DRIPLINE

PNDU
Parenteral Nutrition Down Under

ISSUE 15
February - April 2016

Welcome to the latest issue of Dripline. There are several articles by, and with contributions from, our members. Read about Jodie's and Ryan's family holiday, and some hints and tips for living with HPN, as well as thoughts about life on HPN. Read about an HPN visitor from Canada, who attended a PNDU Sydney get together in February, and we meet Teresa, a new PNDU member. For those with liver problems, there is an interesting paper from Dr Jeejeebhoy's team in Canada (a pioneer of HPN) about a case study showing the benefits of Omega 3. We join in congratulating Dr Stanley Dudrick, a pioneer of clinical nutrition and hear of PNDU' involvement in a Taking Healthcare Home Ideas Lab, and more.

Gillian - Editor

In this issue:

PNDU invited to the table!

WORDS BY *KAREN*

It seemed like just one of those emails – one of the increasing number PNDU receives from various medical lists. I read it through though and noticed it was an ideas forum about healthcare in the home – "Taking Healthcare Home Ideas Lab", sponsored by Baxter Healthcare. HPN certainly fits that category, so maybe there would be something worthwhile that we could learn or contribute? Our passionate HPN advocate, Chris, was willing to attend. I wasn't sure of my availability that day. I let the organisers know about our group and how this would be a relevant event for us. Time passed by and eventually my diary cleared so I sent our formal RSVP. We were then sent the discussion paper for review before the event. Lo and behold – HPN, home dialysis and hospital in the home were the home therapies in focus at this discussion forum, specifically focusing on the barriers for uptake, including the difficulties of transitioning home! It was totally relevant to us!

In a rush and scramble a couple of days before the event, we canvassed our member HPNers and carers to get feedback on what worked and what didn't work for them in their transition to home as well as ideas on how it could be done better. Using this member feedback as well as PNDU's existing standpoints, we put together a Position Statement (see below) in preparation for the event in case there wasn't much opportunity to speak on behalf of our members and give the patient perspective. We also gathered some material in case there were opportunities before or after the event for us to talk and network with HPN clinicians who may not be aware of PNDU.

So on 23rd February 2016, proudly wearing my PNDU 'I live with a drip' t-shirt, Chris and I arrived early at the venue within the grounds of Western Sydney University. Chris knew the venue well – the historic Female Orphan School from the early 1800s, which one of his forbears attended. We met with various Baxter representatives and a few HPN clinicians, but not many. Maybe like us, they didn't realise until after RSVP-ing how much focus on HPN was planned for this event?

The ideas forum was run like the ABC TV program Q&A, with 5 panellists from various professions in the health sector – Professor Stephen Leeder, Dr Michael Crampton, Lynne Pezzullo, Debbie Fortnum, and Dr Evan Alexandrou – as well as Dr Norman Swan, ABC Health, Journalist and Host, as the facilitator. There was a lot of general discussion amongst panellists, and academics and area health employees in the audience about the general concept of hospital in the home, including difficulties such as carer burden, the financial burden of chronic illness, the saved costs to our healthcare system, etc. There was also quite a lot of discussion about how to get GPs heading up and coordinating patient home therapies. Home dialysis and HPN were touched on but not in depth which, admittedly, was disappointing. We were also rather disheartened by a concluding remark from one of the panellists that investing in HPN was 'like backing a loser'! We all know there are challenges with the HPN system but we desperately want everyone to know that we are mighty glad HPN exists down under – we're alive and not living in hospital! Yay!

Although we didn't have opportunity to contribute to the official discussion on the day, we did appreciate the opportunity to meet and talk with various attendees, organisers and panellists before and after the forum. Following the event, we also shared PNDU's Position Paper with some contacts, including with the event organisers, offering to answer any questions and give ideas about HPN from the patient and carer perspective.

This ideas forum may not have panned out quite as we anticipated, however we are still really grateful that PNDU was invited to the event as the HPN patient representative 'down under'. For PNDU to be 'invited to the table' to discuss HPN is a huge step forward 'down under', and we are very grateful for the opportunity. We are also encouraged that there are discussions taking place to look at the problems and the challenges, and brainstorming workable ways to overcome them. We applaud and thank Western Sydney University, Baxter Healthcare, Dr Norman Swan, the panellists and attendees. We also look forward to more ideas forums, with more opportunity for PNDU to be involved, and that ultimately ideas will lead to improvements for HPN down under.

PNDU's Position Paper:

Taking Healthcare Home

PNDU Inc. is a patient support group for patients and carers living with Home Parenteral Nutrition for Intestinal Failure in Australia and New Zealand.

In short, PNDU desires to see an equitable system of care for all HPNers across Australia. And, in recognition of the complexity and impact of this life support therapy on an HPNer's life and family, PNDU advocates for an holistic

approach to promote Quality of Life, particularly when transitioning to home.

The current experience:

HPN has a huge impact on the life of a family. Even HPNers who have received the best clinical care when transitioning to home, speak of the trauma of beginning such complex life support therapy (including the realisation in most cases, that it is for life), the fear and isolation.

In addition to the traumatic process of starting HPN, differences between Commonwealth, State and Local Area Health Districts have a significant impact on the level of care that is available throughout Australia to existing HPN patients. Our member experience is of a silo system – where each hospital does things differently – clinical care, funding, etc.

What we support:

- PNDU supports the work of AuSPEN, including its range of guidelines for HPN (clinical practice, trace elements, vitamins) and looks forward to the update of their clinical practice guidelines expected soon. If there remain any important local clinical needs which have been overlooked, we would encourage and support further review and amendment.
- PNDU supports re-establishing and maintaining the AuSPEN HPN register, and we acknowledge and thank AuSPEN for their ongoing efforts to re-establish this invaluable resource.
- PNDU advocates for the sharing of information and HPN expertise between hospitals, and a move to a national standard of HPN care, resulting in equity of care for all those on HPN.
- PNDU supports a national standard of HPN care that specifically ensures:
  - access for all HPNers to a multidisciplinary team of professionals trained in HPN procedures
  - no out-of-pocket expenses for HPN, ensuring all HPNers can maintain optimum care
  - an holistic approach to support particularly for the transition from hospital to home, including (alongside full clinical support, 24hr assistance, home set-up inspection and advice, and ambulatory pumps), information about PNDU, access to counselling, assistance in accessing benefits/services, as well as ease of access to HPN supplies.
  - an ongoing focus on the Quality of Life of the HPNer (as well as carer and family), through appropriate ongoing clinical monitoring and assessment, access to appropriate treatment and services, technologies and equipment, as well as assistance to gain and maintain independence and mobility.
- PNDU supports ongoing collaboration between the various stakeholders, including PNDU, to work towards a system that is achievable for all, and provides and maintains the best possible Quality of Life, and care, for all HPNers, their carers and families.

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Mobile Family Fun

WORDS BY *JODIE*

Daniel, Jodie (HPNer) and Ryan

Holidaying can be challenging at the best of times, let alone when you have a chronic health condition and large bags of PN to infuse.

I recently went on a motorhome holiday with my husband Ryan and our four-year-old son, Daniel. We hired a Ford Transit from GoCamper for five nights and made our way south from Busselton, WA, to Esperance, then back home to Busselton again.

There were several reasons why we chose to 'motorhome it'. Ryan and I are accustomed to tent camping for short periods of time, close to home, but because we were travelling much further this time (and had our young child with us) we decided a home-on-wheels was the more convenient option.

The motor home slept up to six people but there's no way I could have lived in such a small space with five other bodies! For us, two adults and a child was enough to accommodate.

One of the reasons we chose the Transit was because it had a toilet. I infuse 1.5L of PN overnight and need a toilet close by. Without our own toilet, I would have had to walk to an ablutions block, with a flashlight, several times during the night. It was a luxury to not have to do that, especially when the weather wasn't being kind.

We made one overnight stop at a 24hour rest area, in the middle of nowhere. There were public toilets available but they were of a state that made me grimace and recoil in OCD terror. Having our own toilet, I was glad to not have to use these below standard facilities, no doubt crawling with invisible bacteria. In fact, if I had to, I don't think I would have used them – I would've chosen the 'natural' option of bush toileting.

There're a couple of major downsides to using a motorhome toilet. Firstly, if you're using it for anything besides urine, it really starts to stink after 12hours or so. Secondly, you have to dump your septic waste responsibly and receptacles are hard to come by. It's also not a nice job to have to empty human waste, as you can imagine.

One of our preparation issues, before leaving on our road trip, was creating enough fridge space for eleven bags of PN. As we weren't going to be home for one usual weekly delivery, we had to order more bags prior. We managed to get all the bags into our fridge, but it's something to be mindful of when organising time away from home.

Another small problem we encountered was that I couldn't plug my pump into a motorhome power point because it wouldn't charge unless connected to mains electricity. We think (but aren't entirely sure) that the Bodyguard 323 pump takes about 5 hours to charge. So this posed a problem if we wanted to be out and about for most of a day (which we did).

Fortunately Ryan is clever and brought an inverter to plug my machine into for charging, otherwise we would've had to either spend more time connected to mains (which would have meant less time spent out and about) or I would've had to infuse PN overnight while Stella was plugged in, via an extension cord. Which was doable… but slightly tricky.

In the Ford Transit, there was plenty of room to store supplies and everything needed to set up my PN in a sterile manner. Fresh water was available for hand washing anytime, as long as there was water in the storage tank (which we topped up every day). So no compromises had to be made in that regard. The inside lights worked 24-7 so there were no problems setting up at night.

I found it easier to connect to my PN in the motorhome than in a tent. The bed I set up on was waist high and the space was comfortably big enough to hook up to Stella, my Bodyguard 323 pump.

The fridge was the size of a bar fridge, so there was enough space for my PN bags, though this reduced space for how much food we could store. The fridge worked around the clock (like the lights), even when our motorhome wasn't plugged into mains power.

One of the great things about holidaying in a motorhome, when it comes to dealing with illness and needing PN, is that you can maintain a high level of privacy. For example, with our own mini kitchen, I didn't need to do runs to and from the communal facilities while connected.

Another advantage is having a bed to lie down on wherever you go! I found that very helpful, as I usually get so tired and holidaying activities with a four-year-old were sometimes exhausting.

So all in all, I'd say a motorhome is a great way to go on a camping-style Aussie adventure. It's much more convenient and comfortable than tenting. However, considering the high price of renting a motorhome, it wouldn't be the best accommodation choice for every journey. But it's a great option and that's one thing we need as PNers – good options!

Hints and Tips for Living with HPN

Editor's Note: *Our website is currently being upgraded (see article this issue) and our members were asked if they had some more useful tips that might benefit others on HPN (Home Parenteral Nutrition) which could be added to our Hints & Tips page.*

- Something that helps me is that once a week I pack all the supplies I need for the week at one time. I use large ziplock bags and pack seven morning and seven evening bags with everything needed. That way if I am busy, I only have to pick up a bag and get going and don't have to remember what I need from my supplies.

- Re travel for short trips, I have a plastic crate with all I need (in addition to the pre-packed bags) – handwash, soap, paper towels, scissors, spares of everything I use – so I can just pick it up and go. I have a list typed of everything I need to remember, including pump, backpack, HPN (cold and long life) and TauroLock™, so I can't forget.

- When [my wife's] infusaport was on the other side of her chest, she had a doctor's letter which she kept in the car

as she couldn't wear a seatbelt in the usual way. It went right over the needle and was very uncomfortable. On a side note: We went to Tasmania once and she was a passenger and did that. We didn't have a letter with us (and at the time in Tasmania you needed it on your driver's license) and got a $400 fine! She now has another port and is able to wear a seatbelt.

- Lists are great for packing and going places.
- We use a spreadsheet for calculating and ordering stock, also for checking it off when it is delivered.
- One handy hint I have is when I am desperate for a swim, I feed my CVC into a stoma bag and then enjoy a couple of hours in the water... Then it's a couple of hours before both my bags need attention!! I firstly I do a sterile one on my line then the very-far-from-sterile one on my stoma. I have a very understanding friend with a very clean pool. I have a few spare stoma bags which I received as samples that I use.

Editor's note: *As with all medical information, if you have questions or concerns, these need to be raised with your medical team.*

From Victoria (British Columbia, Canada) to Sydney (Australia) (and points north)

WORDS BY *LAURIE*

Editor's note: *Laurie is a Canadian HPNer and a reader and supporter of Dripline. Some of our Sydney HPNers met Laurie and his wife, Shirley, during their holiday.*

Laurie was diagnosed with Crohn's disease in his early 20s and has a 50 year history with the disease. He has short bowel syndrome ("short gut" or SBS) as a result of several surgeries. He was on HEN (Home Enteral Nutrition) briefly and has been on HPN since 1990. He has travelled extensively, nationally and internationally. He is a dedicated sport fisherman of both salmon and trout. [Courtesy of Oley Foundation's Ambassador webpage]

Laurie E. McBride (HPN)

My wife Shirley and I had planned our holiday for some years. We wanted to cruise from Sydney north along the Australian coast to Bali, Indonesia. Our cruise dates were confirmed about a year before our February 2016 departure.

Packing for travel of this length and distance always takes some planning. The medical solutions and supplies were pretty straight forward given we have made trips of this nature before. For us it starts with an inquiry to our medical supplier asking if they can arrange for medical solutions to be delivered at our destination. In this case, Fresenius Kabi of Europe is the parent of our Canadian supplier and we were able to arrange for non-refrigerated solutions (Kabiven®) to be delivered to our downtown Sydney hotel before our departure from Canada.

HPN supplies were carefully counted and packed into daily use zip lock baggies, one for every day of our travels. This collective volume of medical supplies occupied a 13 x 13 x 13 inch box by itself and was shipped as personal luggage (no-cost medical supplies) together with our 3+ suitcases (too much clothing for a 12 day cruise and ten days of visits in Sydney and Bali).

I do not attempt to infuse while flying. I am able to eat and drink some foods orally and prefer this to hooking up etc while flying. It works for me. At our ages (70s) we have determined that we will no longer fly economy across oceans, and business class provides a greater degree of comfort and freedom to move around and access a toilet. This route expands our ability and willingness to consider travelling for a few more years.

Phase 1: Flying from Victoria, Canada, to Sydney

Our flights to Sydney totalled 17.5 hours of flying time and about 20 hours of travel time in total. We flew to Sydney via Auckland, New Zealand.

Meeting fellow HPNers in Sydney

While we were in Sydney, Karen had arranged to pick us up downtown and allow us to join several of the local HPN community at the home of Miranda and David. We had a wonderful time sharing medical histories, travel stories, life stories and were provided with generous directions as to what we should see while in Australia. We marvelled at the experience of Miranda and David with the birth of their HEN and HPN dependant daughter. What a very frightful

Miranda with Eadie, Jane (HPN), Lindsay, Fay (HPN), Karen (HPN), Shirley and Laurie (HPN), David with Ariel (HPN)

HPNers – Karen, Jane, Fay, Laurie and Ariel

introduction they must have had to paediatric digestive diseases for their first child.

We heard of Jane's life and travel experiences, and also that of Fay and Lindsay. Karen was most thoughtful in making the arrangements and Miranda and David outdid themselves with their hospitality.

I explained about travel from the Canadian and US experience. In countries where non-refrigerated solutions cannot be arranged, our solutions are packaged with ice packs in cardboard boxes lined with Styrofoam™ and usually shipped in either the cabin as carryon luggage or in the belly of the plane as Fragile baggage. Fortunately in 25 years of travel I have only had one breakage event, and never a lost luggage event. With Air Canada as my preferred airline we have been treated well, our medical solutions and supplies are shipped at no cost to us and we don't experience loss or damage. For this we are loyal and appreciative travellers with Air Canada. Personally I have the option of using non refrigerated solutions while travelling and this, together with the option of having my solutions most often delivered at my destination, is a blessing. I have travelled with refrigerated solutions and the only drawback is the logistics of getting these boxes to the airport and checked in and then picked up at the destination. Once checked through to our destination by our first airline, every succeeding connection is obliged to accept this baggage without charge.

Another major consideration before travelling is having International Medical coverage and perhaps flight cancellation, baggage loss, and flight interruption insurance. We have generally been able to justify purchasing an annual travel policy which will cover us for any number of trips of up to 30 days. The cost of an annual policy is usually less than individual trip coverage if we will be travelling more than a single trip in a year. My questionnaire for medical coverage is one page, discussed annually, or as necessary, with our insurance agent (who by now is very familiar with our health issues). Where necessary, I have been known to phone the insurance underwriter to clarify a coverage issue. We fortunately have never had to make a claim on our travel insurance. I have accessed medical supplies that were forgotten in Hawaii, Illinois and in Sydney, Australia.

So, you are asking "what did you see in Sydney and Australia after flying for a full day?" In Sydney we were adjusting to the heat of your summer. We had left a climate with a wet, cloudy winter (your summer) and temps of 2 to 10 C generally. Your temperatures of a sunny and warm 27 to 30C were a shock to my system and I spent time ducking the sun. Shirley, on the other hand, loves the heat. We explored the downtown waterfront walkways and restaurants, the Opera House (what a marvellous building!), a trip to Taronga Zoo, a brief harbour cruise, and a train ride around the Royal Botanical Gardens. Having forgotten my ties [for cruise ship dining] and Shirley's bathing suit we did visit some stores for shopping. We did not try to venture out of town, finding driving on the right side of the road to be too much of a challenge in a big city.

Sydney Harbour view from our hotel room

Hamilton Island

Phase 2: cruising from Sydney to Bali

Our cruise took us north, stopping in Brisbane for the day, (successful bathing suit shopping), Hamilton Island at the edge of the Barrier Reef, Thursday Island (where the weather was too rough for going ashore) and finally a stop in Darwin, which surprised me as I'd expected a small outpost town and to my surprise found a city of 120,000 people. Our next port of call was Komodo Island, Indonesia where the feature was two cruise ships dropping 700 passengers each to invade the grounds of the Komodo dragons. A little too much pressure for my taste. The dragons probably did not appreciate the crowds either!

Darwin Harbour

Our final stop was Bali, Indonesia. We took a partial day excursion while docked with the cruise ship to see the Royal Temple, the rice fields and a typical communal Balinese housing compound. My observation is of a far-too-crowded island where observing the native Balinese culture was perhaps possible some 40 years ago. We were booked into a very nice Nusa Dua resort for 4 nights where we soaked up the sun and humidity, lounged around the very warm 32C pool, and enjoyed walks on the large grounds while sampling the food at one of the 4 onsite restaurants - a very leisurely visit without the need to exit the resort area and engage with the traffic. We have 'been there and done that' and each of us came home with either a urinary tract infection or gut bug.

Views of Bali

Phase 3: Bali to Victoria

Our return flights from Bali were another story. Our departure from Bali airport was at 1:40 AM and we flew to Seoul, Korea. Here we had a very long layover where we rented a hotel room within the airport so I could sleep. We then had to spend several more hours in the Lounge in Seoul before our 6:30 PM departure for Vancouver, Canada. This flight was 10 hours and we arrived at 10:30 AM in Vancouver. We then had a short 20 minute flight to Victoria, arriving at 2 PM. The flights from Bali were also some 17 hours of flying time with layovers adding another 9 hours to our travel time.

Home, Sweet Home

All in all we were very pleased with our experience. The most enjoyable part was meeting with local folks and hearing their stories. Having read the PNDU newsletter for many years and admired the production and content, I was very pleased to meet Karen and sorry to have missed meeting Gillian.

We look forward to reconnecting with David and Miranda if they are able to make it to the Oley Annual Conference in California in July 2016.

Editor's Note: Prior to Laurie and Shirley's trip to Australia

Laurie sent these pictures from a previous trip, boarding a cruise liner in Lima, Peru. All Laurie's HPN supplies, including PN, travelled with him from Canada. The HPN boxes are on the dock, having been screened by the white van in the photo and the sniffer dogs, to check for drugs. An unusual start to their trip!

Birthday Corner

Logan had a wonderful 4th birthday. Paw Patrol was the theme for today, with a little party for dinner with Logan's favourite food- sausage on a bread roll. A lovely card arrived from the PNDU birthday fairy, Aunty Katie baked a cake which featured 'Rubble' from Paw Patrol.

Logan says a big thank you to everyone.

Editor's Note: *As you will read, Dr Stanley Dudrick has had a huge impact, through his work, on all HPNers' lives.*

A.S.P.E.N. Congratulates Former President Dr. Stanley Dudrick on Being Named One of the Most Influential Physicians in History by Medscape

FOR IMMEDIATE RELEASE

Contact: Amber McCracken

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Silver Spring, MD, March 23, 2016 Silver Spring, MD - The American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.) celebrates an extraordinary honor given to the organization's first president, Dr. Stanley J. Dudrick who was recently named one of the 50 most influential physicians in history by Medscape.

"Dr. Dudrick is a pioneer in the field of clinical nutrition. We believe this recognition could not be more deserved," said Debra BenAvram, CAE, A.S.P.E.N. CEO "Because of his unwavering passion for developing parenteral nutrition,

millions of people around the globe have benefited from his life-saving research."

Medscape, a division of the WebMD Health Professional Network, ranked Dr. Dudrick 42nd on the Most Influential Physicians list, highlighting contributions including his research leading to the invention of intravenous hyperalimentation, a medical technique used worldwide to prevent malnutrition in patients unable to receive necessary nutrients through their digestive system.

Dr. Dudrick — who is medical director of Misericordia University's physician assistant program in Dallas, PA, and professor of surgery at The Commonwealth Medical College in nearby Scranton — was one of 35 dedicated healthcare professionals who came together in 1975 to create A.S.P.E.N. This founding collective had the unifying mission to provide "optimal nutrition to all people under all conditions at all times." With his seminal role in A.S.P.E.N.'s history, the organization established the Dudrick Research Symposium and Stanley Dudrick Research Scholarship in his honor.

"As our first president, Dr. Dudrick helped build A.S.P.E.N.'s strong foundation and continues to provide us with unwavering support and guidance," continued BenAvram. "We are very proud of this most recent recognition."

Omega-3–Enriched Lipid Emulsion for Liver Salvage in Parenteral Nutrition–Induced Cholestasis in the Adult Patient

by Jurewitsch, B et al JPEN 2011:35;386-390

[summarised by Prof Gil Hardy. The full paper is available on request from the Editor]

Editor's note: *As with all medical information, if you have questions or concerns, these need to be raised with your medical team.*

Summary

When intrahepatic cholestasis occurs in patients receiving long-term PN, it often necessitates transplantation, which has a poorer 5-year outcome than home PN. The team of Professor Jeejeebhoy in Toronto Canada, report the first case of adult cholestatic PN-associated liver disease (PNALD) that failed conventional therapeutic measures but was reversed by the administration of ω-3–enriched fatty acids in the PN. The patient's liver biochemistry returned to baseline, and the patient's liver biopsy results showed complete resolution of cholestasis; the only abnormality was mild portal inflammation. There was no biliary obstruction, and liver size was reduced. The PN regimen remains the patient's dominant source of nutrition.

Case Report

A 75-year-old female underwent a massive small bowel resection for an intestinal obstruction. Three months later, the patient presented with an enterocutaneous fistula that necessitated further resection, leaving only 12 cm of proximal jejunum attached to ascending colon.

At the time PN with Intralipid 20%® was initiated at 40 kcal/kg/d the patient had lost 12 kg from her usual weight of 50 kg. She was trained to self-administer cyclical PN over 12 hours, 7 nights a week at home and her weight slowly increased, but she developed cholestasis and her weight plateaued at 40 kg.

One month after discharge, the patient's alkaline phosphatase (ALP) and transaminase aspartate aminotransferase [AST] and alanine aminotransferase [ALT]) levels rose drastically. GGT value was 466 [normal range 8–78 U/L]. Four weeks later, her total bilirubin started to increase, and 110 days after PN initiation the patient became deeply jaundiced. Ultrasound examination of the liver did not show any abnormalities but the hepatic histology was complex

Clinical Management

PN energy was reduced to 29 kcal/kg/d and then to 20 kcal/kg/d in the face of increasing bilirubin and liver enzymes with deepening jaundice. The patient was given oral ciprofloxacin and metronidazol in order to reduce the luminal endotoxin burden, but she was unable to tolerate the drugs because of nausea and dysgeusia. She consumed 1 oz of Scotch whisky daily about 4 weeks after discharge, which was just after the elevations in transaminases levels were observed. There was no evidence of copper or vitamin A toxicity, as her ceruloplasmin and vitamin A levels were normal: later she discontinued all alcohol intake, but her jaundice continued to deepen and she was considered for a transplant.

The patient was then given an ω-3–enriched lipid emulsion (Omegaven 10%; Fresenius Kabi) 0.25 g/kg/d in a dual-chamber PN bag. The total daily long-chain ω-6 triglyceride dosage was 0.5 g/kg/d, and the dosage of dextrose was increased to 5.0 g/kg/d to prevent further weight loss. Over the subsequent 4 weeks, the mixed-lipid regimen curtailed the increase in liver enzymes but did not reduce total bilirubin. It was then decided to give only ω-3–enriched lipids at a

dose of 0.25 g/kg/d, and to increase the dextrose dosage to 6.3 g/kg/d. The patient progressively became less jaundiced to a point where finally her natural complexion was restored. Sixteen weeks after starting the ω-3–enriched lipid PN, her total bilirubin was at a normal level of 23μmol/L; her enlarged liver span and spleen size had decreased and her gallbladder and biliary tree remained normal. A second liver biopsy showed absence of lobular cholestasis with no hepatic steatosis. Complete resolution of the intrahepatic cholestasis from 5 months earlier was the most obvious improvement.

Discussion

Transaminitis is a frequent occurrence with extended PN in adults, and liver abnormalities due to steatosis are commonly observed. This may be partially attributed to the ω-6 lipids in Intralipid® and/or its associated phosphatidylcholine emulsifier. There is a rationale for the use of ω-3 fatty acids in PN to modulate the adverse effects of ω-6 fatty acids, which are the dominant fatty acids in conventional lipid emulsions.

Recent trials have suggested that ω-3–enriched lipid emulsions will reverse PNALD in pediatric patients and have preempted abnormal liver enzymes in critically ill adult patients. These findings confirm that in an intestinal failure adult patient, an ω-3–enriched lipid at 10 g/d, (70 g/wk) can reverse PNALD and can reduce liver size.

In conclusion, the first use of an ω-3–enriched lipid emulsion in the adult patient with PN-induced cholestasis normalized biochemical patterns and resolved the histochemical and ultrastructural abnormalities in repeated liver biopsies.

Plane Travel – Advice from an HPNer

WORDS BY *EMMY*

an American HPN visitor to Australia

Emmy (Emily) travelled to Australia with a group of students to spend a semester as a university student at Sydney University. She attended our October Sydney get together (see article issue 13), as well as enjoying a day on the Hawkesbury River with Karen(HPN), Gillian (HPN) and Ray (see article in issue 14)

Emmy (far left) at our October 2015 Sydney gathering

When giving advice on how to travel with PN, my number one trick is to just get on the plane. Yes, there are many secondary tricks. Always, always, be running a bag of hydration while flying. Have you ever noticed people guzzling water before security or take off? It's because the majority of aircraft cabins maintain a lower humidity than what is at sea level. At sea level, the average range of humidity is 40% – 70%, but in most aircraft it is 20%. Although the majority of travelers will not become severely dehydrated, patients with short-gut, like myself, will feel a greater impact and will take longer to recover. It is far easier, and more comfortable, to prevent dehydration than to rehydrate later. I always carry enough hydration, usually one liter bags of sodium chloride or a bag of PN if it's a night flight, to be continuously running something from the moment I enter the airport to when I exit. In addition, carry on board enough supplies to get you through a day. This means everything; ostomy supplies, dressing change kits, and an entire bag of PN with its required supplies. It is wise to carry extra batteries or a spare pump charger. Be prepared for the worst case scenario, such as the airport losing your checked baggage or missing a connecting flight. Hope for the best while planning for the worst. I know this means carrying a ton of stuff on board. If you're traveling as a family, ask to throw some things in a friend's carry on. If traveling alone, you can petition at check-in that you are carrying medications and supplies essential to your personal wellbeing. If you live in a country with disability right, like the U.S., it is illegal and considered discriminatory to charge you any additional fees. If your country does not have disability protection rights, it is very much worth the additional fees for your personal safety. Traveling is very stressful, especially when the flight doesn't go as planned. It's much easier to cope with sufficient nutrition and hydration.

My number one piece of advice when travelling is to just go for it. Yes, walking through an airport with what is very obviously a medical device is nerve wracking at any age. Going through security insisting you need to bring on board more than 3 oz of fluids, more like a couple liters, is daunting especially in a world that has become more and more fearful of backpack concealed bombs. It was my fear for a long time that if I show up at security with my pump, without connected to any fluids, they would give me one look and call bomb squad. This is why, again, I highly recommend you go through security already connected to running fluids.

Going through security connected to fluids isn't as bad as it seems. You will get through security faster than if you

were not connected. Security will be less tense and therefore ask less prodding questions. Nobody will threaten or insist you leave your medical supplies behind. The thing is, most adults know what medical supplies look like. Sure, the pump is in a backpack instead of on a pole and it's considerably smaller, but the medication hasn't changed. On the pole or in the bag, the sight of an IV sends a clear message. Yes, your pump will set off security alarms. You will be given additional screening. Security will pat you down. You and all of your belongings will be tested for traces of explosives, including the all too valuable bags of hydration and PN. At first, it will be very embarrassing. My solution is to ignore everyone else shifting through security and focus on getting past them yourself. Also, does anyone ever remember what happens at security? It's out of their memories before they reach their gate.

Editor's note: *for more information about travel, including air travel from and within Australia and New Zealand, please see PNDU's Information Booklet –Traveling with Parenteral Nutrition.*

Life on HPN- some thoughts

Editor's note: *A few of our HPNers and/or carers made these comments about living with HPN, both the positive and negative.*

The question was posed on the Google Groups email forum: what does it mean to live with IF (Intestinal Failure)/ HPN (Home Parenteral Nutrition)? What do you think?

For me, it is the relentlessness of being on HPN....you can never just ignore it or decide you don't feel like it. I sometimes say it feels like living life on a leash! But it does allow a good quality of life compared with the alternative, so I am very grateful. Mervyn, my husband, says he does not find anything difficult, as he has been with me for over 40 years of illness with much more dire circumstances. Of course when things go wrong, e.g. line infections- that can be hard. - *Renee (HPNer)*

Without HPN Jodie wouldn't be alive and I doubt we would have ever even met, fallen in love, married and had our beautiful boy. It gave her a chance at life. HPN has given her freedom to live a life that is outside of hospital, to have a child, to travel and to gain a massive amount of independence. Unless she is really sick I'm not really much of a carer in terms of immediate practical needs. She connects herself and needles her port. I mainly find myself organising any logistical arrangements with the hospital, making sure we're stocked with supplies and that kind of thing.

The hardest part is the emotional support. Someone once said to me, "You must get used to it", meaning that Jodie must get used to living with her limited amount of spoons (equated to energy in The Spoon Theory), not knowing how many spoons she actually has in a day, or how many she can borrow from tomorrow. It's getting used to changing plans over and over. And those emotional spoons, you don't know how many of those the day is going to require either, what life is going to throw our way over the course of a day. The hardest part is that I can only do so much so she can use as little spoons as possible on less important things, but quite often that is not enough. Then, to stand by, helpless, is quite hard. You can't give spoons. - *Ryan (Carer)*

I don't have a carer, but for me HPN is literally a second chance at life that I never expected to have. These are all bonus years for me, and with a Quality of Life better that I could only have dreamt of before. I can't be more grateful. That said, every now and then it hits me hard (especially when I'm dog-tired and just want to crash into bed but need to connect up … like tonight!!) - this is what it will be every single night for the rest of my life. Never a break from it. Never being able to just crash into bed without the routine. - *Karen (HPNer)*

HPN has given me, so far, a 10 year extension of my life. With HPN, I've been able to do all the things I used to do, although some activities have had to be adapted. So I'm extremely grateful for living in a country which provides all my HPN needs. Although I'm by nature easy-going and take most things in my stride, I do occasionally find it a nuisance to have to hook up to my HPN before going out at night to a restaurant or show, having to lug 2.5-3.0 kg with me and find a place to prop the backpack out of the way. Also, having 3L of fluid PN infusing overnight results in several toilet visits, which means disrupted sleep for both myself and husband Ray, a light sleeper. But it's a small price to pay overall. - *Gillian (HPNer)*

HPN means that Gillian, my wife, is alive, which is great! It also means that with Baxter's co-operation, we are still able to go on holidays and share good times. The down-sides are that when she is set up, it restricts our movements and outings; travel options (overseas) are restricted due to obtaining insurance as well as complicated organisation of HPN delivery; the pump sometimes alarms during the night due to air bubbles and the current pump (although the same type as past pumps) makes a loud ticking noise that is clearly audible when mounted on the charger rather

than off charge in the backpack – both of these disturb my sleep; and finally, it is always in the back of your mind that infection can come unexpectedly, resulting in hospital stays – an extra concern when on holidays. - *Ray (Carer)*

I find the thought of living with death hanging over my head somewhat daunting sometimes. Im not afraid of dying as I believe in God and I know where I am going, but since I have had 21 bouts of septicaemia over 14 years it became quite scary! The last 2 years since using TauroLock™ I have had no septic problems and life has been easier or so I should think....but I have got used to living again and would like to continue being able to rely on my diary commitments instead of always saying that I might not be able to do those things in my diary as "I get sick at a moment's notice so don't depend on me".On the other hand life onHPN is another go at life isn't it...so it is a very positive thing. - *Jane (HPNer)*

Limiting Central Line Repairs – our experience with two active little HPNers

WORDS BY *CHRIS*

Editor's note: *This article reflects the experience of Chris, who is one of the carers for his grandchildren. As with all medical information, if you have questions or concerns, these need to be raised with your medical team.*

As grandfather and carer of two young boys on HPN, I've heard many different things said about central line (or Central Venous Catheter) repairs. Among these are:

- They can't be repaired
- Only one repair is recommended

We all know that HPNers require their central lines in order to survive. Since we all have a limited number of major or 'central' veins for positioning central lines, we also know that maintaining and preserving a central line is of utmost importance. Therefore, when cracks or breaks happen in central lines like Hickmans® and Broviacs®, whenever possible, it is better to have them repaired, rather than automatically replaced.

In our family, the most number of repairs to one of my grandsons' single lumen central line has been 3. There could have been an additional repair, but unfortunately at the time our hospital had run out of repair kits. We've discovered that with each repair, the length of the central line increases by 100 - 150mm. Thankfully both my grandsons, Jordan and Logan, have had multiple repairs made to their central lines before eventually having them replaced.

If you have a Hickman® or Broviac® central line, I suggest you talk to your hospital team about repairs, what to look out for, what they suggest you say to the medical staff in the Emergency Department, etc, before the situation occurs. We have been caught out twice on arrival at the Emergency Department - once with the wrong size repair kit, once with no repair kit. Frustratingly, this caused two unnecessary central line replacements.

What has caused our boys' central lines to crack or break?

We found the more active Jordan and Logan became as they grew, the more central lines they broke. The boys seemed to only turn circles in the one direction, thus causing the giving set to twist, until at times the giving set would resemble the old coiled telephone line. The giving set is more resistant to twisting than the central line, therefore multiple twists occur in the central line also. When this happens repeatedly each day it can result in broken/cracked central lines.

It also took a while for the boys to understand they were connected to an IV pole or backpack. While playing the boys would run off and the central line would get pulled tight, before the IV pole came crashing down! To overcome this problem we started using tape to secure a safety loop in the giving set in order to protect the central line. The downside is that the more tape on the boys, their problems with tape and treatment trauma increased. We now secure the central line and giving set in a vest. This has stopped the twisting and pulling on the central line which is a great result.

Another problem I have noticed and corrected with setup/takedown technique is to always hold the central line and twist whatever is being connected/disconnected - the bung, syringe or giving set – rather than the central line itself. For Example: hold the central line in your left hand, twist the giving set with your right, all good. Now change to the opposite side of the bed/patient. I am amazed at how many people will now hold the giving set in their left hand and twist the central line. (Vice-versa for lefties!)

We've found that restricting the movement, twisting and pulling on the boys' central lines has definitely reduced the number of breaks/cracks, which in turn reduces the number of central line repairs and replacements needed . A great result for our family!

What is your Plan B?

Editor's Note: *One of our members posted an interesting question on our Google Group email forum about whether or not others have a 'Plan B' for times when they are unable to hook up to PN by themselves.*

I'm interested to hear what people's Plan B is when things don't go well and you and your significant other are both unable to hook you up. We are really struggling here with us both being sick and finding it all a bit hard. I'm struggling with a temporary PICC which my husband has to hook me up to, but since I was discharged after septicaemia, he too has been very sick and has been in hospital several times. He is currently in hospital once again and he'll be there for a while. I'm hoping the community nurses can come tomorrow and over the weekend. My only other option is to front up at [my hospital's] Emergency Department and wait for.....who knows how long.

So, just hearing what others do would be great.

- Our "Plan B" is that [my wife] connects herself (Plan A is we do it together), but this is "impossible" with a PICC. Plan C would be to co-opt one of our neighbours (we have trained nurses for neighbours in a couple of places where we have lived), or Plan D would be to get the District Nurse to come by, or HITH (Hospital in the Home). I'm not sure how you get HITH to come without having been admitted first, but your HPN nurse should be able to help you there.

- Apart from some bad experiences trying to connect up with a bad migraine, I've always been well enough to do my own connecting/disconnecting (never had to try it with a PICC however). For those whose health is not great however, this is a serious consideration. And it will be for me one day too, I'm sure. My Mum was taught when I first went home, but she's never actually done it on me and I'm sure would be too scared to try.

- My husband connects me up and I disconnect. We found that was ideal for me. My daughter has been trained by ourselves to connect me up when [my husband] can't. She is almost 17 now but we trained her up 3 years ago now, so she was about 14. Considering she wants to do medicine when she finishes school this year, it could be good practice to already know how to handwash, glove up and understand aseptic techniques!!

- I don't really have much of a plan B. My mum has watched me connect up so many times in the past 3 years that she has managed to do it once, with the help of my Aunt, with me talking them both through it. Mum is a needlephobe so really hated to have to do it. If I am too sick to connect up my PN myself I generally have skipped a night or two here or there.

- When I was discharged home from hospital on HPN, because I wanted to live alone my hospital refused to teach any of my family members how to connect/disconnect me because they said I had to prove that I could live independently. However, I think that all HPN patients need a plan B that includes another person who has also been taught to connect/disconnect them, for when they are sick, but not sick enough to need admitting to hospital.

A Day in the Life of an HPNer

WORDS BY *GILLIAN*

I thought I'd write about a common issue for HPNers, one of finding a place to store all of our supplies. Most people don't live with empty cupboard space – we tend to fill all we have, so finding space for a great many boxes can be a problem, one which ideally should be thought about before leaving hospital.

I can remember the day I went home after three months spent in hospital, feeling both excitement and trepidation about going it alone (with my husband, Ray) without medical support on hand. We took a few nights' PN home with us in a polystyrene box to keep us going until our homecare company, Baxter, made their first delivery. Not long after arriving home, there was a knock on the door which heralded a delivery of peripheral equipment for setting up – dressing packs, syringes, saline injections, bungs, wipes, lines, pump and stand, surface alcohol and hand alcohol (and some HPNers receive a few other items also)! All needing to be stored somewhere quite accessible…and my goodness, the size of the 160 pack dressing pack box!

We very quickly realised that despite having a large family sized fridge, there was no room to store up to seven PN bags per week, so we bought a small bar fridge – also needing a place to call home that was easily accessible.

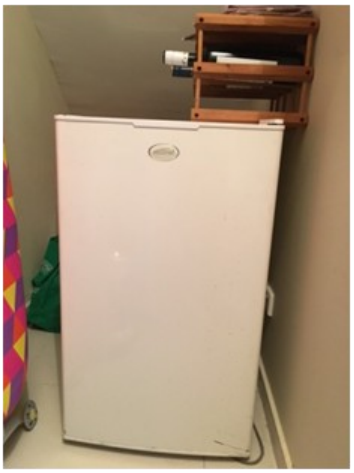
Luckily, in our case, we had one spare bedroom as our daughter, Sally had moved out, so her wardrobe was

commandeered. Seven years later, when we moved, we were empty nesters, but still needed to ensure a place for fridge and boxes. Because our new home was a town house, we also had to consider what we wanted stored downstairs, and what could be stored upstairs. Luckily by this time, the big old 4kg Flo-guard hospital pump on a stand had been replaced by a small lightweight portable pump and backpack, so we didn't have to struggle getting a dripstand and pump up and down the stairs! We were lucky that there was a good sized storage cupboard under the stairs, which could fit our bar fridge – it just needed a power point put in. Built-in shelves in this space allowed the box of peripherals needed for a week's worth of setting up to be stored here, along with the two bottles of surface and hand alcohol. The bulk of supplies is kept in an upstairs bedroom wardrobe – I only need to access these once a week to 'stock the box' for my week's setting up supplies, although it's amazing how quickly that week flies and the box has to be stocked once again for the next week!

Storage issues are just another aspect of life on HPN to be considered

All this needs a home!

My week's supply for setting up



The bar fridge fits nicely under the stairs - and fits 7 nights of PN

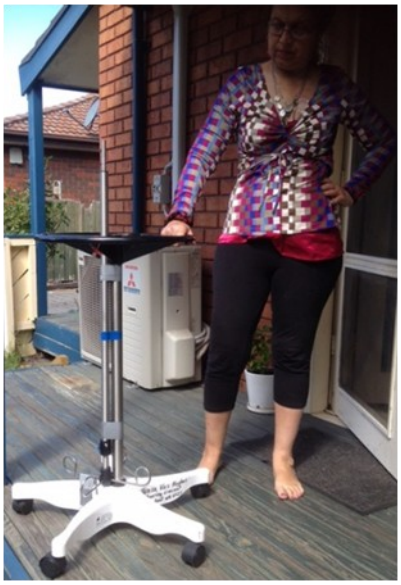
Teresa's Story

WORDS BY *GILLIAN*, FROM *TERESA'S* INFORMATION

My condition is very serious but I will never give up. I have Short Bowel Syndrome, with no bowels at all. I had a GIST cancer (Gastrointestinal stromal tumors) which was removed and weighed 5 kgs. The Gist cancer was against the small intestine and near my pancreas. I hadn't felt any symptoms at all. The cancer then returned to the liver. The specialists, as well as myself, were devastated, but I am very positive! 12 surgeons operated on me in a 9 hour long operation on 5 December 2014. It was successful, the tumours removed and I had a hysterectomy.

However, after I went home, I started bleeding to death! I did not remember anything, but one of the arteries supplying blood to my intestines failed and started to die and I was rushed urgently to the theatre. I was unconscious for weeks. When I woke up, I discovered that my body was paralysed, I was in intensive care, and had woken up to a new year! Every surgeon and nurse said I was a miracle. I had amazing support, kept smiling, thanking God and medical science. Every day I had 7-8 doctors and surgeons by my side checking me. I'm not exaggerating - I was living day to day, attached to many cables, with my potassium failing. In all, I had 4 transfusions and one resuscitation. After my operation, I spent 7 months in Frankston hospital before I was given the all clear, and then 3 months at Monash Clayton for training in HPN. I heard about PNDU through my nurse, but I did not have the energy to contact anybody. I cannot have lipids everyday because it puts pressure on my kidneys. I have been taking it

once a week. I'm healing slowly, inside, with no more operations or I risk my life. I met with the transplant surgeon at the Austin hospital, but unfortunately no transplant is suitable for me.



Teresa with her pump stand

I still see the surgeons in Frankston hospital once a month for moral support - they saved me! I keep telling them about my progress and exploration with food and various activities, because it could help other patients. I'm very grateful! I'm not going to sit and wait for death. I said to myself, 'if I have lived the life equivalent to 5 women, I will live according to 10 now! Till I drop.' I asked for permission to go back to work once a week, which was approved and it's great. I am a high school teacher and I teach Spanish at a K-12 school. I can continue this job with my portable pump and backpack.

I'm very slow and sometimes my ulcer is painful, but I make the effort. I never knew before that HPN existed! What a great invention! My life changed dramatically, but I'm slowly getting back to normal. I have tried not to get depressed for the sake of my children, aged 32 and 33, with partners who are adorable; and mum, 83 cares for me 3 times a week. My beautiful friends and neighbours check on me. My boyfriend, also adorable, is my carer. He is retired, so he volunteered to be trained to change bandages and lines. He also does the stock-taking of the great amount of peripherals to pick up from my hospitals – the amount is unbelievable!

I decided I wanted to travel to Perth to visit family - before my operations I had travelled a lot. My doctors allowed this, but before I left, I was hospitalised for a week. Blood culture tests showed an infection, pseudomonas aeruginosa, in the blood. I begged my surgeons to allow me to do the trip anyway - I had everything ready to fly for a week, my family was waiting to see me, they have good hospitals in Perth, and if I have to die I would do it here or there. So my doctors gave me 2 weeks of antibiotics – ceftazidime - to take to Perth. I'm looking forward to telling them how the trip went.

Teresa travelling to Perth

I have been very busy since! Moving forward to this month, I drove all the way to my daughter's to have Easter lunch with her family. My son-in-law cooked paella for the family, but I could only have a tablespoon, to taste it. They all worry when I do that because my gastro tube could block!! I am in Gippsland now with my carer. We shared the driving. Love and nurturing is helping me.

I can't emphasise enough how wonderful are the staff at my 4 treating hospitals – Frankston and Monash, as well as Dandenong and Moorabbin: not only the surgeons, doctors and nurses, but the rest of the staff as well.

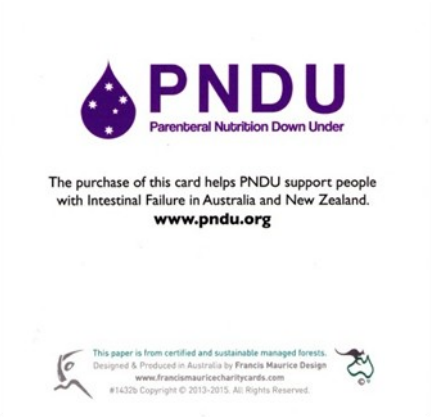
Above: One of Teresa's classes

Left: Teresa cooking

Teresa teaching Spanish

Lots of ways to support PNDU

WORDS BY *KAREN*



Christmas charity cards

Last year's PNDU Christmas charity cards were a great success… so much so that they sold out! So, we are currently ordering more – 2 different Christmas designs this year, which we're sure you'll love to buy and send to family and friends. And all the while, you'll be supporting PNDU's work.

Blank charity cards still available

While the next lot of Christmas cards are being ordered, and as it's a long way off Christmas yet, don't forget that we still have PNDU charity blank cards available for purchase in packs of 10! Each pack contains 5 each of the designs shown above, with PNDU's logo, website and what we do, on the back. $10 a pack plus postage. And again you'll be supporting PNDU's work.

Go to the Merchandise page on our website for more information and to order.

Personalised Charity cards for businesses

If your workplace, a family member or friend owns a business and sends cards or e-cards to clients and customers, why not suggest purchasing through www.charitycardmarket.com.au or www.charityecardmarket.com.au and nominating PNDU as the chosen charity. PNDU will receive a small percentage of the purchase price.

A new look PNDU website is coming!

WORDS BY *KAREN*

With PNDU's registration as an incorporated association last year, we need to upgrade our website, primarily to be able to incorporate PNDU membership sign-up. Unfortunately, the current platform, which has served us well since PNDU began over 7 years ago, is not able to support it.

This is a big step for PNDU and we are very grateful for the amazing generosity of Orange Line as they assist us through this process. A big thank you and shout out to Orange Line's directors, David Einstein and David Klein!

So watch this space! There'll be a new and improved PNDU website up and running soon.

Dietary Restrictions and Kids

WORDS BY *JENNIFER RATH*

[Originally published in LifelineLetter, November/December 2015, Oley Foundations newsletter. Reproduced with permission.]

Editor's note: *As with all medical information, if you have questions or concerns, these need to be raised with your medical team.*

Before I had children of my own, I used to work professionally with families who had children with severe dietary

restrictions. A core part of my job was to teach families strategies and basic skills to help them make sure their child kept on his or her prescribed diet at home, at school, in the community, and at special events. A lot of families struggled to follow these recommendations. It wasn't until I had my first child that I came to understand how challenging this task is, both logistically and emotionally.

Austin was born at thirty-nine weeks, after a healthy pregnancy. After a week in the neonatal intensive care unit (NICU) he was diagnosed with ultra-long segment Hirschsprung's disease with 26 cm of small intestine (8 percent of his entire intestine) remaining. I could not nurse him. I could not hold him. I had no idea how to do his medical care. I was in shock.

When Austin was about seven days old, I sat alone in a waiting room as he had his first central line placed. I picked up a parenting magazine and started thumbing through it. It was summer. There were images of children running through sprinklers, articles about sending your child off to sleep away camp, recipes for homemade popsicles and amazing Fourth of July cupcakes. It hit me like a ton of bricks: parenting Austin, with his ostomy, G-tube, central line and parenteral nutrition (PN), was going to be very different than what I had dreamed of when pregnant. It was as if everything I had imaged about being a parent was erased and I had to start from scratch. It was the start of a lot of grieving for me and also the start of some creative problem solving to ensure life was as "normal" as possible despite the medical challenges.

Food Is Everywhere

Parenting a child with short bowel syndrome (SBS) has had a lot of ups and downs. There have been enormous challenges and equally wonderful times too. In the beginning Austin had a very poor appetite and didn't want to eat. That was really hard; I just wanted him to eat a chicken nugget like every other toddler in America! As he got older, Austin's appetite grew excessively, as did his desire for all the sweets, fruits, and drinks he wasn't allowed to have. The dietary restrictions have been tough, really tough. I now better understand why so many parents struggle to enforce dietary restrictions with their kids.

Austin at his second birthday, surprised by a treat that fits within his dietary restrictions.

First, food is everywhere. It's part of our everyday life as well as at the heart of almost every celebration, holiday, and special event. It's woven into most traditions and celebrations across cultures. Second, it's difficult to maintain restricted diets for some members of a family when the rest don't have dietary restrictions. Lastly, food is emotional—it's how we care, love, celebrate, and socialize. Celebrating a birthday without cake, Halloween without candy, or Thanksgiving without apple pie can seem impossible. My biggest struggle was the emotional heartache that food restrictions created. In trying to figure out how to handle each challenge, I always made "quality of life" for Austin our number one priority, and that has really helped when making decisions.

Managing a Restricted Diet

Austin has severe short gut, so he cannot tolerate even small amounts of sugar, sugar substitutes, fruit, or most drinks without dumping, which can cause dehydration and behavioral meltdowns. At nine years old, Austin craves the very drinks and sugary foods that aren't good for him. In addition to Austin, I also have a six-year-old child and three-year-old twins who don't have any dietary issues. A well planned and predictable approach for how we handle food at our house is critical to keep stress and anxiety to a minimum.

While every child and family is different and a dietary plan needs to be created with direction from the medical team, here are some of the tips that have worked for us.

- Request instructions from the medical team and develop a plan from there. Is any amount of a restricted food permitted? A physician or dietitian may provide this information. When in doubt, consult the medical team.
- Obtain specific and concrete information from the medical team about what foods are permitted and what foods aren't, using volumes or nutritional guideline information whenever possible. For example, the team might instruct, "Any food that has less than 6 grams of sugar per serving size is OK," or "Trace amounts of dairy are OK, but not a full glass of milk." Request sample food lists or menus of appropriate foods to eat.
- Create a written "food plan" of what foods are allowed; volume guidelines (we follow serving sizes); meal instructions (such as have beverages separate from meals); how many meals and snacks per day and at what times; how to handle special events, etc. Review the plan with the child (if appropriate) and all caregivers, including grandparents, babysitters, and nurses.
- Keep expectations reasonable. Some children aren't bothered by their dietary restrictions while other children struggle. Their attitudes may change over time. It's important to set your child up for success and modify the environment whenever possible to help them cope with their restrictions. Pushing too much will create stress for the whole family.
- Be as consistent as possible in ensuring that your child follows the medical recommendations regarding his or her diet. Making exceptions to the plan once can lead your child to expect that the rules will be broken; this can

lead to disappointment, anger, frustration, and behavior issues. If the medical team or family makes changes to the dietary plan, review them with your child at a neutral time, not at meal time or a special event. Never reward tantrums or negative behavior by giving in as this will only increase the behavior. If needed, ask a spouse to assist, leave an event or meal, or use other strategies to deal with behavior issues, rather than give in. That said, no one is perfect, so expect you're going to make an occasional mistake.

- Inquire ahead about what foods will be at an event whenever possible. The unexpected can create stress for everyone.
- Have a plan for when restricted food will be present. For example, if your child can't have sugar and there is a back-to-school ice cream social, decide if you'll skip the event, permit a small amount of ice cream (ask the medical team for direction), bring a substitute food that your child can eat, or substitute a non-food item (extra iPad time, stickers, money, etc.). Review the plan with your child prior to the event, so he or she knows what to expect. Potluck meals can be challenging because you don't know what dishes will be available or what ingredients are in each dish. Again, a plan is important. You could bring "safe" food from home; plan to select foods with your child (and not accept foods offered by others); or arrive after people have eaten. Well-meaning friends and family may not understand or follow your child's guidelines, so supervision is important.
- Provide positive reinforcement in the form of praise, encouragement, and rewards when your child follows his or her diet plan.
- Discretely inform people about your child's food restrictions and request they not offer your child restricted foods. For example, at birthday parties I ask the host to not offer Austin cake or ice cream. Depending on how Austin's feeling, we may leave before cake is served.
- Develop consistent mealtime habits to decrease mealtime distress and behavior issues at home. You may establish rules in your home such as "we don't share food," "you may only have the food you are served," or "no seconds," depending on the dietary issues. Consider keeping restricted foods out of sight such as in a bin on top of the fridge or in a locked cabinet if necessary.
- Make mealtime at home about more than just food (and the stresses that may be associated with that). Make it a time when the family comes together and shares about their day. Some families turn off the TV and screens, play relaxing or fun music, or play a game. In our home, we play "truth or fiction." Each person shares something about their day that actually happened and something that is made up and the rest of the family tries to guess which is which.
- Find a balance between the needs of the child with food restrictions and those of the rest of the family. What works for each family will vary and will change as your child ages. Siblings and family members may initially need to eat restricted foods out of view of the child with the medical condition, with the goal that eventually those foods can be eaten in front of the child. Make a decision about whether or not you will keep restricted foods in your house. Decide when the adults and siblings without food restrictions will have access to food. Austin's siblings get to have special treats such a cupcake or cookie when they are served at school or when Austin isn't present. We don't keep sugar in the house.
- A medically ill child can get a lot of extra attention and siblings sometimes make a lot of sacrifices. Try to make special one-on-one time with siblings. We have "date nights" where each child gets to go out alone with a parent for the "date" of their choice, such as breakfast at McDonalds, a movie, or going to the park.
- At restaurants, inform the hostess or waiter ahead of time that you have a child with dietary restrictions and request that they not offer your child things they can't have. For example, if your child can't have sugar, ask that the waiter not bring the desert tray to the table. Before going to the restaurant, discuss what foods will be selected so there is a plan in place. This makes the meal more enjoyable for all.
- Follow the stop light idea. Younger children may benefit from having lists of foods broken down into "green foods," which they can eat all the time or in large volume; "yellow foods," which are allowed daily, but must be eaten in moderation; and "red foods," which are restricted.
- Plan an occasional "Red Food" day, if OK with your child's medical team. Some children can tolerate occasionally having a small amount of a normally restricted food. This must be planned in advance; you must all have very clear expectations of how much of the restricted food will be permitted; and it works best for children that are older and able to understand that it is a special occasion. Review with the medical team any instructions, such as a need for extra hydration.

Austin, right, enjoying a fun, non-food related holiday tradition

- Teach your child to read nutrition labels to help them determine what foods they can eat and to help them take ownership of their diet.
- Accommodate dietary restrictions by experimenting with different foods and getting creative. We make low-sugar popsicles with oral rehydration solution that all my kids enjoy. Since Austin can't have concentrated sugar, we occasionally have a "sundae" made with whipped cream and ice cream cones or mini graham pies, with a few sprinkles on top. It's tasty and surprisingly low in sugar. For birthdays, I've made "cakes" out of corn bread mix and sugar-free vanilla pudding (see photo above). Connect with other families to exchange recipes and ideas.

- Find new, non-food–related traditions for the holidays. At Christmas, we go to a tree farm and take a tractor ride out to cut down our own Christmas tree. We also make bird feeders for the birds, sing carols, and sponsor a needy family.
- Modify food-related holiday traditions. For the first few years, Austin couldn't tolerate Christmas baking without a major meltdown or trying to sneak food. But now that he's older, the kids each bake and decorate one big cookie for Santa. It's a well-established tradition to bake for Santa and Austin is able to participate and enjoy it along with his brothers. We also decorate gingerbread houses but don't eat any candy. I buy candy Austin has said looks "gross" and that he wouldn't want to eat.
- Discuss a plan for lunch at school based on your child's needs. Can your child eat with other students? Do they need to eat in a separate location? (Try to avoid separating from peers if possible.) Can a reliable adult or nurse monitor the child to ensure the diet plan is followed while they sit next to their peers? Some schools have a closely monitored "allergy table" where all children with allergies sit. Find a balance that works for your child while allowing them to have social time with their classmates.
- Educate your child's teacher and school nurse about your child's dietary restrictions and, again, come up with a plan. I send notes home to the other parents about Austin's medical condition and requesting they not, for example, send candy home. Before an event where food may be present, we always come up with a backup plan. For example, the morning of Valentine's Day I review that if someone forgets Austin can't have candy and sends him some with his Valentine, we will exchange the candy for a quarter or extra screen time (Austin's choice). Once your child is school aged, include them, as developmentally appropriate, in planning how to handle these events.
- Acknowledge there may be a sense of loss if your child can't eat. Beyond the emotional challenges of raising a medically complex child, parents and children may experience grief over the inability to eat; the grief will evolve as your child ages. Not being able to eat certain foods really upsets Austin. Feeling like the "bad guy" or "food police" takes its toll on me, as his mom, emotionally.

Finding support from others dealing with similar challenges may benefit both parents and children. Support can be found through online TPN and short gut groups, specialty medical camps such as the Serious Fun network of camps for medically ill children (many offer family camp, sibling camp, and GI camp), Oley conferences, Childlife, and counseling.

Reviewed by Carol Ireton-Jones, PhD, RD, LD, CNSC, FASPEN, FAND; Laura Matarese, PhD, RDN, LDN, FADA, FASPEN, CNSC; and Marion Winkler, PhD, RD, LDN, CNSC, FASPEN.

Comparison of intravenous lock solutions to prevent CRBSI

Reference:

Vercaigne, L.M., Allan, D.R., Armstrong, S.W., Zacharias, J.M. and Miller, L.M. (2015) An ethanol/sodium citrate locking solution compared to heparin to prevent hemodialysis catheter-related infections: a randomized pilot study. The Journal of Vascular Access. December 7th. [epub ahead of print]. DOI: 10.5301/jva.5000486.

Editor's note: *As with all medical information, if you have questions or concerns, these need to be raised with your medical team.*

Abstract:

PURPOSE: The objective of this study was to compare the initial safety and efficacy of a novel 30% ethanol/4% sodium citrate catheter-locking solution to heparin in a hemodialysis population.

METHODS: This was a prospective, randomized, pilot study of 40 hemodialysis patients randomized to a 30% ethanol/4% sodium citrate or heparin 1000 units/mL locking solution. The primary outcome was identification of any serious adverse events over the study duration. Secondary outcomes included the rate per 1000 catheter days for catheter-related bloodstream infections (CRBSI), alteplase use, catheter dysfunction, and catheter removal.

RESULTS: Three serious adverse events were reported as possibly related to the catheter solutions. Only one CRBSI was observed during the study in the heparin arm. The rate of alteplase use was 1.5/1000 catheter days in the heparin arm compared to 2.8/1000 catheter days in the ethanol/citrate arm (rate ratio = 1.85, 90% CI 0.48, 7.07, p value = 0.45), while the rate of catheter dysfunction was 6.8/1000 catheter days in the heparin arm compared to 1.9/1000 catheter days in the ethanol citrate arm (rate ratio = 0.27, 90% CI 0.10, 0.74, p value = 0.04). Catheter survival to first catheter outcome was longer in the ethanol/citrate group compared to heparin and there were no catheter removals due to bacteremia or thrombosis.

CONCLUSIONS: The ethanol/sodium citrate locking solution was safely used in this study. It appears to prevent CRBSI and may improve catheter survival compared to heparin.

PACIFHAN speaks HPN in many languages

WORDS BY *KAREN*

Following PACIFHAN's official introduction to the world at ESPEN Congress 2015 in Lisbon, Portugal last September, it is now ready and very proud to launch its Home Parenteral & Home Enteral Nutrition Multilingual Dictionary (Dictionary). A list of HPN and HEN medical words have been collated and translated by PACIFHAN members into 6 languages - English (UK & Australasia), English (USA), Czech, Italian, Polish, Swedish. This Dictionary is being made available on PACIFHAN's website – www.pacifhan.org – for use by HPN and HEN travellers when communicating with medical staff, should they find themselves needing medical assistance in any countries using these languages. *[If the Dictionary has not yet appeared on the PACIFHAN website, visit again soon.]*

PACIFHAN is the International Alliance of Patient Organisations for Chronic Intestinal Failure & Home Artificial Nutrition. Home Artificial Nutrition, or HAN, is the term covering both HPN and HEN. PNDU is a founding member of PACIFHAN, along with patient organisations from Czech Republic, Italy, Poland, Sweden, UK and USA, and is very proud to be involved in this Dictionary.

PACIFHAN believes its Dictionary will be a valuable tool, enabling those living with HAN to be better equipped to deal with medical situations when travelling. As such, it's a great step in achieving one of its goals – to improve the quality of life of those living with HAN. PACIFHAN plans to expand the Dictionary – the number of words and languages – as more member organisations join PACIFHAN, and in time, also hopes to be able to develop a smartphone app for even easier access and use by HAN travellers.

Many of PNDU's members have enjoyed the opportunity to travel with HPN, some overseas. International travel can be a wonderful and beneficial experience for those living with HPN who are well enough, even if it requires much greater planning than for the average tourist. We look forward to more HPNers from 'down under' being able to travel with increased peace of mind, knowing they have access to this Dictionary. It will be a great asset should they need medical assistance abroad.

Upcoming PNDU Activities

- March – Work began on PNDU's new website (see article above).
- April – This year's PNDU Christmas card designs have been chosen and sent to print (see article above).
- April – PNDU's second order of medical play puppets arrived at their new homes.
- April – planning begins for HPN Awareness Week 2016.
- April – 29th-30th. AVAS (Australian Vascular Access Society) inaugural Annual Scientific Meeting in Brisbane. Karen to attend, speak and exhibit on behalf of PNDU.
- July – 27th-28th. PACIFHAN/Shire 2 day workshop in London. As convenor of PACIFHAN, Karen to attend and participate

PNDU Membership for Aussie and Kiwi HPNers and carers:

We welcome all Aussie and Kiwi HPNers and carers to become PNDU members. If you are interested in joining PNDU, please email us at contactpndu@gmail.com, telling us about yourself.

Benefits: Through membership you are invited to join one or both of our private forums: our Google Groups email forum is where conversation relevant to living 'down under' with HPN happens; and our closed Facebook group is more of a noticeboard where members can easily keep up-to-date with PNDU activities. You also have access to all pages of our website, and are on our mailing list to receive Dripline and notifications of other important occasions.

No computer? For those who prefer communication the 'good old-fashioned way' – by letter or card – PNDU offers correspondence with one of our members. If you are an Aussie or Kiwi HPNer or carer and are interested (or as a clinician, you have an HPN patient whom you think would benefit from letter/card correspondence), please contact us at contactpndu@gmail.com or PNDU, 128 Rainbow Street, Randwick NSW 2031, Australia to find out more.

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

We also welcome others to join PNDU as Associate Members, giving you access to all pages of our website as well as receiving Dripline and notifications of other important occasions. To join, please sign up on our website www.pndu.org

Donations

If you would like to support the work of PNDU, we would welcome your donation, no matter how big or small. Now that incorporation has been achieved(!), PNDU has its own account!
When making direct deposits, please provide your name as a reference. If you require an acknowledgement/receipt of your donation, please email us at contactpndu@gmail.com.

AUSTRALIA:
Direct deposit (Australian dollars only) to PNDU Inc.'s bank account:
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A/c No: 482738

NEW ZEALAND:
For our Kiwi members, our sister charity IPANEMA (Charities Commission Registration CC21178) kindly continues to receive donations on our behalf:
Online donations: PayPal via our website www.pndu.org
Or **direct deposit** (New Zealand dollars only):
Bank: ANZ
Account name: IPANEMA
A/c No: 0602730308799-00
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Contact us

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If you have an experience with Parenteral Nutrition that you would like to share, or if you have questions please email these to contactpndu@gmail.com

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

Designer: Sal