DRIPLINE

PNDU
Parenteral Nutrition Down Under

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I hope you enjoy the latest issue of Dripline. We have a glimpse into Cataleya's life after HPN; share Sal's joy at her daughter's and her son's weddings earlier in the year; we understand a bit of the struggle for HPNers trying to study with a chronic illness; we learn of the importance of micronutrients in our diet, and hence in our PN bag; and read an abstract of a study re line repairs for our young members. I thank all the contributors for their time and efforts in helping to make Dripline an interesting, relevant read for those on HPN, as well as clinicians.

Gillian
Dripline Editor

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A Child's Life After HPN

Cataleya was born in August, 2014, with a birth defect called gastroschisis. She had surgery when she was born and lost a large portion of her bowel. she was left with 30cm of small intestines and half her large intestine, so she was put on HPN (Home Parenteral Nutrition) from birth.

During her time on HPN she has had several lines removed due to infection, including STAPH; she had long lines and central lines placed, most of them without an issue, but some of them have had complications due to the scar tissue and not being able to place due to her veins almost collapsing due to how long she was dependant on HPN. I've lost track of exactly how many, but it was over 15.

During her time on HPN we had no other complications with her organs (we were very lucky).

We were told she would come off HPN eventually, but the time frame was very uncertain due to her short bowel and lack of absorption with her feeds. Over time, she was able to eat more orally and her feeding tube intake increased and she was able to maintain her weight, but unfortunately that didn't last very long. We have been on and off HPN many times over the years; we are currently 2 years HPN free.

Since then, her life has changed so much. We weren't able to do all the things other families did, like going to the beach and swimming. Even simple things, like bathing, was an issue - we had to be vigilant with that so that we didn't get it her line entry dressing wet.

But since we have been HPN free, we have been exploring the world (in our hometown at the moment) but we are going to the beach more and playing in the sand, building sand castles, we are going to the pool, we are going swimming. Cataleya is getting into swimming lessons. She is loving life and living it to the absolute max!

There are still health issues that come up. When she gets sick, we get sent straight to hospital. She still struggles to put on weight for herself; she is still not growing much either, but we are being monitored to make sure she doesn't fall too far behind. There have been a few times when we have almost ended up back on HPN because she dropped weight so much, but we managed to put it back on with her feeding tube feeds and formula. She does still struggle with eating orally at times, but we are working on that slowly.

Words of Wisdom

Words of wisdom to other parents who have a child with HPN would be to try not panic, trust their own parental guts and listen to the medical advice given to help make decisions around their child's care.

Obtain as much information about your child's health needs as possible. You are their best advocate in decisions around their needs. Keep in contact with those around you who understand the situation you are living in. These supports will help keep you sane during the stressful times.

Birthday Corner

Happy 9th Birthday Logan!

Logan (HPNer) celebrated his 9th birthday with family and friends at the local skate park. Logan enjoys riding his scooter and skateboard and has become quite adventurous on the half pipe and jumps.

Fitting in with the skate park theme was another wonderful cake from Auntie Katie, complete with TEK Deck skateboards and BMX bikes.

A Day in the Life of an HPNer: Studying whilst on HPN

Editor's Note: Two of our members share their stories of studying whilst living with HPN. Many thanks for their insights.

Words by Naomi

My journey through university has not been an easy one. I suffer from digestive tract paralysis. My symptoms started when I was 4 years old and got progressively worse through high school. I remained undiagnosed, though, until I was 25, so this made life and studying very difficult. I graduated from high school in 2004 and received good grades and was accepted in to an Advanced Science program at university. Unfortunately, by this point I was very unwell, and spent many years going in and out of hospital, often for months at a time. I was spending more time in hospital than out after a while, but with no diagnosis, treatment focused on stabilizing me, rather than addressing the underlying problems. Because of this, I had to withdraw from university. I was absolutely heart- broken.

Finally, I was referred to my current colorectal surgeon when I was 25, who is very caring, thorough and knowledgeable and he proceeded to run many tests and I received my diagnosis. I was relieved to finally have some understanding as to what was happening to me and remained hopeful that there would be a solution and my life would improve and I could finally go back and resume my degree! Unfortunately, the diagnosis was just the beginning of trial and error with treatments. Many medications, sacral neural modulation, j-tube feeds, gastric stimulation etc were all trialled with minimal success and I was continuing to lose weight and became weaker and weaker. 5 years after first seeing my surgeon, we took the step of removing my colon and creating an ileostomy and inserting a permanent j-tube for feeds and g-tube for draining my stomach. This improved my situation somewhat, and I was able to return to university. I decided to study part time, as a full-time load was too much for me to handle. I would fatigue easily and find it difficult to concentrate. Pain and nausea meant I often felt too unwell to go to campus and I would fall behind on assignments. I managed a couple of semesters this way, but again, became too unwell to continue. I was so disappointed!

Following dangerously low electrolytes from vomiting, and malnutrition and low weight and complications caused by this, I was once again admitted to hospital. This was 3 years ago. During this 4-month admission, the decision was made to train me to begin HPN (Home Parenteral Nutrition). I was very nervous about this decision and feared complications such as sepsis and liver failure, but my surgeon assured me this was the way forward. With the commencement of parenteral nutrition, my bloods began to improve and I felt stronger physically and mentally. I had more energy and could focus more easily. I went back to university the following semester, again part-time as I was worried about being able to deal with the work load. I have been able to slowly progress through my subjects and am hoping, if everything continues to go well, that I will be able to graduate at the end of this year. Being on HPN has opened up my options again and I'm hopeful I will finally be able to finish my degree. I am very lucky that so far, I have not had anything go wrong because of HPN, such as line infections, so I hope it can continue that way so I can FINALLY complete my degree!!! It hasn't been easy, but I am so thankful for HPN and the fact that it has allowed me to begin to follow my dreams again.

Words by Jemima

I started HPN about 2 years ago. At that time, I had accepted that I was not well enough to continue working in Nursing or truthfully working at all. After a year of adjusting to HPN and getting myself back to a decent weight and energy level, I started thinking maybe I could work toward a career in something besides Nursing. In early 2020 I started a diploma in Life and Wellness Coaching. I found I was able to find the time and energy to do the school work and online placements. I finished in August 2020.

Even though I had this training I felt drawn to Grief, Loss, and Trauma Counselling so in July, I started a graduate certificate in exactly that program at Flinders Uni. At first, I found the course fascinating and I was really managing the work easily. As the semester went on and I had extra medical and life things happening, I found it harder to keep up. I had to keep asking for extensions to complete my essays and assessments. Despite the difficulties, in November I graduated with a distinction.

Fast forward to February 2021 and I hadn't decided how I was going to use my new qualifications; so I decide I need to do a graduate diploma in Psychology at Uni Adelaide. I am not sure where this will lead. I am thinking maybe research, a job I could actually do with my limitations.

Present-day, I have had to withdraw at week 3. I have been in a flare for a few months that I have been ignoring and this had now landed me away from home with many specialist appointments and testing, trying new meds, and basically managing a very angry body. I had to accept that right now I am unable to succeed in any intensive schooling or career.

What I have learned is that losing my nursing gave me an identity crisis deeper than I had known. I felt I had to replace my identity with something else. You know the comments people make such as 'what do you do?', 'what have you been doing with yourself?', and my favourite being 'wow, you look great!'. These comments and more all made me feel inferior, diminished, and that my identity was centred around being sick. I thought if I pushed myself into a new career path, then somehow I would feel different, be more valid, less burdensome, more interesting, and give me something interesting to talk about with others. What I didn't account for was the physical and mental cost.

Interestingly, do I feel grief or loss about my decision? Well, no, I don't. I feel freer, I guess. I am giving myself permission to just enjoy the things that make me happy. I can ride my bike on good days, continue my movie day on a Sunday with a small group of friends, start my dance for fun activities with a couple of girlfriends. On top of all this, I have recently been given the gift of helping my daughter get her life established. This allows me to be a grandma-sitter regularly.

So, what is my identity?... I am a wife, mother, grandmother, daughter, and friend. I am working toward leaving a legacy of the importance of love, happiness, adaptability, and gratitude. Do I think I will ever return to school or follow a career path again? I won't rule it out, but for now I think my life is enough.

What's in your PN Bag?

Words by Prof Gil Hardy

Editor's note: Professor Gil Hardy continues his series of What's in Your PN Bag? which he has written for Dripline. PNDU, of which he is a life member and founding member, is very thankful for his time and efforts on our behalf.

Micronutrients: "Not too High. Not too Low. Just Right" said Goldilocks

[with apologies to author Robert Southey]

Micronutrients (micros) comprise water and fat soluble vitamins (VITs) and trace elements (TEs) that are known to be essential constituents of our diet. A lack or an excess of any of these essential micros can result in nutrient-specific disturbances in metabolism with clinical manifestations. In parenteral nutrition (PN) it is especially important that thiamine, ascorbic acid, pyridoxine, and folic acid are taken daily. Patients receiving a high carbohydrate load are particularly susceptible to thiamine deficiency and cardiac failures have been reported when patients on long-term PN were not supplemented. Megaloblastic anaemia, secondary to folate deficiency has also been reported in patients receiving PN who did not receive folate for several weeks.

Routine, daily provision of a balanced mixture of micros from commencement of PN is now recommended by AuSPEN and all other major international PEN societies.
Micros for PN therapy are normally combined in standard multi-vitamin (MV) or multi-trace element (MTE) products, in formulations that have been largely unchanged, for over 40 years, with few reports of adverse effects. The daily PN dose of water-soluble VITs in MV products is 2-5 times the recommended daily oral dose (RDA). The rationale for higher doses is because of likely malnutrition, plus increased urinary excretion of these VITS during PN. Currently, the daily PN dose of the fat-soluble VITs, provided in most MV, and TEs in multi-trace element (MTE) products, is about the same as the RDA. However, some recommended maintenance doses have recently been updated (see Tables).

Personalised Micronutrition

The AuSPEN and more recent ESPEN guidelines, state that 'the HPN formulation must include adequate micronutrients in amounts that are optimally tailored to the clinical and intestinal status of the patient'. Furthermore, the consensus of other expert groups is that the prescription for micros should ideally be individualised to the clinical requirements of the patient and should be individually tailored in response to any clinical changes observed from routine monitoring. Thiamine deficiency, resulting in lactic acidosis, copper-deficient anaemia and hyposelenaemia are the most frequently reported manifestations of failure to supplement PN regularly.

Generally, if you are receiving a balanced daily dose of micros from a 'standard' product, in your PN, your micro status will be maintained. It is unlikely that significantly high levels nor any micro deficiencies will occur and the risk of an imbalance causing complications is minimal. Nevertheless, there may be changed clinical situations or other events when a balanced maintenance dose of mixed micros may not be optimum, and adjustments may be necessary. Factors to be considered include; micro losses or malabsorption due to, eg. fistulae or anatomical changes in the g.i. system. Increased inflammation, slower wound healing, cholestasis, liver or kidney injury may also alter excretion of micros and necessitate decreased doses or complete omission of some micros. Routine monitoring of liver function and kidney function should generally provide warnings of these possibilities.

What if micro levels are high?
Adverse reactions to high doses of fat soluble VITs up to 10 times RDA, up to 100 times the recommended doses for water soluble VITs and 10-15 times the dose for TEs are infrequent. However, there are some exceptions, eg VIT E is already included in many lipid emulsions, to avoid peroxidation. Consequently, care is necessary, if considering extra VIT E supplements orally or in the PN. If there is any suspicion of toxicity, then it is best to stop all fat soluble VITs and/or all TEs. Then, depending on what is available, individual micros can be gradually added back into your PN regimen.

Hypersensitivity reactions to PN are also uncommon, but there have been occasional reports of allergy to thiamine, B VITS and VIT K. Additionally, the stabilisers used in some MV products have also caused rare allergic reactions.

If a hypersensitivity or allergy is identified, one option is to consider alternative oral/enteral preparations, providing of course that the g.i tract is accessible and partly functioning. Alternatively, a combination of individual parenteral VITs and/or TEs that excludes the suspected allergen can be formulated. Unfortunately, whilst it is possible to obtain individual products of parenteral thiamine, folic acid, VIT B12 and VIT C in Australia/NZ, other single micro products may not be widely available.

What if micro levels are low?
Approximately, one third of Aus/NZ is at risk of VIT D deficiency. Bone mineral density and VIT D levels should be monitored annually in HPNers and corrected according; especially for older HPNers and those in NZ and southern Aussie states. Other specific diseases, such as inflammatory bowel disease (IBD), may cause decreases in micro status. In particular, short bowel (SBS) patients are often VIT K deficient, and because of poor function or resection of the distal small intestine, fat soluble VITS may be low. and B12 deficiency is common.

Micros losses from the PN bag or giving set during infusion can result from light induced photodegradation. VITS A, C, E, are especially sensitive, if not protected from sunlight. Covering PN bags is strongly recommended and is generally routine practice for HPN and hospitals in Aus and NZ.

What if there are shortages of Micros?
Intermittent shortages of some MTE or MV products can also be problematic. Fortunately, this doesn't happen too often Downunder. If it does then the ASPEN website [www.nutritioncare.org] makes some useful recommendations.

For adult MV shortages:

1. Consider administering available individual parenteral VIT products in doses that are appropriate for the patient's age and weight
2. Consider switching to oral or enteral MV. However some oral MV products may not be complete and may cause diarrhoea or g.i intolerance.

For paediatric MV shortages:

1. Consider use of adult MV for children weighing greater than or equal to 2.5 kg
2. Use the full dose of adult MV for children greater than 11 years of age.
   NB. Some adult MV products contain stabilisers that may be toxic to infants.
3. Consider switching to oral or enteral MV when oral/enteral intake is greater than 50% of needs.

For TE shortages:

1. Advice from local manufacturers is to supplement with those TEs that can be sourced individually, and provide a proportion, rather than the full dose, of other TEs, if available.

Unfortunately, whilst it is possible to obtain parenteral selenium, zinc, thiamine, folic acid, VIT B12 and VIT C as individual products in Australia/NZ, other single micro products may not be widely available. In this case there appears to be no alternative but to prescribe oral/enteral supplements, depending of course on the degree of gut function of an individual. This situation is unsatisfactory, but some degree of gut absorption may be possible for many HPNers during micro shortages.

Clinical judgement must therefore prevail by weighing up the pros and cons of the various alternatives for an individual HPNer.

Discuss any concerns you may have with your Nutrition Team and always report any allergies or adverse events you experience.

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1. *Osland E et al. Asia. Pac. J. Clin Nutr.2014:23;545-554*
2. *Osland E et al. Asia. Pac.J. Clin Nutr 2016:25;636-650*
3. *Pironi L et al Clin Nutr 2016:35;247-307*
4. *Blaauw R et al. JPEN 2019:43 (Suppl 1);S5-S23*
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April 2021

Wedding Season

Words by Sal

My eldest 2 children are close in age and have pretty much done everything together when they were growing up. So, when each couple announced their engagements within weeks of each other, we shouldn't have guessed anything else other than for them to have their weddings 5 weeks apart! Some people even joked that they should just have a double wedding and be done with it!

Our daughter Juliet, who is studying medicine in Newcastle, met her now husband Enoch at a Christian Medical and Dental Conference. Enoch is a GP and was living and working in Sydney, so their relationship has been a long distance one. Leading up to their wedding in late November, we had both couples pre-wedding events for the brides and grooms, to organise, host and/or attend. Lots of cooking for me, tidying up and decorating too. Juliet had requested that she have our 1956 bus 'Bridget' as a wedding vehicle, so Matt (Sal's husband) spent the 6 months before the wedding madly preparing and painting the exterior of the bus (which he was in the process of restoring) to make it look good. We also had another Clipper bus like ours (the white one), generously loaned to us to use for the wedding too.

The day started at 5am, but I had been awake with an upset belly since 3am. The bridesmaids had stayed the night and I served them French Toast, with berries and a Raspberry Coulis for breakfast before the hairdresser and make-up artist arrived at 6am. The photographer arrived about 9.30am. Then it all got busy with the florist dropping off flowers and 'Bridget' was being collected by a friend, who was driving if for the groom and his boys. Our sons had already headed to the church to set up for, and practice, the music. Our two little dogs photobombed and had to be part of the action! Before long, we were all aboard our friends' bus, (which is fitted out as a limousine and used for weddings normally). The day was already really hot, and we knew it was only going to get hotter. Matt drove the bus and we sang loudly to the stereo to the church and arrived on time.

The ceremony was beautiful and went smoothly. Matt's AV company, in conjunction with another production company, did the sound and livestream for the service, and we had it watched across Australia and the world! We all melted outside the church for family photos before escaping inside, where I found the bridesmaids hovering over the air-conditioning vents to cool down! Unfortunately, it was so hot (44 degrees) that the air-conditioning in both buses couldn't keep up and we all suffered in the heat. We headed to a park near the reception venue and had photos there for a couple of hours. I had pre-made a light lunch of sandwiches, mini quiches and fruit. It was so hot that the sandwiches turned to toast within minutes of coming out to be served. I had to connect up to some normal saline to keep me going as I was not feeling at all well in the heat. Even though I had kept the saline in the fridge, it wasn't enough. I was wiping ice and wet cloths on me to try and cool me down. It took a good hour of being in the cool air-conditioning at the reception venue before I felt better. Luckily the venue let us come in early to cool down after the photos. The reception went really well, and was lots of fun with some games, and Matt and Juliet sang a Daddy/Daughter duet instead of dancing (Juliet (a dancer all her life) was never going to get him to agree to dancing!) But Enoch took up ballroom dancing classes so he could do a bridal waltz and for someone with 2 left feet, he did very well. Now that's love for you!!

Despite the heat, and poor Enoch literally dripping with sweat in his 3-piece woollen suit, no one collapsed, and it was just what they hoped the day would be. Matt gets the award for wearing the most hats on the day though. He was Father of the Bride, Bus driver, guitarist in the band at the church, photo poser, chief speech maker, got targeted to be embarrassed in one of the games, and sang the Daddy/daughter duet.

In between weddings, we had my Father's 80th, which I helped cater for and made the cake. As well as that, we hosted Christmas at our place and then moved Enoch and Juliet to their new home in Maitland, and celebrated New Year!

Jolyon, our eldest son, has known his now wife, Emily, since they were young, through our church. Emily did try out other churches for a while, but after running into Jolyon at a music gig, Emily returned to our church and the rest is history! Emily is a primary school teacher and Jolyon is a Research Analyst at Christian Super. Trying to create two different weddings, when the couples had similar tastes and style preferences, meant they did have to negotiate a few choices, so they didn't repeat anything. I mean it was tough for me having to choose different dresses and style myself differently... I mean everyone will compare won't they... couldn't possibly wear the same or similar dress or have the same hair style!!

Emily and Jolyon managed to pull off another beautiful wedding that was very much their own. I learned being Mother of the Groom is vastly different to being Mother of the Bride. For starters, even though I got up early, we had to drag the boys out of bed around 7.30am. None of this get up stupidly early to take hours to make yourself look gorgeous. The boys had Matt cook up bacon and eggs while I had a makeup artist/ hairdresser make me look good again. Matt then disappeared with our other sons to again set up the music and livestream. Jolyon and his groomsmen then got dressed when their photographer arrived, posed and then went to the venue. I was left all on my own all dressed up and waited until my lift arrived to take me -rather anti-climactic.

This time the weather was much kinder to us and it was only 22 degrees and it lightly rained just before the Bridal party arrived. Luckily, they were prepared and had sourced 35 clear plastic umbrellas for the guests, as this wedding was being held outside at the Reception venue. Again, I had to wipe away my tears as the ceremony was very beautiful and was made all the more so, as Emily's stepfather, who had been our Uniting church minister for over 10 years, took the service. The rain held off for the rest of the day as well. Jolyon and Emily did win the sibling rivalry of how many people watched the livestream! The reception went to plan except I had failed to run through my checklist of what needed to be brought and we realised we had forgotten to bring Matt's Father of the Groom speech. Our youngest son raced home and brought it back in time for Matt to read it out and again have the guests in stitches.

Instead of a bridal waltz, they opted to have the "shoe game" where Jolyon and Emily sat back to back with a shoe of their own and a shoe from each other and had to raise the shoe that they thought matched the person in the scenario. For example, who out of the couple was the clumsiest, and they got a point every time they had raised the same shoe as each other. Very funny to see who they each think is or does things in their relationship! They drove away from the reception in the 1964 Mini that Jolyon had restored and upgraded the engine adding a turbo.

Again, it was a very special day, despite all the last minute COVID 19 restrictions coming into play, and in fact, both weddings had many adjustments, such as number reductions, etc, causing headaches throughout the planning.

Matt and I escaped the very next day in 'Bridget' for over 3 weeks R and R, exploring NSW, before returning to put together a last minute 18th for our youngest son, Braddon. I feel so blessed that I have been well enough to be so involved in these special events of my children's lives. 10 years prior, I wasn't sure I would be around to see them all through finishing school, yet alone getting married. Thanks to HPN, I am still here and able to still do so much. I am also so blessed to have an amazing husband who is responsible for my care and has supported me all the way. My precious children have also been through so much; it can't have been easy for them as young children to understand what is happening when a parent has serious health issues and needs extensive care at home. But I like to think they have learned resilience, compassion and empathy, which I hope will help them in adulthood and later life.

Central venous catheter repair in paediatric IF patients

Editor's note: The following article is from www.ivteam.com

"Our study showed that CVC repair is effective in prolonging CVC durability in paediatric IF patients without increasing infection rates" Santhana et al (2021).

Abstract:

Objectives: Intestinal failure (IF) patients require long term parenteral nutrition through central venous catheters (CVCs). When damaged, catheter replacement or repair is considered. Limited literature exists on repair outcomes in this population. We aimed to assess the impact of repair on durability of exiting CVCs and infection rates.

Methods: Retrospective cohort study of pediatric IF patients with tunneled silicone CVCs over 10 years. Outcomes were evaluated by assessing CVC longevity, repair success, replacement and post-repair infection rates.

Results: 138 repairs and 45 replacements were conducted in 37 patients with repair and replacement rates of 4.7 and 1.5 per 1000 catheter days respectively. 20 patients (54%) required ≥ 1 repair. For CVCs requiring repair, median CVC durability without and with repairs were at 123 and 391 days respectively ($p < 0.0001$). Overall repair success rate was 96% with significantly lower success in the emergency department at 81% ($p = 0.007$). The 7-day post repair infection rate was 2.2% without specific risk factors identified. Most repairs (76%) were performed by Pediatric Gastroenterology. Variability in practice was noted among services including frequency of peri-procedural antibiotic use and performance of temporary repairs before permanent repairs. A gradual increase in CVC repair rate was noted overtime.

Conclusions: Our study showed that CVC repair is effective in prolonging CVC durability in pediatric IF patients without increasing infection rates. Incorporating a temporary repair as a step before permanent repair may offer a route to address potential intraluminal thrombosis before permanent repair.

Reference:

Santhana V, Davis MB, Rahhal R. Impact of central venous catheter repair in pediatric intestinal failure. JPEN J Parenter Enteral Nutr. 2021 Mar 18. doi: 10.1002/jpen.2109. Epub ahead of print. PMID: 33734463.

Read more like this...

- Repair or replace fractured pediatric central venous catheters
- Central venous catheter repair does not increase infection risk
- Central venous catheter repair is successful in children with intestinal failure

Upcoming Events

There are no upcoming events in the next 3 months.

Thank You

PNDU would like to thank the following people for their generous donations, which totaled $5,020.

- **M Dillon**
- **Takeda Pharmaceuticals, Australia**

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**.

In addition, on its website, PACIFHAN provides an electronic **Dictionary** of Home Artificial Nutrition (HPN and HEN) words, in 8 different member languages, that you may need when in another country.

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**.

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.

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