



# DRIPLINE



# PNDU

Parenteral Nutrition Down Under

Happy 10th anniversary, Dripline!

I find it amazing that Dripline is celebrating its 10th anniversary issue! I can easily recall getting the first issue out, then wondering where I'd get articles for the next issue – but somehow, ideas and articles arrive every 3 months, which are hopefully of interest to our members, HPNers and clinicians alike. I'd like to acknowledge and thank our past designers, who change Dripline from a long Word document to a well-laid out colourful newsletter. Our initial designer was Carla, the young aunt of a paediatric member, who enthusiastically gave her time for the first several issues, until she relocated to Melbourne. Carla was followed by my daughter, Sally, who worked out how to put Carla's work into a programme that she was familiar with, and was designer for many issues until life became too busy. At this point, PNDU had sufficient funds to pay for a company to do the work, so for a couple of years, the designers at MBE have put it together. I'd also like to thank Prof Gil Hardy, a life member of PNDU, who helped get PNDU started, and who willingly writes articles for Dripline, both offering, and when asked. This support has been invaluable. Also, thanks to PNDU's very co-operative members who respond to my requests for input, allowing me to put articles together on a variety of topics, as well as writing stand-alone articles for me on aspects of their lives. They have my gratitude and thanks.

In this issue you're asked to save dates for the November AuSPEN HPNer Consumer Workshop and social gathering of HPNers...and for PNDU's AGM in August. You can read about some more of our HPNer members' activities and/or hobbies; Sal's bus trip to Leeton at Easter; learn about Chyme Reinfusion Therapy; and revisit Revestive, a possible treatment for some members suffering from Short Bowel Syndrome, along with some comments from members about their experience with this treatment.

Sadly, PNDU mourns the loss of another PNDU member, who lost his battle earlier this month. Our thoughts and condolences go out to his family.

I hope you enjoy this 10th anniversary read,

Gillian  
Dripline Editor





- HPN Awareness Week 2022
- HPN: Our Life (Part 2 of 'HPN: Still Living our Best Life')
- PNDU's 2022 AGM
- Introducing Teduglitide (Revestive) – an excerpt plus member feedback
- Sal's Easter Clipper Club Rally at Leeton
- Melbourne Consumer Workshop and PNDU Social Gathering - save the date information
- Chyme Reinfusion Therapy – by Prof Gil Hardy
- RArEST Project - Learning Needs Survey for Health Professionals
- Opportunity to participate in a research study of adults living with Short Bowel Syndrome
- In Memoriam
- Upcoming Events
- Thank You
- Planning an Overseas Holiday
- PNDU information: Membership, donations and contact information

## HPN Awareness Week 9th - 15th October 2022 HPN: - Our Life



HPN Awareness Week is a wonderful opportunity each year for the HPN community to join together and as the name suggests, increase awareness and understanding of this complex life support therapy. A celebration of life for more than 300 adults and children across Australia and New Zealand living with the rare condition, Intestinal Failure, requiring Home Parenteral Nutrition (HPN)

PNDU extends an invitation to all HPNers, family, carers, HPN hospitals, clinicians and our industry friends, to join in the HPN Awareness Week celebrations and help make Awareness Week 2022 a memorable event.

### Resources

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

For hospitals and industry friends, PNDU will again provide a 'Resource Pack' with wonderful ideas and information on how to help celebrate HPN AW 22. The available PNDU resources will include stickers, flyers, posters, quiz, crossword and video.

## PN Pharmacy Tours

PNDU is again making arrangements with our industry friends, Baxter – Australia and New Zealand, Biomed – Auckland, and Fresenius Kabi - Sydney, for guided tours of their PN compounding facilities. A wonderful opportunity to see how our PN is manufactured and a chance for HPNers and carers to share their story with pharmacy staff. Tours are open to all HPNers, family, carers and HPN clinicians. Details will be advertised closer to the event.

## HPN Awareness Week HPN: Our Life

PNDU invites all our Members, Family and Friends to join in HPN Awareness Week and share a little about their LIFE with HPN.

If you would like to share your HPN story please [contactpndu@gmail.com](mailto:contactpndu@gmail.com)

Jordan and Logan, aged 13 & 10 respectively, both boys were born with a rare genetic condition XCIPO, causing Chronic Intestinal Failure requiring Home Parenteral Nutrition (HPN). Despite the many hospitalisations, operations and restrictions of being on HPN for 15 hours each day, the boys are always encouraged to enjoy life to its fullest.



### Jordan HPN 13 years

I enjoy fishing trips with my Pop, playing the PlayStation, basketball and collecting Pokémon cards.

The dislikes of being on HPN, are I'm not allowed to play in the rain or have play dates and sleepovers with my friends.

If I wasn't on HPN I would like to go swimming and be able to go camping in the bush with my Pop.

When I grow up, I would like to be a police officer or work in a movie theatre.



### Logan HPN 10 years

I enjoy boat rides and fishing trips with Pop, playing oz-tag and soccer. I also enjoy climbing, going to the skatepark and playing handball.

The dislikes of being on HPN are being connected to an IV pole and not being able to do things like normal people would, like playdates at my friends' houses.

If I weren't on HPN I would like to go swimming and have sleepovers with my friends.

When I grow up, I would like to be a police officer or a construction worker.



*Editor's Note: This is the second part of the series 'HPN: Still living our best life', begun in the last issue of Dripline. However, it fits so well with PNDU's 2022 theme for HPN Awareness Week, 'HPN: Our Life' that I thought I'd rename it for this issue.*

**Ariel** a 11yr old HPNer from birth



I play Splatoon 2 on the Nintendo switch. I like to play it because it is fun and exciting and I play with my friends online. Splatoon is a paintball game where you paint the ground with ink and when you shoot the paintball at others. They explode in a puddle of colourful ink. I am allowed to play the game in the afternoons after school, but I wish I could play it all day.

## Philip

I'm a farmer's child, born in the sixties, old enough to remember this week 53 years ago when you could wander outside and look at the moon and think "there are two humans there at the moment". Science and technology were the big things in my life after that, and they still are today.

I do a lot of reading at the moment, and the online universities that have sprung up offer some interesting courses to do. I'm studying microbiology for a month to make up for not doing it at school. Lots of journals have a big online presence now.

I had to wander into a high school library to find 'Scientific American' many years ago, but now you can look at the NASA website for lots of amazing things, both here and now, and a long, long way away, and a long, long time ago. We live in interesting times, both grim and weirdly exciting. I get the grim at home, but exciting works for me with reading matter. In a time where gene sequencing takes hours, we can edit genetic material with CrispCas9 gene shears and "science communicators" can distill complex ideas into more manageable concepts; there is so much to read about in science and medicine, and I still find the world a remarkable place to read about.... Oh! for a Tardis to take a quick trip (make that many) into the future to see what new ideas have come to fruition.

I still do lots off electronics, being a tech by trade, but 3D printing is just another tool I use to build things you couldn't afford to have a CNC mill build in metal. I like having sub-millimetre accuracy in a plastic part that you can turn from idea to object in a few hours. This technology offering benefits to almost anyone, and is having a profound effect in communities where ordinary manufacturing is limited, and in medicine in 5 years' time, who knows? There are 2 people in this city with 3D printed body parts, and they've had them more than 5 years.

Those things keep me inside in winter, but being a recumbent rider, (much harder to fall out of than a bicycle and genuinely terrifying, even riding it on a road bike track) the local tracks in the inner north of the city are great and not too busy between peak hours. If we didn't live in these odd times, I'd probably walk more, as I did enjoy walking, too, in pre Covid times.

What else...ah... I started on HPN feeding 5 years ago, after spending a few very miserable years with severe malnutrition and a barely functioning intestinal tract, being 50 something and feeling 90 something. HPN and PNDU have been life-savers. Even in HPN, there are big developments to be amazed by: Revestive,

new surgical procedures, new electronics and manufacturing processes to provide improvement in HPN delivery. Flash blood glucose monitoring is here now, and what are implantable sensor devices going to do for HPN? It's a world of both horror and wonder at the moment, but humans can be remarkable, so I still look at the moon, but like me, look at this small green planet and read and wonder.



Philip on his recumbent bike.



Parts made on my 3D printer: the semi-transparent part on the stainless pump took half an hour to print, and an hour to design; if it was hand made out of brass, there'd be half a day of machining. The cute white dinosaur on the right (also printed) snuck in while I was assembling the shot!

## Karen



I've been on HPN for 15+ years now. While I recognise the pandemic has been incredibly difficult for many, I'm one of those grateful for the opportunities it's provided - primarily to take life more slowly, and even discover new interests. For me that's been watercolour painting and watching beach sunrises, both so relaxing and enjoyable. Sometimes now I'll combine the two and paint from a beach sunrise photo, as provided (A5 size). My mobile phone photos never do justice to the stunning sunrise colours, but I take them anyway! To avoid accumulating a pile of amateur paintings, I mostly paint very small paintings which I stick on cards and give to family and friends.

One of Karen's watercolours

### PNDU's 2022 AGM

PNDU's 7th Annual General Meeting which will take place on Friday, 26th August, 2022, at:  
2.00pm (NZ time)  
12.00pm (Australian EST)  
11.30am (Australian CST)  
10.00am (Australian WST)

All members of PNDU Inc. are cordially invited to join this meeting, which will take place via Skype. The agenda for the AGM will be emailed to all members prior to the meeting, and details of how to join in will be posted on the email forum and Facebook

Election of PNDU's Management Committee will take place at the AGM and PNDU invites nominations for all roles in the PNDU Management Committee. Members will be informed about voting/proxy votes/ nominations in due time.

We hope you can join us!



**Words by Peter Lim Medical Director of Intestinal Failure / Gastroenterology Staff Specialist at Royal Prince Alfred Hospital, Sydney**

*Editor's Note: Although PNDU doesn't support any particular drug/treatment for Intestinal Failure, we support educating our members in the latest developments which can then be discussed with their hospital team. Teduglutide (Revestive) was written about in Dripline issue 4 and, more recently, issue 28. Since many of our members haven't had this treatment brought to their attention by their teams, I have reprinted an excerpt from the article in issue 28. To read the whole article, control/click here: [Dripline-Newsletter-28-May-July-2019.pdf \(pndu.org\)](#) Please discuss this with your team if you are interested.*

## Introducing Teduglutide

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

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

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

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

## Teduglutide in Australia

*Editor's Note: Teduglutide is available on the Pharmaceutical Benefits Scheme. PNDU was involved for nearly 3 years in helping this come to pass. The following members share their experiences with this drug.*

### Pete

My name is Pete. I'm 62 years old from South Australia and have been on HPN since 2014. I started Revestive in May 2021. At the start of my treatment, I was on four 2.5 litre bags of PN and three 2.5 litre Hartmans fluid per week. After a few weeks of Revestive treatment, I started getting fluid overload and therefore my team started to drop the volume of PN and Hartmans fluid. Over the next 5 months I was able to start having nights off of PN and Hartmans fluid until eventually I was having nil PN and fluids. I managed reasonably well without fluids, only having the occasional 1 litre Hartmans when I felt a bit dehydrated. At the end of January this year, I ended up getting Covid. I'm not sure when Revestive stopped working within that period, but I ended up malnourished. At the end of February, I started having HPN and Hartmans again. Three 3 litre PN bags and three 3 litre Hartmans fluid. Fast forward to July and I'm on two 2litre PN and two 2 litre Hartmans fluid.

Throughout this time, I have continued to have my daily Revestive injections. I'm unsure if we were too quick to drop the PN and fluids, or whether Covid had any influence on things, however I'm going well now and we are taking it slowly reducing PN and fluids. Overall, Revestive requires a bit of measurement of fluid input and output and keeping a diary and inputting totals on the Revestive web page. I believe it is worth the effort and enjoy having nights off of PN and fluids. The support from Revestive is fantastic, and extremely helpful.

### **Brett**

My name is Brett. I am a 44yo PNDU member, who has surgically acquired short gut syndrome / intestinal failure.

A little brief history: I got my acquired short gut syndrome when I was 8yo back in 1986. From the ages of 8, until I was 38 years of age, I subsisted on intermittent HPN (generally 3-4 infusions per week, sometimes more, sometimes less), and oral feeding.

For the last 6-7 years I weaned off PN entirely, and have managed to get by with high dose loperamide, creon supplements, and a SGS diet. (And sometimes 'getting by' would better be defined as 'scraping by'. But anything orally achieved is the better option over PN, vascular access for PN, and the inherent issues with vascular access, assuming one is stable.). Recently, during June, I copped 2 very bad RSV viral illnesses, one after the other, just as I was starting to recover. That forced me into a severe state of dehydration and malnutrition due to diarrhoea and vomiting, high temps and night sweats, complete lack of appetite, and fluid loss; in fact, the whole gamut of symptoms the RSV viral illness offers. And I got it twice over. Consequently, I was hospitalized from the 6-27th June 2022, and I received high dose PN, to stabilise. (Which thankfully I have done).

Due to how terribly physically depleted I got, and how quickly it happened to me, due to those RSV bouts, it has been decided by my gastro and surgical care teams, and myself, that I will be going back onto PN - hopefully as a double measure, and with luck, a temporary one. I will be restarting intermittent PN sometime in the next few months (I have to have a new AV fistula created, and then have that mature before I can obviously use it - my date for surgery for that at this stage is the 2.9.2022).

One point of going back onto the PN is physical repletion. However, once I have restarted PN, I can also start the REVESTIVE program, and so the second and the ultimate aim of going back onto the PN, is to prove I can wean off it, so that I basically tick all the legal boxes to be able to get on the REVESTIVE program to start with, to attempt getting of PN protocol permanently (to be eligible for Revestive; you must be CURRENTLY receiving minimum 3 x IV infusions per week for 12 months (Not historically received IV support as I can prove in droves - unfortunately for me). It is a bit of a merry-go-round, but the obstacle is the way, as I stoically say.

*Editor's Note: I'll ask Brett for an update in a few month's time.*

### **Jacqueline V W**

Just a short note about my Revestive experience.

My gastro was really keen to start me on it, so I tried it. A nurse came to my house in the morning to teach me how to set up the needle and how to inject it. Everything went well. The next morning, she came as well. Everything went well. But during the night, I started to get terrible pains on the right, under my ribcage. Had no idea what that was. The pain nearly became unbearable and wanted to ring an ambulance. But I decided to wait till the morning, because the nurse was coming back at 7-8am.

When she saw me that ill, she rang the ambulance herself. To cut a long story short...I had gallstones and Revestive made the inflammation worse. Later on, I was reading the pamphlet and it stated not to start Revestive if you have gallstones or gallbladder problems. (I didn't know beforehand).

I spent 3 days in hospital on painkillers and antibiotics. This was 3 years ago. I can't try it again because it's too dangerous to remove my gallbladder, because of so much scar tissue in my abdomen.

It was a shame because I was really keen. I am on HPN 7 nights a week, so I was hoping to halve it by going on Revestive.

Good luck to everyone else...it's worth a try!

### Ariel (a 11yr old HPNer)

Ariel has been on Revestive for a while now with excellent results. The first 6 months were tough- a lot of monitoring and adjustment of regime, a heap of blood tests and a lot of time in hospital. Getting the hydration levels right was really tricky; we still struggle with that somewhat, but overall we have had great results, having gone from 7 nights of PN to 4 nights. The 3 nights off PN has given Ariel SO much relief and joy! She really looks forward to those nights when she can be free from the tubes and parents fussing over her medical routine. Consistency is key- we have noted that since the mandatory "month off" required to demonstrate her need for continued access to the drug under the PBS, the efficacy of the drug has waned a little - Ariel's weight gain trajectory that we saw in the time prior to the break has not been as great after recommencement. We are so grateful however that with the drug, we have been able to maintain her 3 nights off.

We were actually VERY annoyed about the PBS requirement to have the month off to demonstrate need - there is already evidence that a break in taking the drug for many, means that the drug will not be as effective on recommencement. Absolutely the case with Ariel who was going great guns beforehand on the drug before it was withdrawn from us in order to demonstrate its impact.

## Easter Clipper Club Rally at Leeton



*By Sal*

It's been a while since I shared with PNDU about our adventures in our Clipper coach. Matt and I did escape in January to explore Armidale and the surrounding region north, up to the Queensland border (as it was still closed then). Our daughter Juliet and husband Enoch had moved to Armidale for Juliet's final year of studying medicine. But this story is about our recent Clipper club rally at Easter, as we were the main organisers for it.

Matt and I had been planning the rally at Darlington Point, in the Riverina region NSW for several months along with another couple from the club. We had done a reconnaissance trip in January, to make sure we had enough details for what needed to be organised. We were initially expecting about 20 or more Clipper Coaches to arrive and had to make sure the caravan park we were staying at, was going to be suitable and fit us all in. Plus, we had to work out where to place each coach, as some people wanted to be next to that person, or not next to that person. Some of the sites would involve tight parking, and we knew some of the drivers were less competent at parking than others, so all these little finicky details that go into organizing an event for about 70 people. There were lots of last-minute change of plans as people had to withdraw unexpectedly and then there were forms to fill in for the local event, we were going to be involved in. Matt had designed the Logo for the weekend, along with a sticker that reflected an unwritten club motto "Failure is not an option". I had the Logo printed on bags for each family, and we made up a show bag for all that came.



We left on the Wednesday evening before Easter, and as Matt had recently washed our Clipper "Bridget", of course it rained as we drove through the Blue Mountains. With all the rain of late, we discovered a few roof leaks and things inside had got wet; fortunately, Matt had managed to find and stop all the leaks in the roof,



decided to go on roads we hadn't yet travelled on and ended up in a small town called Barmedman, so Matt could rest and have lunch.

We then high tailed it for Leeton and did some last-minute shopping for the BBQ we were running the next evening. We made it to the local butcher at Darlington Point, just before they closed for the day, and collected our huge order for the BBQ. It was good to be able to give the locals our business. We arrived at the Darlington Point Caravan Park, by the Murrumbidgee River, and there were already quite a few club members parked up. After finding a fridge to fit all the sausages, rissoles and salads, we were able to say hello to everyone there. We had a lovely evening catching up with club members, some we hadn't seen due to border closures, for a couple of years.

The next morning was Good Friday and the rest of those coming arrived and we set up a table for the members to register and receive their bag of goodies. The other lady who was organizing the rally with us, had handmade bowl cozys, and everyone got to choose a colour they liked. I had become famous in the club for my triple choc brownies, and in the lead up to the event, there was a fair bit of hype and expectation that I would be bringing some. I had made several batches, along with my also very popular passionfruit slice. They got to choose between a small tub of the brownies or the passionfruit slice. Surprisingly, the passionfruit slice was more popular. Maybe they thought that it was the healthier option and wanted to be seen as doing the right thing, but the amount of sweetened condensed milk in there, it wasn't really that healthy! I ended up with a few tubs of the triple choc brownies leftover, and I must say, it wasn't difficult to find willing takers for them, much to Matt's disappointment!

We had planned to make the event as relaxing as possible and didn't make it full of set activities. Some folks had travelled a long distance (including a couple from WA, who managed to escape) and wanted to chill and check out each other's Clippers and the kids wanted to play and explore the river. We enjoyed catching up with everyone. That evening we hosted the BBQ, and I must say it was good to get the smell of raw onions and raw sausages out of Bridget at last! We had heavily catered and tried to pass on all the extra bread rolls and sausages.

Saturday was our main event, as we were to be part of the Leeton Sun Rice Festival, in their street parade. They hadn't been able to hold the event due to COVID-19 for a couple of years, so the organisers were expecting a big turnout. All the fellas were out doing last minute washes and polishes of their prized Clippers, to make them clean and shiny. We left the Caravan Park and headed in a convoy with 16 Clipper coaches. This is always fun. I do pity those who get stuck behind us or try to overtake us! But for those we drive past, it is a sight to behold. My sister is a Griffith local, and she came along for the ride.



We headed to the local showground for the assembling of the street parade. It was a good thing we had so much food leftover from the evening before, as it meant we could provide lunch as we waited. We pulled out the hundred odd bread rolls and sausages and fed the club again! They split us up in to 2 groups of 8 Clippers. With some truck floats featuring local community, school, or sporting groups. There was a

marching band as well. We were part of the second group and as we slowly drove through the main streets of Leeton, thousands of people waved and cheered us. There were some areas where there were groups 4-5 people deep, all eyes on us and waving. Matt gave the horn a regular blast to the joy of young and old. The Clipper ahead of us was revving its loud engine and its original side arm indicator was flapping up and down to high five the crowd in the median strip of the main street. My sister would spot people she knew, and would stick her head out and say hello, much to their surprise. We have never experienced anything like this, or the volume of people. It was so heartening to see their enthusiasm and joy and to be able to bring that to them, in this way. The feedback we got, was that this was the best parade ever, and the Clippers made the event! Some of us parked up near a local oval, and had many onlookers come and have a closer look. Our youngest son Bradden had come to the rally in his own car and heard a few comments as people walked around the carpark of Clippers and people were saying that our Bridget was their favourite, and we won't argue about that!

After exploring the stalls, and activities in town, we headed home to get ready for our evening event. After dinner, we held our club meeting and had sticky date puddings made by a club member for all to enjoy, as they watched one of the fun movies, a club member had created about Clippers and his dog. It was a lovely way to finish the happy day.

Easter Sunday morning, and I had organised a church service on the beach by the river, for those who wanted to celebrate the Christian Easter. After all the local birds joining in our songs, we headed back to the caravan park and the kids had fun finding all the Easter eggs hidden around the Clippers. The kids did really well on the chocolate, as the caravan park also held their own egg hunt for the kids to enjoy. The caravan park had posted on Facebook, photos of all the Clippers, and as a result we had a steady flow of people coming out to specifically see the Clippers and take photos. In fact, the caravan park had over 199,000 visits to their Facebook page over 3 days and an influx in people booking to stay at the caravan park, as it had appeared to be so beautiful in the photos. The park was indeed beautiful, with tree lined sites and the river just nearby. My sister and nephew came and joined us that afternoon, as we headed back into Leeton for the Balloon Glow evening event. This was a most spectacular event of 12 very colourful hot air balloons lined up, with the flames being blasted and lighting up in time to music. It was amazing, and to add to the sight, a new moon was rising in front of us between two of the balloons. This was then followed up by fireworks. Again, thousands of locals attended the event. It was a wonderful way to spend the evening.



On Monday, half those attending, headed home. The rally had been a success, and everyone enjoyed the freedom to relax or explore the region at their own pace but also loved being in the street parade. It was lovely that as part of the rally, I got to see my sister and nephew and spend time with them too. They spent the Monday with us, and we headed home on the Tuesday, in convoy with another Clipper, and who were our fellow rally organisers. As I celebrate in May, 10 more years of being able to enjoy life, thanks to TPN, I am able to reflect on how truly blessed I have been to still be here, and to experience such wonderful fun, as these Clipper rallies end up being. Thanks to TPN I have also been able to see my children not only finish school but see my eldest son finish a uni degree and get married; my daughter almost finish her medicine degree, and also get married; my next son is half way through his uni degree and my youngest son is almost half way through a mechanics apprenticeship. I am able to keep working for my husband and keep our business afloat.

We have had many family holidays and adventures in our two coaches and been able to give back to a few outback farmers with volunteering. I have been able to support and care for my church community and

also of course care for my own parents and wider family. I am so grateful to be able to have TPN, and look forward to more adventures and joy in the future, to keep life in perspective and balance, aside from my ongoing health issues. This year I have written some of my own memoirs, to be able to read later when I am old and can't remember who I am! I am very proud of writing over 100,000 words, that I never thought I could write, or that my life had that much action. It has been therapeutic and if anyone in my family cares to be interested, they can read it and know who I am and how I got to be me. No takers yet. I might even keep adding to it. Maybe I can encourage others in PNDU to take up the pen or keyboard and put their life in words for their loved ones.

## Melbourne Consumer Workshop and Social Gathering, November 17 - 20, 2022. Not To Be Missed! Save the Dates!



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

### **1. PNDU Social Gathering: - 20th November 2022** **Venue and time to be confirmed**

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

For more information and to register email [contactpndu@gmail.com](mailto:contactpndu@gmail.com)

### **2. AuSPEN HPN Consumer Workshop. Thursday 17th November, 2022** **Venue:** Crown Conference Centre, Melbourne **Time:** 9:30am – 12:30pm

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

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

How to Register will be advised at a later date.

Due to the uncertainty of COVID 19 and possible restrictions, AuSPEN has organised both in person plus virtual HPN consumer workshop, please [contactpndu@gmail.com](mailto:contactpndu@gmail.com) if you are interested and available to join a virtual HPN consumer workshop. We need to gauge numbers to make the virtual workshop viable.

### **PNDU Travel Sponsorship to attend these two events in Melbourne**

PNDU is offering Two Travel Sponsorships, to the value of \$600 each, to assist HPNers and Carers attend these events. Priority will be given to PNDU members who haven't before attended an AuSPEN HPN consumer workshop plus the PNDU Annual social Gathering. If you have attended past events, you can still apply again. If you're not yet a PNDU member, complete the membership form on our website today.

To apply, simply write two paragraphs describing why you would like to attend these events and what benefit attending will have for you. Send your email to [contactpndu@gmail.com](mailto:contactpndu@gmail.com)

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

**Winners announced 1st September.**

# Chyme Reinfusion Therapy (CRT): "From the Top of the World to Downunder and Beyond"



**Gil Hardy 1.6.22**

## Historical background

In the 1980's Ian Bissett, a colorectal surgeon from 'Downunder' New Zealand was working in Nepal (the roof of the world) but found he had little or no access to nutrition support products or services to aid recovery of his post operative patients who were malnourished because of intestinal failure (IF). He therefore resorted to reinfusing chyme, following the pioneering work in the 1970s by Dr Etienne Levy in France. More recent examples where chyme reinfusion therapy (CRT) has been successfully utilised by Professors Bissett and O'Grady at Auckland City Hospital, include a patient referred for a gynecological malignancy with an abdominal dehiscence resulting in a failed absorbable mesh repair with a mid-small bowel fistula. A less intense but still highly problematic case was a male patient who underwent emergency surgery for a perforation and was given a lifesaving but high-output proximal enterostomy.

An enterostomy is an artificial opening or stoma through the wall of the abdomen or the small intestine. Any abdominal surgical procedure may require the surgeon to perform a temporary double enterostomy (TDE), to divert intestinal contents (chyme) away from the surgical site as it heals, especially if there has been a resection of the small intestine, anastomosis for peritonitis, mesenteric ischemia or radiation enteritis. Entero-atmospheric fistulas (EAF) are intestinal fistulas in which the small bowel is completely exposed through the abdominal wall. EAF are typically left open for many months, during which time chyme has usually been discarded, often leading to intestinal failure (IF).

## If the gut works: Use it!

The incidence of IF in patients with enterostomies is underestimated. Many may develop Type 2 IF due to short bowel syndrome, requiring parenteral nutrition (PN), sometimes at home (HPN) until they have recovered enough for surgical re-establishment of intestinal continuity, typically 6-12 months after primary surgery [1]. Patients may need to be nil by mouth and are at high risk of dehydration and disease related malnutrition (DRM) due to high fluid losses and intestinal malabsorption. Dehydration occurs in up to 20% of patients with enterostomies and is the cause of 40% of readmissions [2], with a high relative risk of acute renal failure [3]. Prolonged therapy with artificially administered nutrition or hydration (AANH) is often necessary, but PN dependence can frequently lead to development of IF-associated liver disease (IFALD), which has been associated with risks of increased morbidity and mortality [ref] mainly related to central venous thrombosis, catheter-related infections, and sepsis [4]. Almost all these complications could be minimized if there was a way to simply return the nutrition-rich stoma contents back into the downstream gut by reinfusion of the patient's own chyme from their stoma bag.

## Chyme Reinfusion Therapy

Chyme is a semifluid mass of partially digested food, saliva, gastric juice, biliopancreatic and intestinal secretions, whereby food is transformed into absorbable nutrients by enzymatic digestion and under the influence of bile salts. When all of the nutrients have been absorbed from chyme, the remaining indigestible or non-absorbable waste is eliminated as a stool. Chyme reinfusion therapy (CRT) establishes an extracorporeal circulation of chyme between the collection stoma bag and the downstream small intestine. CRT is one of several distal feeding or fistuloclysis techniques all of which are recommended by ASPEN [5] and ESPEN [6] for restoration of digestive function to the downstream intestine and to potentially reduce the need for PN. Distal enteral feeding, in which the chyme is discarded and enteral feed instilled into the distal gut has been tried with some success, but CRT has clear advantages including accounting for stoma losses and the physiological nature of chyme. Unfortunately, despite the apparent simplicity of this 'natural' solution, CRT as a treatment for type 2 IF, associated with high output TDE or EAF has not been easy to achieve and is very rarely reported in the literature.

Nevertheless, clinical experiences in France since the 1970s, have demonstrated that CRT can correct IF and restore enterohepatic circulation. In a retrospective analysis of over 300 patients from 2000 -2018 Picot et al [1] reported that PN weaning was achieved in 188/211 (89%) of cases. Weight and albumin increased with intestinal losses less than 2L / day. CRT patients experienced better intestinal absorptive function, with the majority of patients experiencing enhanced nutritional status and improved IF-associated liver disease (IFALD), frequently leading to PN independence for those with a TDE. In a follow up major prospective RESCUE study [7], CRT re-established small intestinal continuity and restored the enterohepatic circulation of bile salts and the authors postulated that the benefits of CRT are partly mediated by bile salt recirculation with rapid activation of bile salt-signalling by fibroblast growth factor 19 (FGF19).

Most recently in China, the role of preoperative CRT in reducing complications after surgery for small intestinal EAF was examined in a retrospective study over 8 years to 2019 [8]. Postoperative complications were manifested in a total of 126 cases (79.3%) but with only 68% in the CRT group versus 89% in the non-CR group. CRT significantly reduced recurrence of fistula and provided a protective factor for patients with postoperative ileus. It was concluded that preoperative CRT is effective in reducing postoperative complications after surgery for EAF

### **New technology for CRT**

Meanwhile, in Auckland, Bhat et al [9] conducted a systematic review, which revealed 24 articles and 481 cases describing CRT in the literature. These publications reported multiple significant benefits with no serious adverse reactions or mortality events in adults. Nevertheless, all studies reported major practical barriers to chyme refeeding, including complicated manual methods that were time consuming and distasteful to both patients and nurses with one nurse reporting that there was no faster way to have a nurse give up nursing!



Following discussions between the surgeons and university biomedical engineers, a simple innovative device was developed that overcomes these practical limitations and facilitates CRT in a closed system.

### **Closed system CRT device**

The 'insides system' has been well accepted by nutrition and stoma therapy nurses, allows the patient to recommence oral feeding earlier and in many cases to manage the CRT themselves at home. A subsequent feasibility study examined 549 IF patient days of device use (10) and reported 80% weaned from PN, 60% accelerated discharge, 85% rapid GI recovery at reversal and all maintained or gained weight. After obtaining CE marking in Europe, the system has been successfully trialed in over 100 patients in Australian IF units in Victoria, South Australia, NSW as well as in several centres in New Zealand, France, Switzerland and UK, and a multicentre randomized controlled trial is planned to start at major IF centres in the UK and USA later in 2022. At Nottingham university hospital in the UK, a successful CRT case involved a male patient who underwent a laparoscopic right hemicolectomy and double barrelled jejunostomy that healed well but his high fluid losses necessitated prolonged PN.

He was eventually discharged to self-manage his PN and CRT, with the Insides System at home, supported by the Nutrition and Stoma nursing teams until his jejunostomy was successfully reversed.

**In summary,** CRT improves intestinal function in IF patients with a temporary double enterostomy or enterocutaneous fistula and can now be considered as first-line treatment in Type2 IF patients with a TDE. Nutritional status and intestinal absorptive function are enhanced, intestinal secretions are reduced, and oral nutrition can be started earlier, with either pureed food or enteral nutrition via a feeding tube. Consequently, PN dependence can be shortened, with concomitant improvements in outcome.



## References

1. Picot D et al *Nutrients* 2020;12;1376
2. Mesari E et al. *Dis Colon Rectum* 2012;55;175
3. Jafari MD et al *Am. Surg* 2013;79;1034
- 4 Burden S et al. *Clin Nutr ESPEN* 2018;28;222
5. Kumpf VJ et al. *JPEN* 2016;41;104
6. Pironi L et al *Clin Nutr* 2018;37;1798
7. Koelfat et al *Hepatology* 2021;74;2670
8. Tian W et al. *Frontiers in Nutrition*. 2022;9;1-12
9. Bhat S et al. *NCP* 2020;35;254
10. Sharma P et al. *Br.J. Surg* 2020;107;1199.

1353 words

## RArEST Project Learning Needs Survey for Health Professionals



Did you know that an estimated 2 million Australians live with a rare disease? Despite variation among different rare diseases, people living with a rare disease face common challenges including a lack of awareness and timely and accurate diagnosis as highlighted in the National Strategic Action Plan for Rare Diseases.

The Rare Disease Awareness, Education, Support, and Training (RArEST) Project is a partnership between the University of New South Wales (UNSW), Rare Voices Australia, the University of Western Australia and Macquarie University.

The RArEST team is developing a range of resources to support health care professionals in coordinating comprehensive, family-centred care for chronic and complex patients with rare diseases and their families. In particular, they will soon be launching a rare rare disease ProjectECHO—a free real-time, case-based virtual community of rare disease practice to support multidisciplinary health professionals as well

well as Rare Disease 101 Australia, an e-learning module.

To enable the RArEST team to deliver resources that are most helpful for health professionals, they want to hear from you about your experiences delivering rare disease care and any learning needs. You are invited to complete a short anonymous survey: [https://unsw.au1.qualtrics.com/jfe/form/SV\\_ekrFTyHvfQLDkcm](https://unsw.au1.qualtrics.com/jfe/form/SV_ekrFTyHvfQLDkcm)

If you have any questions about the survey or RArEST, please contact the RArEST team on [rarest@unsw.edu.au](mailto:rarest@unsw.edu.au).

## Opportunity to participate in a research study of adults living with Short Bowel Syndrome



Cat Bird Seat are doing a study on behalf of a pharmaceutical company to understand the experience of:

- **adults living with short bowel syndrome, as a result of surgery for an underlying condition**
- **those who had short bowel syndrome surgery in the past 5 years**
- **those who are receiving home parenteral nutrition and/or intravenous fluids.**

Cat Bird Seat are particularly opportunity to participate in a research study of adults living with Short Bowel Syndrome

Interested in experiences regarding:

- **time to diagnosis**
- **time to start therapy**
- of both **regional and city** based individuals

We would very much appreciate the opportunity to include your experiences and opinions. It is our hope that the information we gather will be used to further improve the care and quality of life of those experiencing this condition.

The interview will be undertaken by Nerida Newman, an experienced healthcare researcher from Cat Bird Seat market research. The interview will be conducted in compliance with the Australian Market and Social Research Society (AMSRS) Code of Professional Behaviour, Medicines Australia Code of Conduct – Edition 19 and the Australian Privacy Principles and the information you provide will be treated confidentially.

A few things about the interview:

- It will be conducted via video link from the comfort of your own home
- It will be conducted at a time convenient to you.
- We ask you to put aside 2 hours of your time for the interview
- As a thank you for your involvement we will cover your costs and the time you have taken to speak to us with a sum of \$120
- If you think that you qualify and would like to participate in the interview please contact:

Nerida Newman

Cat Bird Seat Pty Ltd

Email: [nerida@catbirdseat.com.au](mailto:nerida@catbirdseat.com.au)

Mobile: 0400103004



**Editor's Note:** Lynden's wife, Kathy, tells us that he was nearly always a half-glass-full person, and to quote his words, "I have mostly enjoyed my 8 or so bonus years...thanks to HPN". Lynden died at home, with support of community nursing, palliative care, and family, especially daughter Kate and herself. They were also supported by Tracey, an end-of-life doula.

## PNDU remembers past HPNers

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



- Lynden** – 14 July 2022, aged 68
- Tracie** - 5 February 2022, aged 47 years
- Aidan** – 21 May 2020, aged 14 1/2 years
- Lara** – 24 April 2020, aged 37 years
- James** – 9 November 2019, aged 28 years
- Elise** – 19 August 2019, aged 43 years
- Ross** – 23 January 2019, aged 67 years
- Celena** – 27 November 2017, aged 43 years
- Emma** – 9 April 2017, aged 35 years
- Lara** – 16 February 2017, aged 7 years
- Teresa** – 15 February 2017 aged 58 years
- Natalie** – 18 September 2016, aged 27 years
- Sam** – 13 September 2016, aged 14 years
- Carol** – 2 September 2016, aged 67 years
- Jessica** – 24 January 2014, aged 20 years
- Tynesha Rose** – 29 October 2012, aged 5 years
- Aria** – 20 June 2011, aged 5 years
- Pauline** – 29 April 2011, aged 38 years
- Hebe** – 3 January 2008, aged 2½ years

May the cherished memories of these dear ones  
never fade



## Upcoming Events



PNDU's AGM Friday, 26th August, 2022

HPN Awareness Week 9th - 15th October 2022

World Home Artificial Nutrition (HAN) Day 15th October 2022

AuSPEN HPN Consumer Workshop Crown conference centre Melbourne 17th November 2022

PNDU Annual Social Gathering Melbourne 20th November 2022

## Thank You



PNDU is very grateful for the support given by the donors listed below. We wish to thank the following for their generous gift. Total donations \$15 740.

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## 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](mailto:contactpndu@gmail.com).





## Membership for Aussie and Kiwi HPNers and carers:

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

Benefits:

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



**For HPN clinicians, industry employees, overseas HPNers, carers and those just interested:** We also welcome others to join PNDU as members, giving you access to all pages of our website, receipt of our newsletter Dripline and other HPN-related news, as well as opportunity to contribute to PNDU Inc.'s work in raising awareness of HPN and supporting HPN research. To join, please go to our website Membership page.

## Donations

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

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

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



## Donating via direct deposit

Please provide your name as a reference. If you require an acknowledgement/receipt of your donation, please email us at [contactpndu@gmail.com](mailto:contactpndu@gmail.com).

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