.

Japanese Toilets for Ostomates

Editor's Note: ***One of our members posted this photograph and another responded with the text. I thought that, as many of our members are also ostomates, this might be of interest.***

I love Japanese toilets, having travelled there twice. Not just heated seats, music to cover any embarrassing sounds, built in warm bidet with pulsating water you can remotely direct as needed ... but then a quick blow dry. It's like a free high-tech car wash for your bum!

Upcoming Events

The PNDU Annual Gathering

11:00am - 3:00pm Friday 22nd November

Minor Works Building
22 Stamford Court, Adelaide SA 5000

The AuSPEN HPN Consumer Workshop

12.30pm - 4.30pm, Saturday 23rd November 2019

Room 3066, Level 3,
Adelaide Health and Medical Sciences Building,
Cnr North Terrace and George Street, Adelaide, SA

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 for their generous gifts, totalling $4200:

- Aschner J
- Bevin M
- Chew G
- El-Kadhi A
- Ezekiel A
- Heffer D
- Hunt J
- Jakovljevic N
- Kwan G
- Lee J
- Lesser A
- Levi Mrs
- Low S
- Mammen S
- McMullen S
- Miehs A
- Mirabelle P
- Narushima H
- O'Lone E
- Palmer S
- Parker K
- Rowlands A
- Sinha S
- Thabrew H
- Tuckfield D
- Vitek D
- Wilson J
- Winterbourn K

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.

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

Management Committee Members

President - Chris
Vice-President - Gillian
Secretary/Public Officer - Miranda
Treasurer - Belinda
Editor - Gillian
Committee Member - Fay and Ryan

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

Designer: MBE Hurstville