DRIPLINE
PNDU
Parenteral Nutrition Down Under

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Welcome to the latest issue of Dripline, which has a wide variety of HPNers' stories, ideas and innovations, as well as information about the latest happenings with PNDU, and interesting research results related to HPN (Home Parenteral Nutrition). It's especially exciting to read about Emma's trip around Scandinavia and Miranda's and David's first overseas' venture travelling with their 4 year old HPNer, as well as a two year old. We have two poignant articles by a married couple, one HPNer sharing with us as she nears the end of her life, and the other from the perspective of her husband/carer, which I'm sure other carers will identify with in many ways. Reflecting a different aspect of life for some on HPN, read about four of our youngest HPNers transitioning to their local pre-school and school, as well as several PNDU get-togethers. All this, and much more!

Gillian - Editor

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- Thank You

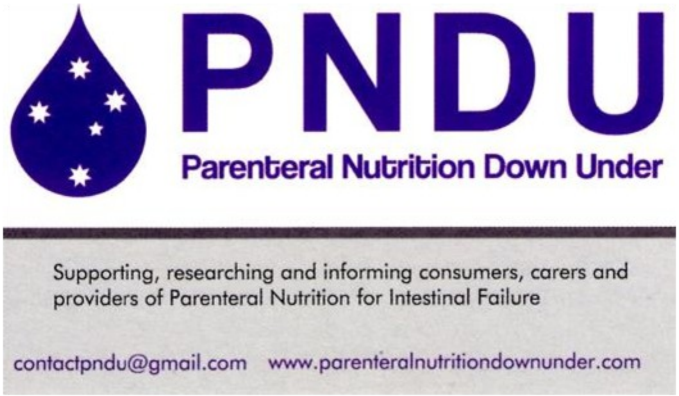
We are www.pndu.org

WORDS BY *KAREN*

We know you'll all agree that our new web address www.pndu.org is so much easier to remember and type! Our old web address www.parenteralnutritiondownunder.com will still be valid for some time to come (we've still got printed material with the old address), but from now on, please start using www.pndu.org . And if you haven't visited PNDU's website for a well, why not visit now – www.pndu.org !

New PNDU Business Cards

WORDS BY *KAREN*



PNDU

Parenteral Nutrition Down Under

Supporting, researching and informing consumers, carers and providers of Parenteral Nutrition for Intestinal Failure

contactpndu@gmail.com www.parenteralnutritiondownunder.com

Along with our new and updated PNDU Restaurant Card (see Dripline Issue 10), we also recently had new business cards printed with our new logo. They look great, don't they!

If you would like some to pass on to others when mentioning the work and activities of PNDU, we'd be happy to send you a bunch. Just email us at contactpndu@gmail.com

Editor's Note: *The following two articles are by a wife (an HPNer) 'Anne's Story' and her husband (her carer) 'Carer's Note'. Anne's doctors did not expect her to pull through after ceasing IV hydration but amazingly after an initial downward spiral she has levelled out and is still with us, after 15yrs of PEGs and catheters. She has no idea what this means for the future and says she's very thankful, though this rollercoaster ride "does her head in a bit"… I think many of us can relate to that!*

Anne's Story

G'day my name is Anne and thankfully we came across the PNDU group as it was getting on its feet, forming committees and printing and circulating the Dripline newsletter. I have a mitochondrial disorder and multiple health issues including intestinal failure and needed 24/7 IV hydration via a pump and also IV morphine 24/7 for pain relief, piggy-backed onto the hydration line but using a 2nd pump for the morphine. I was trialled for PN in a private hospital and reacted to 3 out of 6 components, but was 'good' for the other 3, however due to hospital 'bureaucracy' and me being unable to physically meet certain demands, if I wanted the 3 components of PN, we would have to pay for it. My family chipped in and I had some for 3 months which was a big help – so we knew it was beneficial for me, but couldn't sustain the cost, along with paying for all the other accessories that come with being connected to 2 pumps via a tunnelled Hickman's catheter.

I had had symptoms of mitochondrial disorder all my life, but for the most part was not adversely affected despite pain and certain symptoms, etc. Then in 2000 I literally 'hit a brick wall' and could no longer function normally, and I became acutely ill. I had multiple tests done and though some showed clear systemic problems, others didn't fit into the jigsaw that lay before us and subsequently I was misdiagnosed, mismanaged and mistreated in our local area by a well-meaning but 'inappropriate' doctor. And so began the long road of multiple PEG tubes for 5½ years, jejunum tube and naso-gastric feeding with us making up our own feeds (I reacted to the commercial ones). I'd had an ileostomy performed in 2000 but it didn't stop the 'poo' and bacteria building up in my colon. So with it 'fit to burst' and no longer responding to enemas (tests had showed I have 'total gut inertia' including severe gastroparesis and no motility in my large bowel in 2000), in desperation we moved all my 'doctoring' and visits to hospital, to Sydney.

I quickly got help from more appropriate doctors, surgeons and a private hospital's admitting doctor who all decided to work together wherever possible. It was at this time we got a diagnosis, had major surgery, and worked on better pain relief, and finally, properly recognised and addressed the dehydration issue, along with many of my other symptoms including epilepsy and 'reactive' seizures, etc.

I am writing this in February 2015 after 9½ years of tunnelled Hickman's catheters providing a life line for IV fluids. Many decisions over the years ie my medical treatments, have had to take into account the multiple allergies, reactions, sensitivities etc I have and a general anaesthetic and Hickman's catheter were always the best option to treat dehydration but with each catheter, it became harder to get the next one in (portacath was tried, but failed), especially because the surgeon said there were 'abnormalities' re my veins, and anatomical structures (whatever that means!) in the right side of my chest. The last 2 catheters took at least 2 hours to get in, and the most recent was put in an extremely 'awkward' position, being challenging for the surgeon and myself, as an on-going appendage, alike.

I had always said I never wanted a catheter in my neck (the only other place to put one was my groin, but with the ileostomy – well, it's 'germ central' down there and I have an extremely compromised immune system, so the doctors agreed the groin wasn't an option for me).

I had discussed with my husband and all doctors, other options eg PICC lines, but I needed something permanent, and they felt a PICC was not appropriate for my situation anyway, so we moved on to discussing the fact that at some point in time I would run out of sites for the Hickman's and what that would subsequently mean for me.

At this point I have to say that if I didn't believe in God, I would not have got through the past gruelling 15 or so years. Emotionally I carried a lot of anger regarding my initial mismanagement and mistreatment and realised that even though talking to a counsellor to 'get stuff off my chest' helped, ultimately, if I was to find peace I needed to forgive – this took time but bit by bit it happened. I have lost count of the number of times I have almost died – I know this sounds dramatic, but it's true and again the emotional and mental cost, especially to my husband, has been huge. A lesser man would have walked out on me long ago, but he takes his wedding vows very seriously – to care for me in sickness and health, and as he also believes in God, he loves me just as Jesus loves those who believe in Him. I cannot begin to say how much I owe Matthew (also known as Tim) for his care and love throughout our married life, but especially these past 15 years.

So, back to the decision about catheters. I had long talks with my 3 main treating physicians including surgeon, who all agreed that a catheter in my neck would reduce my quality of life significantly and believed me when I said "I couldn't stand it". (I'd had a long line put in my neck for some treatment during the PEG days and I found it so distressing I had to have it removed after 24 hours.)

The discussion then included my husband and my immediate family who also accepted my decision. The last catheter had been inserted in August 2012 and as many of you would know – anything can happen to a catheter – blockages, leaks, infections, clots… In my case it was all of these that contributed to the demise and eventual removal of my catheter for IV hydration in January 2015. (Fortunately, I'd had discussions with one doctor re the problems of going 'cold turkey' off IV morphine, in the event of the above, during a prior hospital admission for infections in the catheter, and we decided to wean me off IV morphine and trial NORSPAN® morphine patches – the only ones not tried previously. (NB I had also tried oral morphine and then sub-cutaneous morphine for 18 months but it led to cellulitis, and was so thankful this discussion and weaning had occurred prior to the catheter's failure!)

I have learnt that none of us – whether we believe in God or not – pass away unless He says "it's time", and I am now entering a period of absolute unknown in my life. Of course I am going to die – but how and when, I don't know. Sometimes the 'how' does scare me a bit, but I've also learnt that knowing God or not, we're all human and these emotions are natural and not to be denied. However, whatever happens I do also know even if I'm scared, God is with me on my journey and that is a comfort, and I don't fear death, because I know for sure that this journey will end in the most fantastic place – Heaven – and to be really honest, sometimes when the suffering is really bad, no matter how much I love Matthew …I can't wait to get there!

Anne (at 34kgs) and Karen – January 2015 just before she headed home without IV nutrition or hydration.

During this time, I've been truly grateful for the support and encouragement from PNDU, which has been important and helpful to me, including prayer support, cards, and Karen ringing and visiting me in hospital.

Over the years I've had some really low times but believe God has always held onto me. I have not enjoyed the suffering that goes with long term chronic/acute illness, but have enjoyed the fellowship of other Christians, many who have faithfully prayed for our family and especially myself over the years. People have often prayed that I would be healed…and I haven't physically been healed, but God has always got me through, sometimes miraculously so.

A Carer’s note

WORDS BY *MATTHEW, ANNE’S HUSBAND*

What does it mean to say that you are a carer? We all care. Even bad people care. Sometimes you might say – “oh, who cares!”, or perhaps “take care” which is a common expression I often use myself. It can be a very motivating term – care. I guess it means all sorts of things to everyone.

If you are a carer to a medically dependent other person – you might have a few extra things to do or think about – perhaps nothing too much that adds to your usual daily routines. Other people have heaps extra to do – being a carer can be massively physically demanding for such as these – perhaps also mentally challenging too, or in other ways – eg emotionally exhausting, or organisationally.

There is no doubt that the sick & disabled person can need a lot of attention – and deservedly so. However the carer doesn’t always get a look in – that is, we are a somewhat forgotten mob that are often not acknowledged or written about or supported. Additionally, often the publicity I have seen shows carers as wonderfully happy souls, smiling in photo shots on Government websites having a lovely old time… perhaps lending a helping hand to someone in need or looking at an IPad, for goodness sakes!

Well, if you are a carer and are surviving well in the required duties – that’s a good thing. Unfortunately many of us carers do not have such a wonderful time. I fall into the latter category and seek to relate a small part of my “journey” below. I hate that word “journey” – I must be more of a “destination” type person I guess.

Anne & I have been married over 34 years now. Back then, we were both well – no talk of carers then! Oh for the good old days, eh! 34 years ago I was training as an accountant & Anne was part way through an Enrolled Nurses course. However, Anne had started to become sick with gut issues before I even knew her – and before she really knew much of it herself. Such is the human gut – it deviates behaviour away from the created structure in very stealthy ways & the gut does not always tells us about it – often only when it is too late to correct the problem. Yes, a good saying: “I’ve had a gut full of this!”

In very brief summary, Anne suffers from a complicated form of intestinal gut failure including channelopathy (calcium ion) disorder with likelihood of associated mitochondrial disorder. Now what does a bookkeeper know about such things – give me a debit or a credit any day and I’ll tell you where to put it, but having to gradually understand (kind of) such medical conditions was (and still is..) beyond me. I would type up the notes & do some research trying to “understand” what all this medical stuff meant. I haven’t really succeeded in the last 34 years – the failure I saw as mine – I had failed as a husband to protect & provide healing to my wife. It’s only recently that I am now kind of understanding that the stress of being a carer is a thing that has potential to stuff the carer too. This is the real message – how to protect the carer during the process of time when stress is gradually reducing one’s ability to provide the care. In my case, I ultimately became a physical wreck, stressed out way beyond normal. This could have been avoided if I only knew how to take care of myself. People would always say “take care of yourself – get some respite in.”

So how does a carer actually “take care of one’s self”? I’m still learning – I just wish it was taught at school!

And another thing - I get tired of having to ask the “why” questions continually: Let’s list a few – this might be good therapy in itself!

- Why me?
- Why not me?
- Why did this horrible illness happen to my wife?
- Why can’t I have a “normal” life like other people? What is “normal” anyway?
- Why do I have to grapple with complex medical terms & stuff?
- Why do I have a stress system that can’t handle things anymore?
- Why am I taking so many medications these days – I never did before?
- Why do I never sleep properly & wake up every hour & feel disgustingly sleep-deprived all day?
- Why am I so scared that my wife might die?
- Why do we have to have talks about end of life & death arrangements?
- Why does some of my extended family get to lead a “normal” life?
- Why do carers / cared persons sometimes just want to be dead? Be honest here.

That’s a few “why” questions – just for starters. I could easily think of maybe another million without too much effort.

If truth be told – it might be good therapy to ask the “why” questions – but there are no particularly good answers – there are lots of frustrations – ultimately there is no point asking “why” – it’s all about acceptance, letting go & moving on. Sounds easy doesn't it? Well, no, it's almost been impossible in a chronically ill situation of being a carer for decades which has involved my wife suffering countless hospital stays (hundreds!), many, many procedures & interventions, total colectomy & abdomino-perineal resection, a good deal of medical mismanagement, blood tests that could not be counted, agonising pain every day, systemic dehydration that has stopped any sense of a normal life, severe multiple chemical sensitivities, bodily attachments that are constantly infected (PEGS & catheters, etc for 15 years), unexplained countless seizures, special daily diet (mostly pureed & very unexciting) – all while often being wheelchair bound, on 24 hour IV hydration with IV pain management plus an ileostomy, together with life threatening infection issues and medications up to the eye balls. There have been a number of near death experiences. Ah, I hear you say, you know others who suffer such things – well that is true - many other people do suffer these afflictions – but as for me, it's way over the top, and I am the sole carer. Plus, comparing one carer's load to another carer's load is not always helpful.

Clinicians will always want to say "get rid of the stress" – but my wife won't kick me out – and there is no way that "respite" starts to help – and holidays are a thing that happened when I was at school in the 60's. You see, there is something about chronic long term illness that affects this carer's headspace – ie the mental stress. So the mental stress, I think, is the thing to primarily manage. I was once reasonably okay at handling stress – but that was the golden era of me thinking of having a normal family & lots of fun. Ha – how the world has shrunk for me. I have retired early. I have lost my career. I have lost the profession for which I trained so many years ago, plus I have lost the friends it gave me. I have lost a good deal of financial resource. I have even lost the family cat – I can't even manage to keep a cat these days – how pathetic is that - and this from an animal lover that kept a minor zoo in the back yard of my parents' suburban house during all the years until I was married.

So, back to the original proposition: How does a carer effectively cope? I have had my banter – now let's be practical and put forward some possible strategies. Perhaps, for fun, I shall use some animal memories mostly from my days in the backyard at Mum & Dad's Sydney home in the 1970's as well as a few other insights.

Get yourself a pet or borrow someone else's pet – but learn stuff from the natural world. Ok, I admit it – I am a cat person. This is really the subject of an entirely separate carer's article, but in essence, a good cat gives love. The carer gives love & this can be uniquely replenished by receiving a cat's love (not one of those demanding, loud-mouthed types though!). An appropriate cat will impart lots of love to the carer. Alternatively, a good dog will help the carer understand discipline needed to manage carer routines. A bad dog will be nothing but noise & fleas. I sometimes visit a Dog Beach nearby, where dogs are allowed off their leads and it can be fun just to walk & look at all their tricks. Better still (almost) keep some chooks. There is nothing so good as some nice chook pets – never mind the eggs. The note here is that the carer always needs to be scratching around for new ideas, medical insights, a new book to read just for self-indulgence. Scratch around for a new neighbour to say g'day to. Beware though, chooks like to brood – not a good idea for carers – so make friends with a chook today – they can give a lot of love back too. We feed the neighbour's two chooks. Shared communal chooks. Great fun & the eggs are a bonus. If you have kids, try a rabbit. Carers have to run for cover sometimes. This is a self-preservation thing. Find a hole and stay there for a period of time, away from all the stress. You can't stay there forever. I have a shed or two in the backyard – something like a men's shed with gym equipment & radio where it's just me and a gentle work-out listening to a good choice of music. Then there are guinea pigs, which kind of go with rabbits, too. My pigs were always active little critters – always on the go. When a carer is active, the mind is not quite so depressed. Carer duties can dictate a lot of continuous activity at times – it's OK, just remember to take a break and relax too – be a tad selfish. I kept a few tortoises also. This reminds me of where the carer has to pull the head in. There are lots of occasions where the carer must submit, retreat & refrain from talking/instructing/suggesting etc. Also, there are the lessons that a mouse can teach. I am thinking of the treadmill mouse here. The carer's duties just seem, at times, to go on and on and on. This can call for acceptance on the part of the carer – not always achievable, but part of the psychology. To break it all up, I like to sing like a magpie. The maggie sings its song, carolling is the correct term I think. There is almost no better therapy for a carer than singing to oneself – although the cat therapy comes close. My father taught me this therapy – although he never knew it. He would sing hymns – often just humming – or repeating the same verses. You can even make up the words. Singing can even be done silently in the carer's head. Singing has its own endorphins, I'm sure. Don't sing the rubbish that is commonly aired today though – you probably have old favourites tucked away on cassettes & CD's that might help. Oh and something else the maggie does is gardening – they like nothing better than strolling across the lawn and gardening – a good & useful thing for carers to do as well.

Whilst on the birdie theme – remember the days when people seemed more often to keep budgies, and boy could they talk. I hate to admit it somehow, but talking is great for the carer. At my place, Anne does all the talking – I do a lot of listening. Whatever the mix – talking is good for the carer household. It does need a brake on it however, you don't want to drone on and on like a tree full of cicadas, and sometimes the talking party has to be told to shut up! A daily routine at our place is wallaby watching, and we notice how they love to smell (and eat) the daisies. Our yard has recently been invaded by wallabies, who love to eat Anne's daisies. So carers, take time to smell the flowers. Maybe take up slow walking some place – I'm fortunate to have endless beaches nearby which are great for just walking slowly and gazing at the horizon trying to think of nothing and soak it all in. We had a lovely monitor lizard crawl his way across the wallaby yard one day – these huge creatures just love to slowly make their way home – not exactly walking for them I 'spose – but you get my meaning.

Probably my favourite animal of all time is the koala. When I was a kid, the koala needed lots of hugs, and he gave lots of hugs back too. The carer needs to learn to hug. Start small and take it from there. You may not receive a hug in reply, but I reckon that most persons needing care like a hug – a minor hug or a larger hug. Learn to say "I love you" – Anne says this to me all the time – I wish I said it as easily to her! Think of a koala and think of love. Every carer is unique – a bit like a wombat who likes to dig burrows and live alone. This does not mean that carers should live alone, but in a headspace sense, the carer is alone. Fortunately, the wombat likes to keep his burrow near other wombat burrows – so keep yourself in the community and be part of it. We all need each other.

This makes me think of a kookaburra, too – we have lots of them. Every year they breed and the young ones have laughing lessons for some months – quite an ordeal & loads of fun watching it happen. So the kooka helps the carer to remember about laughing – LAUGH OUT LOUD (LOL) – great carer therapy. If you can laugh enough, you can, maybe, start to cry with the laughter, too. I'd like to develop this skill – that would be great therapy for the carer. Which reminds me that more regular crying (sadness-related) has its proper place as well. I've had times of extended crying as a carer, unable to fix a medical situation. In a sense, I love to cry in these latter situations – stress relieving I guess. Maybe if you are a carer, this is something you need to let your system do occasionally, better than holding it all in.

Not unrelated to crying, is the need to make a noise when you find something bad going on. Make an endless noise, a bit like the possums on our tin roof at night. I recently made a substantial noise in the hospital when the nurse taking Anne for her last catheter removal refused to allow her to take seizure medications, which are sublingually dissolved. What happened: a whole bunch of seizures post-op, just because the nurse made her stupid stand on nil-by-mouth orders. That gave me the signal (much later) for a good loud rant at the medical staff – probably some crying thrown in there too somewhere – and these certainly were not crocodile tears, although we did see plenty of crocs on Elcho Island in the NT where we once worked & lived in an aboriginal community. Thus the carer made his or her stand. Does any of this sound familiar?

The carer can be like an investment banker. This is to know that the carer's efforts act as an investment. This is the accountant talking now. See the unwell/disabled person as a means for the carer to invest in the best. The carer is investing where it really matters – in another's life and well-being. The trouble is that this investment can cost the donor a fair bit – up to everything you have. For my part, I see that I am investing with a sure rate of return – love dollars. The trick is to make sure I do not over-invest with care effort that I really cannot afford. That's when I become a bankrupt carer – ie I'm too stressed, or I am too physically run-down, or I am financially at risk etc. Don't risk over-investing – this brings burnout and that is not worth it because nobody wins then.

Remember too, that the carer needs nutritional support to self. I wish I knew this one a few decades ago. If you are a carer, go find at least one medical, really smart, professional who can identify your nutritional gaps. The gaps exist, it's just that we tend to not see it, and the carer work tends to expand the gaps. Often times we think we are fit & healthy enough – but we get run down in insidious ways. I have a GP in Sydney that I make myself visit monthly. I live on the NSW Central Coast – and at present I have to pay someone else to drive me to the visits. The GP I see is worth the effort – full of insightful medicine. Be prepared to pay for the special supplements – a whole new world. Someone recently said that we are not in charge of our bodies, and in many ways this is true, but keep scratching around for help. There are professionals other than GP's too – psychs, naturopaths, hypnotherapists etc etc – good recommendations from others can help avoid the quacks, and there are plenty of them! Good nutrition is my number one strategy at present. Need to minimise the carer being crook.

The carer also needs the cared person. Oxymoron, incongruous & self contradictory? Yes I guess so. However, some people end up separating or divorced – and there can be good reasons for this. Sometimes relationships with a cared person are fraught with difficulty and friends/family need space to keep their own head together. For myself, I need my wife now more than ever. Carers can learn a lot from highly-stressed situations. Don't get me wrong, I would rather not have the stress – but the deep truths of life are often more clearly seen when caring.

On the literary side – carers do well to learn a poem – great brain food and good for insomniacs too. My all times favourites are 'The Man From Snowy River' and 'Now Westlin Winds'. Brilliant.

Ok it's a bit crazy – but it works for me, and I've given you a bit of my carer story as well – plus a few secrets. I have a great wife, two excellent boys, and a great family all round – in-laws and out-laws. I hope maybe this is helpful to some other carers too. The PNDU carer's lot is not an easy one – but we are part of a very big carer community full of all sorts of care-givers and care-receivers and it's good to help each other out where we can. PNDU is a great support, including the newsletter, helping us through the fog of PEG tubes and catheter lines etc.

Matthew (Tim) & Anne 2015

HPNers are a special world of needy persons that most of the community does not know even exists. Unfortunately these little samples I have selected apply to carers who help all manner of sick and disabled persons, young and old – not just HPNers.

Anyway, if you are a carer, the carer's contribution is a valued component of parental nutrition. Creatures are our teachers and they have a way of often conveying forgiveness to us as well – which is a very healing balm for carers and cared-for persons alike. Look at what nature exists near you when you can; and listen to the peace it can impart. Keep on caring, and take care.

First Day of School

WORDS BY *GILLIAN*

The first day of school is an exciting and sometimes over-whelming event for all children and their families. The child is now part of the 'big wide world' of school, one of usually hundreds of other children, instead of being home, or in a small pre-school or day-care situation. It is an especially exciting milestone for families who have a child with medical needs, living life day-to-day knowing that an infection or some other problem could be on the cards any time. Four of our little HPNers have begun school this year, and you'll read in the article "Coping with School" a little about three of the children's experiences. For a later edition, I'm hopeful that their parents will write about the preparations needed to ready the local school for their child so that carers of young children on HPN might benefit from their experiences.

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Emily, NSW

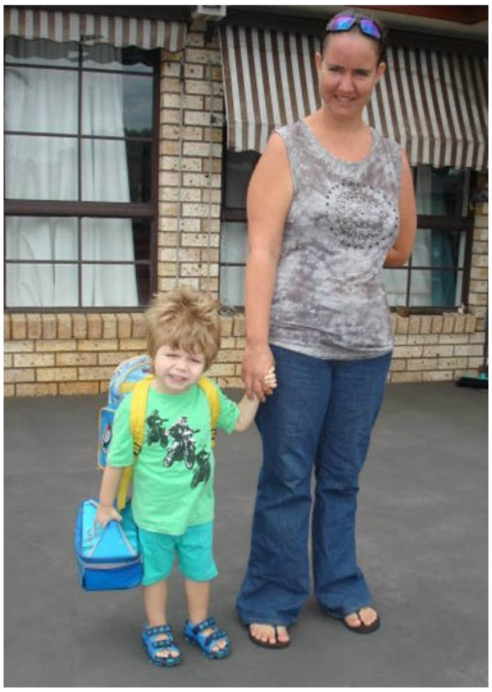
Sam, NZ

Jordan (HPN) & older brother Dylan

Jordan, NSW

This year saw a major milestone for Logan - his first day at Pre-School, where he stayed for four hours. Logan Joined in happily and had a great day. One cheeky little monkey was in bed and asleep early tonight. Pictures of Logan below.

Logan , 3 , (HPNer)



Logan and mum, Brooke

Logan with Aunt Katie, watching big brothers' Easter Hat Parade

Nominations for PNDU's Annual Awards are open!

WORDS BY *KAREN*

Now is the time to start thinking about those whom you believe deserve recognition for their work in the field of HPN! PNDU's annual awards began in 2014 with great success and we look forward to once again being able to congratulate those whom our Aussie and Kiwi members recognise as doing a great job. **<u>You have until 31st of August 2015 to nominate as many times as you like for the various awards</u>** (below) by emailing your completed nomination forms to contactpndu@gmail.com. More details and the nomination forms can be found on the PNDU Annual Awards page (under the 'Get Involved' tab on our website).

Parenteral Nutrition Down Under (PNDU)

PNDU
Parenteral Nutrition Down Under

The PNDU Roll of Honour

Nomination Form for Lifetime Membership Award

Life Membership and induction into the PNDU Roll of Honour is a special award for any member who, as an HPN consumer, parent or carer, has given their time "over and above" for PNDU. It is the highest accolade that the group can bestow as a token of appreciation for the individual's exceptional contribution to development and growth of the group's support for people on HPN. As a general principle just being a member of the Management Committee (MC), for example, will not necessarily be sufficient and self-nominations are not permitted.

Nominations for the Roll of Honour should ideally be with the permission of the nominee and include background information such as primary diagnosis, number of years on HPN and reasons for nominating the person. Submissions to the Honorary Secretary should be by 31st August for consideration and bestowal around October/November each year.

The award will not necessarily be restricted to one per annum and will not necessarily be awarded if, in the opinion of the MC, no suitable candidate is proposed.

An update of present and past Life Members on the Roll of Honour will be kept in the PNDU records and on the website.

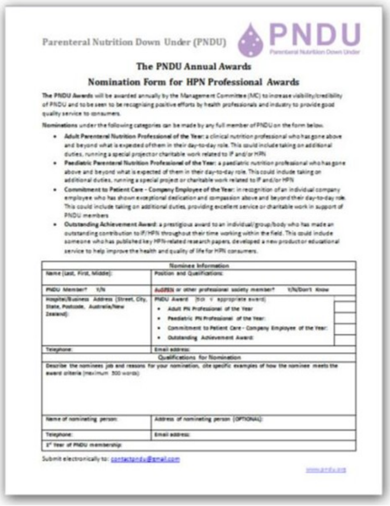
Nominee Information	
Name (Last, First, Middle)	**1st year of PNDU Membership?**
Telephone:	**Address (OPTIONAL):**
Email address:	
Qualifications for Nomination	
Describe the nominees activities and reasons for your nomination, cite specific examples of how the nominee meets the award criteria (maximum 500 words):	
Name of nominating person:	**Address of nominating person (OPTIONAL):**
Telephone:	**Email address:**

Submit electronically to: contactpndu@gmail.com

www.pndu.org

PNDU's Awards

- **Lifetime Membership Roll of Honour Award** is a special award for any member who, as an HPN consumer, parent or carer, has given their time "over and above" for PNDU.
- **HPN Professional Awards** recognise positive efforts by health professionals and industry to provide good quality service to consumers. There are 4 categories of HPN Professional Awards:
  - Adult Parenteral Nutrition Professional of the Year
  - **Paediatric Parenteral Nutrition Professional of the Year**
  - **Commitment to Patient Care - Company Employee of the Year**
  - **Outstanding Achievement Award**: a prestigious award to an individual/ group/body who has made an outstanding contribution to IF/HPN throughout their time working within the field.



Parenteral Nutrition Down Under (PNDU)

PNDU
Parenteral Nutrition Down Under

The PNDU Annual Awards

Nomination Form for HPN Professional Awards

The PNDU Awards will be awarded annually by the Management Committee (MC) to increase visibility/credibility of PNDU and to be seen to be recognising positive efforts by health professionals and industry to provide good quality service to consumers.

Nominations under the following categories can be made by any full member of PNDU on the form below.

- **Adult Parenteral Nutrition Professional of the Year**: a clinical nutrition professional who has gone above and beyond what is expected of them in their day-to-day role. This could include taking on additional duties, running a special project or charitable work related to IF and/or HPN
- **Paediatric Parenteral Nutrition Professional of the Year**: a paediatric nutrition professional who has gone above and beyond what is expected of them in their day-to-day role. This could include taking on additional duties, running a special project or charitable work related to IF and/or HPN
- **Commitment to Patient Care - Company Employee of the Year**: in recognition of an individual company employee who has shown exceptional dedication and compassion above and beyond their day-to-day role. This could include taking on additional duties, providing excellent service or charitable work in support of PNDU members
- **Outstanding Achievement Award**: a prestigious award to an individual/group/body who has made an outstanding contribution to IF/HPN throughout their time working within the field. This could include someone who has published key HPN-related research papers, developed a new product or educational service to help improve the health and quality of life for HPN consumers.

Nominee Information		
Name (Last, First, Middle):	**Position and Qualifications:**	
PNDU Member? Y/N	**AuSPEN or other professional society member? Y/N/Don't Know**	
Hospital/Business Address (Street, City, State, Postcode, Australia/New Zealand):	**PNDU Award** (tick ✓ appropriate award)	
	• **Adult PN Professional of the Year**	☐
	• **Paediatric PN Professional of the Year:**	☐
	• **Commitment to Patient Care - Company Employee of the Year:**	☐
	• **Outstanding Achievement Award:**	☐
Telephone:	**Email address:**	
Qualifications for Nomination		
Describe the nominees job and reasons for your nomination, cite specific examples of how the nominee meets the award criteria (maximum 300 words):		
Name of nominating person:	**Address of nominating person (OPTIONAL):**	
Telephone:	**Email address:**	
1st Year of PNDU membership:		

Submit electronically to: contactpndu@gmail.com

www.pndu.org

Let's recognise and celebrate the great work of those involved in our/our loved one's care, in the work of PNDU, and in HPN in general. For more information, go to our website or email us at contactpndu@gmail.com. We look forward to being able to congratulate and celebrate with the 2015 PNDU Annual Awards.

Nomination forms and more information can be found on the PNDU Annual Awards website page

Ideas for Backpacks

Editor's Note: *Below are some ideas invented/created/found by various members to assist with getting out and about with HPN packs and pump.*

Rosie and Karen – both looking very glamorous with their home-made backpack cover bags!

Graeme's portable dripstand…

...in pieces for transporting.

Brenda's conversion of a shopping trolley to a HPN backpack trolley

Shopping trolley

HPN backpack trolley

Lynden's portable IV pole which can hold IV bag plus pump

Not a member's idea/creation, but great to see nonetheless. Micrel Medical Device's display of infusion gear at ESPEN Conference 2014

Colourful backpack plus over-shoulder infusion bag

Adult backpack on wheels

Children's backpack on wheels (showing inside) plus lightweight infusion pump and charger

Several pictures of Brodie, with various aids for greater mobility while on HPN

Overseas Adventures on HPN

WORDS BY *EMMA*

Dreams can still come true for those of us on HPN. When I started HPN 18 months ago I told my hospital team that one of my passions in life had always been travel. They were initially taken aback when I said that I thought I would be able to have a few more overseas adventures on HPN. It felt like I had asked to fly to the moon. Eventually we negotiated that for my first trip overseas on HPN I would visit countries that have reciprocal healthcare arrangements with Australia.

So last year I spent 6 weeks in the UK, Scandinavia and Iceland. I was able to organise, through Baxter, to pick up HPN in the UK, Norway and Finland. All of my ancillaries were supplied by Baxter UK and then freighted to the Norway and Finland. I took 3 compartment bags unmixed so as not to need refrigeration.

My trip was amazing. The long days, sunshine, new people and places made me feel more alive than I had done in years. I took time to stop, smell the roses and admire my surrounds. I will cherish my memories and photos.

I flew first to London with Qantas and British Airways. I will admit I flew Business Class which certainly helps with being able to set up PN inflight. I found it easier to set up my PN in my seat than in the airline lounge. I managed to hook up my PN on 3 of my flights.

I was in London for the Queen's birthday long weekend. I watched the Trooping of the Colour at Buckingham Palace. I waved to the Royals. I saw musicals in the Westend, ballets and shopped on Oxford and Regent Streets. From Southampton I left on the Summer Solstice Princess Cruise, along the coast of Norway. The ship called into many beautiful port cities on its way to the North Cape.

I visited Bergen and took the Mt Floyen Funicular to admire a spectacular view of the city. I rode on the famous Flaam Railway passing by a couple of magnificent waterfalls. I saw the Fjords and stood on the North Cape Cliffs and gazed out over the North Sea. In Trondheim I saw the Nidarous Cathedral and the Norwegian crown jewels. In Honningsvag I bought quirky souvenirs at the Gallery East of the Sun and drank cocktails from ice glasses with a polar bear at the Artico Ice Bar. In Stavanger I took in the old wooden buildings and then saw a music recital in the Utstein Kloister. At night on the ship there were shows and music. I would often stay out at night forgetting the time due to it still being light. I saw the midnight sun which was a truly bizarre and amazing experience.

On returning to the UK, I flew from London to Oslo. From there I country-hopped and visited the capital cities of Oslo, Copenhagen, Stockholm, Helsinki and Reykjavik.

In Oslo I visited the Viking Museum, and Vigelands Park full of statues and the Nobel Centre. I took the overnight ferry to Copenhagen. In Copenhagen I took in Christiansborg and Amalienborg Palace – home to Princess Mary. The Tivoli Gardens were full of fun-filled rides and indulgent food. I saw the little Mermaid and spent an evening in Nyhaven.

At this point I had my one and only disaster of the trip. Whilst taking a train from Copenhagen to Stockholm, I had a YouTube worthy fall at Stockholm train station. I fell between the train and the platform trying to get my heavy suitcases off the train myself. I picked myself up and thought the bruises will heal, but I won't be taking a train again if travelling alone on HPN. I was then grateful for the complimentary port and dark chocolate at my hotel. Although they did little to beautifully preserved Royal Palace, City Hall and Opera House. I took the overnight ferry to Helsinki. In Helsinki I did a coach tour of the city. A day trip by ferry to the medieval city of Tallinn in Estonia was fascinating and I wandered the markets and saw the expansive Song Grounds.

From here I flew, with Icelandic Air, to Reykjavik, the northern-most city in Europe. It was here that I was almost as far away from home as I could possibly get (someday I will fly to the moon!). The landscapes in Iceland were dramatic, filled with the smell of sulphur. Memorable! I took the famous Golden Circle tour. I saw the Geysir hot springs, Gulfoss Waterfall, and Pingvellir National Park. The Blue Lagoon was the brightest blue water I have ever seen. It's unfortunately not somewhere a HPN patient is able to swim, but maybe paddling a little is possible. The old town and cathedral were magnificent. I went whale-watching and learnt about the Puffins. From Reykjavik I had to make my long way home. When I reached home I was completely exhausted!!

- -

I have already planned my next adventure. I hope to fly with Qantas and LAN to Buenos Aires, Argentina. From there I will take a Celebrity Cruise around the tip of South America to Valparaiso, Chile. Then I will fly with American Airlines to Fort Lauderdale where I will sail on a Princess Cruise to the Caribbean. I have organised my HPN and ancillaries for this trip two different ways. For South America they will be supplied by Baxter, Argentina. For the US, Baxter has organised to freight them from Australia. (*Editor's note: Emma has promised an article about this trip when she returns, so that is something for us to look forward to.*)

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Editor's Note: PNDU has an information booklet Travelling with Parenteral Nutrition, which PNDU recommends any Aussie or Kiwi HPNer/carer thinking about local or overseas travel, and their hospital, should read. It is a comprehensive source of information when planning your trip, including Baxter Healthcare's new requirements.

When it comes to travelling overseas on HPN, planning is absolutely essential. Download and read the travel booklets on the PNDU, PINNT and Oley websites. Ask fellow HPN patient's for advice. Allow at least 6 months, and have patience for the all the planning and organising. I suggest taking a trip within Australia first for a week. Packing for this is a great learning experience before contemplating an overseas trip.

Below is my suggested outline of how to plan an overseas trip on HPN.

1. Decide where to go, for how long and how to travel. A good travel agent is invaluable. Decide on an itinerary, number of PN bags needed and an ancillaries list/s. Ensure you take extra fluids and ancillaries. Consider – e.g. faulty bags, baggage loss, dehydration etc…
2. Consider travelling with multi-chamber PN bags that do not refrigeration. Consider if there is no hotel fridge.
3. Have a meeting with your hospital team to discuss your plans. Get approval and ask for help.
4. Provide Baxter with your itinerary and ancillaries list/s. ***(Editor's note: this is usually organised through your hospital team)***
5. Discuss the 3 options for organising HPN and ancillaries for your trip. Either take it from home, or freight it from Australia to your destination, or ask Baxter if one of their overseas branches can supply it. ***(Editor's note: Baxter no longer arrange for ancillaries to be supplied overseas – ancillaries need to be freighted from home or carried with you)***
6. If an overseas homecare company is to supply your PN, you will need to find a prescriber in that country. I suggest you ask your treating doctors, Baxter and PNDU members if they have contacts overseas. If having PN and ancillaries freighted to your destination, then find out from the freight company if you need to be in the country when the delivery is made (essential in some countries).
7. Book hotels willing to accept deliveries of medical supplies on your behalf. You will need the name of a hotel representative for the freight company. Make sure the hotels can guarantee access to a refrigerator for medications.
8. If freighting HPN and ancillaries from Australia, then the HPN will need to be labelled, the boxes will need to contain a copy of the prescription, and a letter outlining the reason for freighting the items and name the accepting hotel person.
9. Complete medical clearance forms for all airlines, tour and cruise companies. Make sure your need for special assistance is included in your bookings. Be warned that even if this is requested well in advance, it may not eventuate and you may be left to cope on your own.
10. Have a letter for the airlines stating what you are carrying with you and why.
11. Have letters from all your treating doctors with instructions on how to care for you should you become unwell.

12. Have emergency plans – register with DFAT (*Department of Foreign Affairs and Trade)*, have the contact details for embassies and the tertiary hospitals at your destinations. Know where your international airports are. If possible, have a doctor at your destination who is aware that you are travelling and would be prepared to assist you if you become unwell.
13. Take out travel insurance – shop around as some insurance companies may be willing to cover pre-existing medical conditions for an extra fee.
14. Have a medical folder with you containing all of your documentation (plastic pockets and easy access).
15. Take adequate medication. Consider travelling with a port lock, IV antibiotics, anti-emetics, and a thrombolytic. ***(Editor's note: this is something to discuss with your HPN doctor)***
16. Always have at least 2 PN bags with you and enough ancillaries.
17. Pump – take an extended life battery and disposable batteries. Extra batteries need to be pre-approved with the airline. Perhaps an extra pump. Take your lines from home.
18. Take chlorhexidine swabs for the plane.

I have come to realise that almost anything is possible with life on HPN - you just have to be able to think outside the square to find a different way of doing things.

Coping with School

Editor's Note: Having commenced school, we learn how three of our HPNers are coping – Jordan (NSW), Sam (North Island, NZ) and Emily (NSW)

Jordan

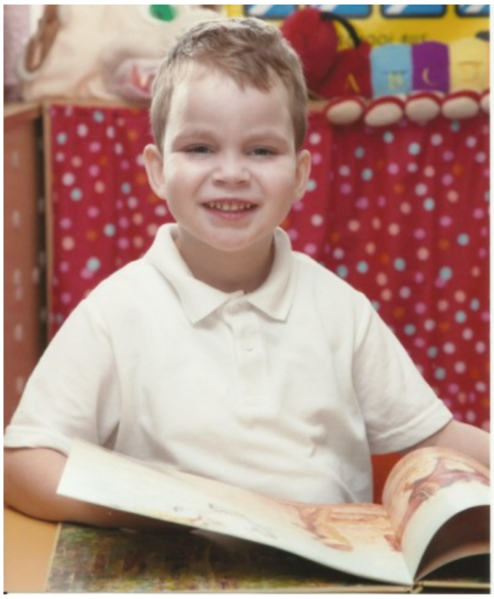
WORDS BY *CHRIS AND BROOKE*

School started slowly for Jordan. Attending for only 2 hours each day for the first 2 weeks, we increased Jordan's attendance by 2 hours each fortnight until he finally attended for the full 6 hour day.

The transition to school has been both exciting and very tiring for Jordan. Adapting to the classroom has been made so much easier for Jordan, with the amazing help of the school learning support officer, who stays with Jordan throughout his entire school day. A dedicated bathroom has been fitted out with an electric change table and 2 support staff have been trained in Jordan's care needs while at school.

Jordan is integrating well with the other children and has made many new friends. He says his favourite things at school are playing games, painting and story books.

Jordan finished his first term with the Easter Hat Parade- meeting the Easter Bunny and leading his class from the assembly hall were highlights of his day.



Jordan

Left: Jordan (HPNer)

Right: Jordan with brother Dylan at the Easter Hat Parade

Sam

WORDS – SUMMARISED BY *GILLIAN* FROM *SHIRLEY'S BLOG*

Each day Sam wakes squealing with delight, wondering what letter they will do at school today, or because it's library day. Because of the hard work of the people [involved in caring for Sam, both at home and at school] it hasn't felt like a transition - he just woke up one day and ran into school and hasn't looked back. There were discussions on various ways we can help him get physically stronger through specific exercises and how we need to create times of quiet for him, as he is so desperately social, but he gets exhausted trying to keep up and not miss out on a thing.

After school, Sam is so excited to tell me they had done the letter F today and then sings the little ditty that goes with it.

Since school started, it hasn't been plain sailing - he has had 3 hospital admissions. But with the support of Starship (Children's Hospital in Auckland) and the community nurses, we are managing to mostly keep him at home and having daily IV antibiotic infusions.

I am constantly amazed at the patience and skills the teachers and teacher aides have - I truly admire anyone that sets foot in front of 20 little individuals and seeks to inspire and herd them for 5 hours.... phewf, tired just thinking about it!

Sam 'eating' his lunch

Emily (story next page)

Emily

WORDS BY *MEL*

Emily is settling in well and loving school. She gets quite tired though, and often needs to be picked up early for some extra rest at home. We have increased her infusion volume and time to 14 hours to help her body cope with the extra demands of school. Emily has three lovely aides who are with her always at school. Their main role is to observe her for any changes that may indicate an infection or similar issue. They are also responsible for making sure she is safe at all times and that no rough or dangerous play may harm her, her central line or her colostomy. A disabled bathroom has been designated for Emily and her carer has the only key. Colostomy supplies, spare changes of clothes etc are kept in there. As they get to know Emily more, they will be able to just observe any changes, but for now, her temperature is also taken daily at school.

It took a while for the teachers to see that most of the time she is just a normal kid and to give her the same access to activities, such as play at lunch time and sport, as the other children. They have also had to step up to the plate and ensure their staff have not only their generic department training, but training specific to Emily. This has taken quite a lot of time and convincing. We are now having fortnightly meetings with all staff involved and district governance officers to ensure the school is providing a safe environment for Emily.

Aluminum Accumulation in the Bones of Patients on Long-term PN

Pamela C. Kruger, PhD; Patrick J. Parsons, PhD, FRSC; Aubrey L. Galusha; Michelle Morrissette; Robert R. Recker, MD; Lyn J. Howard, BM, FRCP

The purpose of parenteral nutrition (PN) formulations is to provide a healthy diet for patients who are unable to process or absorb nutrients through their gastrointestinal tract. But while health care providers are trying to formulate a perfect balance of necessary components, what other ingredients, or contaminants, are slipping into these solutions? We do know that aluminum (Al) contamination of PN formulations is widespread and variable. Since Al is the most abundant metal, making up 8 percent of Earth's crust, human exposure is inevitable. Al is present in the food we eat, the water we drink, and the air we breathe. Normal gastrointestinal function keeps absorption of Al into our bloodstream at a minimum (less than 1 percent of ingested Al gets absorbed), and healthy kidneys help our bodies remove any Al that has been absorbed into the bloodstream.

However, patients supported on PN, which bypasses the gastrointestinal barrier, are at risk for acquiring a significant amount of Al in their tissue. Patients with renal impairment will be less able to excrete Al, and may be at risk for Al buildup. Most Al exposure in PN patients comes from contamination of the ingredients that make up PN solutions, and further contamination occurs when these ingredients are stored in glass containers, since over time, Al leaches out of glass.

Early Sources of Al Contamination

Accumulation of high levels of Al in the body can adversely affect bone, brain, and other organs. However, Al accumulates mostly in bone, and its toxicity usually appears in bone first. Too much Al in the bone reduces bone density and can lead to bone fractures.

In the 1960s, patients receiving PN for several months complained of bone pain, and some developed osteomalacia and other bone-related disorders. Shortly before these PN issues arose, similar problems were reported in patients receiving hemodialysis for renal failure. In the case of dialysis, the water used to prepare the dialysate solutions was identified as the source of Al contamination. So, when PN patients began to exhibit the same problems, Al was the prime suspect. PN solutions were tested, and Al contamination was found. Most of the contamination was traced to hydrolyzed proteins, used early on as a source of amino acids. Later, when synthetic crystalline amino acid solutions were developed, the Al contamination dropped remarkably. Subsequent studies reported improvements in bone formation rates in PN patients receiving crystalline amino acids rather than hydrolyzed proteins. It was thought that the Al problem had gone away!

However, investigations of Al levels in the bones of infants, and neurological function in neonates receiving PN, revealed that exposure via PN solutions remains, despite the discontinued use of hydrolyzed proteins. Concern shifted from Al contamination in large volume parenterals (LVPs) to contamination in small volume parenterals (SVPs), especially those sterilized and stored in glass containers. Glass contains Al that can leach into the stored solution. (LVPs are the PN components that are added in large amounts, such as dextrose, amino acids, and IV fats; SVPs are the components that are added in small amounts, such as electrolytes and micronutrients.)

Measuring Al in Bone

We became very aware that infants are especially vulnerable to the toxic effects of Al due to their underdeveloped bone, brain, and other organs, and several studies have been conducted on Al toxicity in infants. Our next question was whether adults who have been on PN long-term might also remain at risk for Al toxicity. To answer this question, we measured the Al content in autopsy bones of seven long-term adult PN patients, who had never received hydrolyzed proteins. These patients were enrolled in the Albany Medical College home PN program in Albany, NY, and had been cared for through this program the entire time they were on home PN, which spanned from two to twenty-one years. None of the patients had symptoms of excessive Al exposure, such as bone fractures or bone pain. Three of the seven patients developed some degree of renal failure toward the end of their lives; this could be an additional factor affecting Al toxicity.

The Al content in hip or knee bones from eighteen patients who had undergone hip or knee replacement surgery was also measured. These patients did not have gastrointestinal or renal problems and were not on PN. Their bones provided us with a control group for our study.

The average Al content of the control patient bones was 2.6 ± 1.8 µg/g, while the average Al content in long-term adult PN patient bones was 32.0 ± 18.7 µg/g. Thus, PN patient bones had on average about ten times more Al than control patient bones. The levels of Al in each of the seven long-term PN patients are shown as blue and red bars in Figure 2. The red bar indicates the PN patients who developed renal failure at the end of their lives. These patients had even greater Al accumulation in their bones; the difference between the Al content found in their bones was statistically significant from the amount of Al found in the rest of the PN patient bones. Al levels in the non-PN control group are shown as the green bar. One PN patient's bone Al level was only slightly higher than the control patient average, but that patient had only received PN treatment for two years before death.

The results indicate that Al exposure through contamination of PN solutions is highly significant for long-term PN patients, and especially for those with kidney impairment (up to twenty times greater). These results support the earlier studies of infants, demonstrating that Al contamination is still a problem for adult PN patients. However, the problem is now in the SVPs rather than the LVPs.

Monitoring Al Levels in the Body

In 2004, following recommendations from the American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.), the U.S. Food and Drug Administration (FDA) mandated that LVPs should contain no more than 25 micrograms of Al per liter (µg/L). The FDA also required SVPs to be labeled with the maximum amount of Al that may be present at the expiration of the solution (due to Al leaching from the container). Manufacturers must also provide a warning label, disclosing that toxicity may result if more than 5 micrograms of Al per kilogram body weight per day (µg/kg/d) are infused. Currently, there are no restrictions on Al content in SVPs. [Gil's note. There are currently no Australasian regulations controlling Al content in either PN LVPs or SVPs]

Monitoring and reducing Al accumulation in the body and preventing Al exposure remain important issues for long-term PN patients. While monitoring bone Al provides the most reliable assessment of Al accumulation in the body, obtaining serial bone biopsies from PN patients is not feasible. Further, few laboratories are capable of accurately measuring bone Al content from biopsies. Measuring Al in blood serum may be a viable option. Serum Al measurements can provide some information about the amount of Al circulating in the body. Researchers are working on an assessment tool that is similar to tests used for measuring bone density. This may allow us, in the future, to recognize patients who are getting into trouble with Al levels and to modify their PN solution accordingly.

A new study is being considered, in collaboration with Albany Medical College, through which we may determine the best time to monitor serum Al levels (e.g., before, during, or after infusion, two days after infusion, etc.) to assess exposure. This knowledge might help health care providers monitor Al accumulation in patients more accurately.

Conclusion

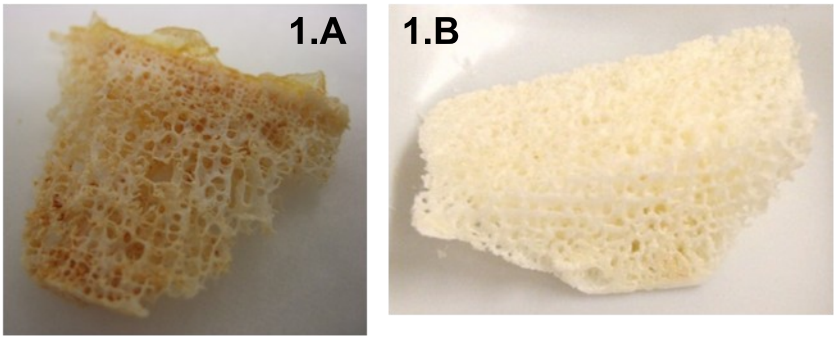
Considering viable techniques for reducing potential Al contamination in PN solutions is crucial. Research has shown that replacing certain SVPs with others containing less Al may significantly reduce contamination in formulations. However, it is imperative that any changes made are safe and effective for patients. Packaging SVPs in plastic containers, rather than in glass bottles, could reduce Al contamination. Additional studies of Al exposure and effects of Al accumulation in PN patients are needed to assist the FDA with further regulations restricting Al contamination.

Acknowledgements

"This article has been shortened for Dripline by Prof Gil Hardy from the original published in *LifelineLetter* (Mar/Apr 2015), with permission of the Oley Foundation and the authors."

The study was funded in part by the Oley Foundation, which acknowledges support from Baxter Healthcare. The tables and figures presented here have been reproduced with kind permission from the Journal of Parenteral and Enteral Nutrition (Kruger PC, Parsons PJ, Galusha AL, Morrissette M, Recker RR, Howard LJ. Excessive aluminum accumulation in the bones of patients on long-term parenteral nutrition: postmortem analysis by electrothermal atomic absorption spectrometry. JPEN 2014; 38(6):728-735).

Figure 1. *PN patient (A) and control patient (B) bone samples after cleanup. Note that the PN patient's bone appears less dense than the control patient's bone, and has a lacy appearance.*



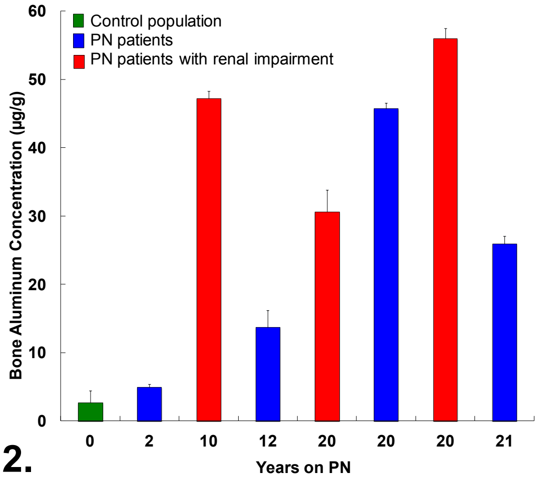


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Figure 2. *Bone Al (µg/g) as a function of years on PN.*
Red bar = control patient population (n=18);
Blue bar = individual PN patients.
Green bar = non PN controls
Error bars = standard deviations of two Al measurements for each sample.

PNDU Charity Cards

WORDS BY *KAREN*

As a way of raising awareness of and finances for PNDU, we have ordered 3 different designs of charity cards which, upon receipt and PNDU's registration as an association, will be available for purchase from our website www.pndu.org.

PNDU's logo and website will appear on the back of the card. There will be 1 Christmas card design as well as 2 blank card designs (shown here) for purchase in packs of 10.

We hope you will help support the great work PNDU does by buying the cards and sending them far and wide.

Nat's Amazing Pump Stand

WORDS BY *LYN, NAT'S MUM*

Editor's Note: *For problems which may be able to be solved by the TAD (Technical Aids for the Disabled), clients can self-refer, or if they are unsure, then it is usually helpful if they can have a therapist to assist with their written requests. See the end of Lyn's article for contact details.*

Nat now has multiple infusions running 24/7 which involve using 5 IV pumps. This created enormous difficulties to get around, as Nat wanted to be independent once up in her electric wheelchair, and not reliant on me standing beside her pushing a pole!

I called upon TAD - Technical Aids For the Disabled - as I have used their expertise many times. I'm not sure if they are only in NSW, but they have many volunteers who use their range of skills to help make 'unique' pieces of equipment. And you only pay for the volunteers 'out of pocket' expenses, eg materials, petrol to and from, but not labour.

We were very fortunate to have an amazing man who was a metal engineer. After several attempts and many trials of many configurations, he was able to weld a metal frame to attach to the back of Nat's chair so that she could independently go from place to place with all her lines attached. He then took it a step further by making a separate base so that if Nat wanted to lie down while in her chair, we could remove the frame and attach it to the base, so that she could rest if need be. Amazing work done by a very patient, ingenious and dedicated man.

TAD Australia Inc is the national federation of the disability charity, TAD across Australia. www.tadaustralia.org.au
Australia-wide Phone: 1300 663 243
Each state also has their individual contact details, eg NSW: tadnsw.org.au

Above - 5 IV pumps on bracket at back of wheel-chair – HPN runs 18hrs from 6pm till 12 midday. Below - Nat at Coogee beach

http://tadnsw.org.au/what-we-do/apply-now/guidelines-for-completing-a-custom-designed-equipment-project-application-form.pdf

http://tadnsw.org.au/what-we-do/apply-now/custom-designed-equipment-project-application-form.pdf

If any of our Kiwi members know of an organisation in New Zealand offering similar services, we'd love to hear about it and let others know. So please email us at contactpndu@gmail.com

Out and about with HPN etc.

Bracket removed from chair and attached to a moveable base.

Nat is now able to lie down while IVs still running

What do we do with our rubbish?

WORDS BY *GILLIAN*

One of our members on our Google Groups email chat forum posed the question: Just wondering what everyone does with all their packaging that HPN (Home Parenteral Nutrition) comes in? Below are some of the varied and often creative responses.

I usually collect a huge stack of it [silver insulation wrap] in the garage, then stick it on the verge with a sign and it goes pretty quickly.) I did try selling it at one point to try and make a few bucks, but it didn't work. I'm just happy it doesn't all go in landfill. **-** *Ryan*

I've found fishermen & children's sports clubs are pretty happy to take the ice packs. Boxes are a bit harder, as only so many people you know are moving, so it's usually recycling bin for those for us if we're not using them ourselves; but the silver wrap has always been the hardest thing to offload. Only so many robot, tin man and knight costumes can be made.- *Celena*

I too, find it hard to get rid of the silver wrap. The boxes I keep for some local farmers to sell their produce in and recycle the rest. - *Susan*

My friend takes the silver bubble wrap linings, as one of his friends used it to insulate under his house and now someone else is doing the same, as it's the same material used for underfloor insulation. - *Natalie*

I, also, give the silver linings away for insulation. My sister and brother-in-law have been renovating their very old house since forever and now they also have two sheds on the property, one of which is absolutely humongous, so more insulating required. That said, I think they must be stockpiling the insulation because I can’t see how they could use 8 years’ worth, even on a big old house and 2 sheds!? There have been various uses for the icebricks – horse-trainers was one, but I too have run out of avenues at the moment and they are currently being tossed in the bin, unfortunately. I have a stockpile of boxes ready for my next move, but there are only so many boxes you can use even for moving and I don’t know anyone else moving at the moment, so most are now going in the recycle bin. - *Karen*

With bubble wrap x 4, boxes x 4 and the ice packs x 12 each week, avenues run out as fast as you find a new one. Sometimes we have resembled the hoarders shown on TV, waiting for promised pick up. I give boxes and bubble wrap to a local engineering company because manufacturing machine shops love them for small machined parts. All boxes which we can’t give away, now go to a local company who have a cardboard compactor and are recycled. Lions club, Rotary and the senior citizens may be able to help. They will even collect them if they want them; it just takes a few phone calls. It’s a great chance to fly the PNDU flag also, with all 3 groups. - *Chris*

Sam’s HPN is delivered and made by Biomed in Auckland. We asked the Biomed delivery guy about recycling and every second day when he drops in new PN he takes away the previous box. I keep the polystyrene chill boxes and freezer blocks and then take them back to hospital when I’m next in. I asked the pharmacy, who sends out Sam’s scripts, and they are happy to recycle them. So I have been really pleased with how easy people have made it for us. I have a friend with [another medical problem] and he gets his supplies in big chill boxes - he kept them all and insulated under his house for free! - *Shirley*

I’ve found someone who regularly takes my bubble wrap to wrap his internet sales chocolates in. Every now and then I get requests for my chill packs, but mostly they get thrown (there’s only so many chill packs my friends/colleagues can use). Many times I’ve been able to supply friends and colleagues with the boxes when they are moving (and used many myself for this reason last year). Sadly, the rest of the time, they go into the recycle bin. I’ve found that my council now accepts all plastics in our recycle bin, so I try to recycle the plastic bits from the dressing packs which don’t come into contact with blood. - *Gillian*

The ice packs are made in Drouin, which is not very far from our home, and only a few kilometres out of our way when we are making one of our frequent trips to Melbourne. So, I squeeze test them, the toss out the leakers, and when I have about 5 Baxter boxes full (about 35 in each box) I take them back to the manufacturer. The previous supplier said they give them away to charities who come in and ask for them. No idea if they just sell them again as new ones, but at least they aren’t going to landfill. - *Graeme*

We give most supplies to the kids’ preschool! It's amazing what they make out of it! Everything from boxes, to sterile trays and tweezers!! They love it! - *Mel*

In Tasmania, we have tip shops, which are places where anyone can leave usable items, metal, netting (in fact almost anything) and are located at the rubbish dumps. I used to give my chill packs to various sporting clubs, scout and guide groups and schools, until they all said "NO MORE", so now the tip shop gets them. Sometimes the local thrift shop rings me and asks for some, so I take a box full to them. But the bubble wrap goes to work where we wrap all blood culture bottles that are sent to the lab. Also, one of my art groups takes them and we use it for felt making and painting. The local primary schools also like it. But the boxes go to the recycle. Just recently the chill packs have come in handy when our fridge and a friend's fridge broke down. - *Jacqueline*

Picture framers like the silver bubble wrap. - *Lynden*

My boxes go to a mission aid group at Kingsgrove, but that will finish in 2016. The bubble wrap goes to the local art group, which can’t get enough, to make bags to transport paintings. - *Jane*

My sister is off to a big music festival over Easter. She's collecting silver insulating paper to 1. Sew together and use as a groundsheet under the tent and 2. Use as disposable picnic blankets over at the stage area that can be thrown away when they don't need it anymore. - *Lara*

Rebates and Concessions in Australia

INFORMATION SOURCED BY *CHRIS*

Editor’s Note: *It was mentioned on our Google groups email chat forum that in NSW, people with pumps for HPN were able to apply for a small rebate on their electricity bill. The appropriate application form needs to be signed by your doctor, and re-submitted every few years. Chris was able to add the following information, which was correct, to his knowledge, at the time of writing. Some changes may have been made subsequently.*

I would like to add to information about available Rebates and Concessions [in Australia]. Some of these may help our members.

Low income earners, pensioners, as well as customers with certain medical conditions should be happy to know that there are various rebate and concession opportunities available for them in order to help them pay their energy bills. Depending on the state where you live, different rebates and concessions may be applicable to you. Your retailer may be able to provide information on government rebates or concession programs that apply to you, or you may check with your state or territory government agency if you are eligible for a rebate or concession.

The following is a list of different states and a summary of their rebates and concession programs:

New South Wales

The government has various rebated programs that offer to help consumers pay for New South Wales Utilities. The Low Income Household Rebate is for those consumers who have eligible concession cards that are provided by the Federal Department of Human Services, as well as the Department of Veterans Affairs; the Family Energy Rebate is for those who have received the Family Tax Benefit; meanwhile, the Life Support Rebate is for those who use certain medical equipment to sustain life; and lastly, the Medical Energy Rebate is for those eligible customers medically diagnosed to be unable to self-regulate body temperature when exposed to extreme environmental temperatures.

Victoria

The Department of Human Services in Victoria offers concessions and benefits to low-income Victorians. If you hold a relevant concession card, you may be available for any of their concession programs, which are as follows: Annual Electricity Concession; Winter Gas Concession; Service to Property Charge Concession; Non-Mains Energy Concession; Medical Cooling Concession; Controlled Load Electricity Concession, formerly known as the Off-Peak Electricity Concession; Life Support Concession; Electricity Transfer Fee Waiver; Excess Electricity Concession; and the Excess Gas Concession.

Queensland

In Queensland, pensioners and seniors may be eligible for the Electricity Rebate of $282.54 per year, as well as the Reticulated Natural Gas Rebate of $65.58 per year. All these rebates are GST inclusive. Rebates are offered to people who hold a Pensioner Concession Card, a Department of Veterans’ Affairs Gold Card and the Queensland Senior Card.

South Australia

A state government concession is made available to eligible South Australians who are on low or fixed incomes. Those who hold the following cards will be eligible: Pensioner Concession Card; Gold Card from DVA; Low Income Health Card; Commonwealth Seniors Health Care Card; State Concession Card. Aside from the current energy rebates, the Medical Heating and Cooling Concession is also available for those who have been clinically verified with a condition, which requires heating/cooling in the home to prevent the worsening of their condition.

Western Australia

The Western Australian government offers various subsidies and assistance to people in financial difficulty, provided they hold concession cards, to pay their utility bills. Caravan park residents may apply for concession cards and be eligible for the State Government Energy Rebate, Dependent Child Rebate and Air Conditioning Rebate. Medical subsidies are also available such as the Life Support Equipment Electricity Subsidy and the Thermoregulatory Dysfunction Subsidy Scheme.

Tasmania

Tasmanians may avail themselves of various discounts and concessions provided they hold the appropriate concession cards for the Annual Electricity Concession. Life Support Concession, as well as the Medical Cooling Concession could also be applied for by those who have or live with someone suffering from related medical conditions.

Northern Territory

The Northern Territory Pensioner and Carer Concession Scheme offers subsidies to eligible members for a diverse number of necessities such as electricity, water, sewerage, council rates, garbage rates, spectacles, motor vehicle registration, urban public bus travel and driver's license renewals. Meanwhile, an interstate or overseas travel subsidy is also available for women over 60; men over 65, totally and permanently incapacitated veterans, as well as aged war service veterans.

Australian Capital Territory

The ACT government has an Energy Concession program, which covers both electricity and gas. It provides a maximum amount of $292.82 annual rebate. However, the Utility Concession provides an additional $82 to those who have eligible concession cards in order to minimise the cost of living.

Source: https://utilities.com.au/utilities-articles/rebates-and-concessions/8789-rebates-and-concessions 28 April 2014

Dry mouth

Editor's Note: *There was a brief discussion on PNDU's Google Groups email chat forum and a few ideas were shared for people suffering from a dry mouth. I thought they were worthwhile sharing with you, although naturally you need to discuss with your doctor/hospital medical team if you have dry mouth symptoms (due to dehydration or other causes) and to ascertain whether any of these ideas are suitable for you. The discussion was sparked by this question:*

'Who gets dry mouth? I read that it is caused from PN- is this true?'

Replies:

I don't use a mouth wash but a spray-it's called Hamilton AQUAE, dry mouth spray. Another thing to try is what they suggest to chemo patients......frozen pineapple pieces to suck...this is very refreshing.

I'm always drinking water – always have a glass or water bottle with me. At night, I sometimes wake up with a very dry mouth, but this has only been happening over the last few months, and I've been on HPN for over 8 years now.

Dry mouth...since I have been on PN I always get very dry and thirsty, particularly at night. I always have a glass of fluid next to my bed and drink every time I get up to go to the loo (which is frequently!!).

As many of you know, I drink very little water but at least 1.5 litres of St Mark's solution per day, on top of PN, which helps with hydration.

NB. The formula for St Mark's Solution, and further information on the sometimes related topic of dehydration, can be found in Issue 3 of Dripline, in the article 'Oral Rehydration Issues'.

Family Holiday

WORDS BY *MIRANDA*

Drunk on stories of jaunts abroad from fellow HPNers, we knew that there would no better travel opportunity to cut our teeth on, than attending the PNDU symposium in Auckland in November 2014, followed by a family holiday in Lake Hawea, South Island. It would be the first-ever holiday plane trip with Ariel, our 4yr old daughter who is reliant on daily HPN and also continuously pump fed.

Anxious about this daunting holiday plan, we erred on the side of caution in everything in our preparation.

We started the planning in August, armed with a draft version of the soon to be published PNDU Travel Information Booklet (a thorough and useful resource!), the Oley travel kit and the helpful advice of Karen and other experienced HPN travellers. Our hospital team was our first point of call to establish contact with physicians and providers overseas, then we worked on the airline medical clearance and insurance arrangements. We found the paperwork to be fairly uncomplicated and that while most people we encountered were unfamiliar with HPN, they were eager to help make our trip possible. We finalised the travel paperwork in much shorter time that we had anticipated.

Then it came down to the laborious task of packing. Oh my! We prepared several excel packing lists to work out how much and how to carry our medical equipment and consumables.

We carried 3 days' supplies of everything in-cabin in case of lost baggage. Our packing included 36 large cans of liquid formula plus several PN bags (requiring cold storage transport) and emergency glucose bags.

With seven in our party, being a 2 year old, a 4 year old, two frightened parents, two grandparents and our trusty German au pair, our party zipped up 10 large suitcases plus 10 pieces of hand luggage, a stroller and a coolbox - not exactly travelling light. We had arranged to be taken to the airport in style and chuckled all the way- in a minibus towing a trailer!

The most difficult parts of our plane travel were not the parts that we had anticipated. Airport security and customs ushered us to the express counters and then waved us past with a cursory check on our baggage and documents (carefully laminated and looking so formal!).

Instead, in the end, the most challenging aspects were keeping the kids entertained in the normal tedium of waiting for flights (the bubble mixture had spilled and interest in the iPad waned, to be replaced by a hell-bent desire to run and squeal wildly), and the physical difficulty of travelling with so many pieces of luggage. We became champions at car boot suitcase Tetris, a skill most parents develop over time.

Once we arrived at our destination, all the stress of the travelling was forgotten. We had a very busy and interesting few days at the PNDU Symposium and with great pleasure, got to meet some of our NZ HPN friends face to face.


Ariel

Adapting our PN setup procedures for new environments was unproblematic and the delivery of Ariel’s PN bags was, on the whole, smooth.

Once the Auckland Symposium finished we flew down to South Island where we lazed, feasted, hiked, rode bikes and swam in the stunningly beautiful places around Lake Hawea and generally had a tremendous holiday.

With the benefit of this first and great experience, we feel optimistic about future overseas holidays with Ariel and recognise the additional medical-related arrangements to be just another part of preparing for a family holiday. Ariel likes to recall stories from our NZ holiday still and we look forward to creating more holiday tales for her to tell.


David with Ariel (HPNer), Miranda with Eadie

Past HPN Practice

WORDS BY *A MEMBER*

Editor’s note: *We received this post on our Google groups email chat forum, which I thought would be of interest to the majority of our members, to see how procedures have changed over the last quarter of a century.*

I have been on HPN (Home Parenteral Nutrition) for over 25 years. There have been lots of changes over the years to setting up techniques. In 1978 it was wearing a sterile gown and mask, sterile gloves, sterile trolley and dressing pack and everything was opened onto that pack with extreme care. Everything was dosed or 'flooded' with betadine, then alcohol. This happened for every little interaction with any CVL (Central Venous Line).

It varied in late 1980's-1990's from the same as above for dressings and complete line changes (lines were only changed every two days); to clean ward gowns and sterile gloves and dressing pack. We still used Betadine AND chlorhexidine, until a study showed fungal growth in Betadine, so then we used just chlorhexidine.

A.S.P.E.N. Clinical Guidelines:

Support of Pediatric Patients With Intestinal Failure at Risk of Parenteral Nutrition–Associated Liver Disease (PNALD)

Paul W. Wales, Nancy Allen, Patricia Worthington, Donald George, Charlene Compher and Daniel Teitelbaum for ASPEN *JPEN 2014:38;538-557*

Background

Children with severe intestinal failure and prolonged dependence on parenteral nutrition are susceptible to the development of parenteral nutrition–associated liver disease (PNALD). The purpose of this clinical guideline is to develop recommendations for the care of children with PN-dependent intestinal failure that have the potential to prevent PNALD or improve its treatment.

Method

A systematic review of the best available evidence to answer a series of questions regarding clinical management of children with intestinal failure receiving parenteral or enteral nutrition was undertaken and evaluated using concepts adopted from the 'Grading of Recommendations, Assessment, Development, and Evaluation' (GRADE) Working Group. A consensus process was used to develop the clinical guideline recommendations prior to external and internal review and approval by the ASPEN Board of Directors.

Questions

1. Is ethanol lock effective in preventing bloodstream infection and catheter removal in children at risk of PNALD?

Recommendation: A suggestion is made to use ethanol lock to prevent CLABSI and to reduce catheter replacements in children at risk of PNALD.

Evidence: Low and very low

Recommendation Grade: Weak

Rationale: The evidence for decreased Central Line-Associated Bloodstream Infection (CLABSI) and catheter removal is low. The desirable effect of both decreased infection and catheter removal has to be interpreted in light of the unknown effects of increased thrombus formation and disruption of catheter structure integrity. No recommendation can be made regarding the risk of catheter thrombosis due to ethanol lock therapy secondary to small sample sizes in observational studies, variable days of lock therapy, broad differences in observation time, and lack of clarity about the procedure with regard to ethanol concentration and withdrawal vs instillation of the ethanol solution after the dwell time.

Research is needed to define more clearly the most effective concentration of ethanol in the lock, the number of days per week and the optimum duration of instillation of flush, and whether the best practice is flushing the ethanol through the catheter or withdrawing it after the instillation time.

2. What fat emulsion strategies can be used in pediatric patients with intestinal failure to reduce the risk of or treat PNALD?

Soybean Oil Emulsion (SOE) [Intralipid],

Recommendation: Since the only IV fat emulsion available for use in the United States is SOE a suggestion is made to reduce the dose to ≤1 g/kg/d to treat cholestasis in children with PNALD. The quality of evidence supporting this recommendation is very low. Higher doses of SOE have been associated with cholestasis, at increasing prevalence rates with longer duration of SOE therapy. Several studies prospectively, in a nonrandomized fashion, have demonstrated that reduction in the amount of SOE results in decreased severity or incidence of PNALD. The desirable effect of reduction of liver indices has to be considered in light of the unknown effects of poor growth and development when lipids are restricted.

Evidence: Very Low

Recommendation Grade: Weak

Fish Oil Emulsion (FOE)

Until FOE is approved by the U.S. Food and Drug Administration (FDA), no recommendation can be made for use in the United States. The evidence supporting the use of FOE is very low quality. Included studies are small observational studies that are confounded by concurrent lipid dose reduction and advancement of enteral feedings.

Evidence: Further research needed

Recommendation: No recommendation

Soy oil, medium-chain triglycerides, olive oil, and fish oil (SMOF)

SMOF is not available in the United States. Until it is approved for use, no recommendation can be made for use in the United States. If available, the evidence supporting the use of SMOF for the treatment of cholestasis is very low quality. The studies are primarily safety and efficacy studies in preterm infants with the primary outcome of plasma phospholipid profiles and adverse events.

Evidence: Further research needed

Recommendation: No recommendation

Rationale: The available studies evaluating SMOF are limited by evaluation of cholestasis as a secondary outcome, small sample size, short observation time, and studies in premature patients rather than patients with longer term PN-dependent intestinal failure. The French study by Goulet et al was high quality, but only 28 children were studied, with 13 and 15 children in each group. While bilirubin levels were not the primary measure, these values declined significantly more in the SMOF group than in the SOE group over 29 days.

The focus of future trials, therefore, should be on PNALD prevention with short-term hepatic and longer term growth and developmental outcomes. Obstacles to progress include no standard definition of PNALD,

3. Can enteral ursodeoxycholic acid (UDCA) improve the treatment of PNALD in pediatric patients with intestinal failure?

Recommendation: A suggestion is made to use UDCA for the treatment of elevated liver enzymes in children with PNALD. The evidence is of very low quality and confounded with the presence of enteral feeding in conjunction with treatment with UDCA. In addition, the patients studied tend to be premature infants with an intact intestinal tract; therefore, the efficacy of UDCA may not be generalizable to patients with established intestinal failure. In the included studies, no harm from this treatment was reported. The desirable effect of the reduction of liver indices has to be weighed against the unknown efficacy of the treatment and the fact that in most cases, the study participants did not have primary intestinal pathology.

Evidence: Very low

Recommendation: Weak

Rationale: Four studies were reviewed for the treatment of PNALD, defined as elevated total or conjugated bilirubin with UDCA but most children had not had intestinal resections and thus were not at risk for the consequences of the interruption of the enterohepatic circulation of bile acids. Patients with established intestinal failure of any etiology may not tolerate or absorb UDCA, and the proposed treatment benefits of UDCA from these other children may not translate to the intestinal failure population.

Research is needed about dose, timing, duration of therapy, and long-term outcomes in patients with PN-dependent intestinal failure.

4. Are PNALD outcomes improved when patients are managed by a multidisciplinary intestinal rehabilitation team?

Recommendation: A suggestion is made to refer patients with PN-dependent intestinal failure to multidisciplinary intestinal rehabilitation programs. The evidence on this topic is of very low quality, but the improvement in survival is compelling, and the risk to the child of treatment with multidisciplinary practice is not increased.

Evidence: Very low

Recommendation: Weak

Rationale: The data supporting this recommendation are based on comparisons of clinical outcomes after the establishment of multidisciplinary intestinal rehabilitation programs relative to historical controls. In a meta-analysis by Stanger et al, the relative risk of survival from intestinal failure favored the post-multidisciplinary team practice.

The literature would be improved if investigators could reach consensus on definitions of specific outcomes such as short bowel syndrome/intestinal failure, cholestasis, liver failure, sepsis, and PN independence.

A number of related questions remain to be answered. What characteristics of nutrition supportive care employed by these programs are associated with improved clinical outcomes?

Can key practice protocols derived from these groups be translated broadly to improve the care of children who are not able to access a multidisciplinary program? What is the prevalence of other chronic health concerns, such as metabolic bone disease, in long-term survivors of intestinal failure? Now that mortality risk has diminished with establishment of intestinal rehabilitation programs, future research should address the impact of other comorbidities on outcome, long-term neurodevelopmental outcomes, quality of life of patients receiving chronic PN and after intestinal transplantation, and economic evaluation of intestinal rehabilitation programs.

Summarised for Dripline by Prof Gil Hardy who comments: *These guidelines, based on a thorough evaluation of the available medical literature, demonstrate the lack of good quality studies a) in intestinal failure, b) long term PN c) in* *paediatrics and d) with the newer fish oil-containing lipid emulsions, especially in the USA. Nevertheless, these are the best and most recently published guidelines available. There are no similar published guidelines from Australasia or Europe.*

The Full Paper with 9 Tables and 71 References is published in JPEN 2014:38;538-557 and is available from PNDU on request.

A Day in the Life of an HPNer

WORDS BY *GILLIAN*

Several years ago in the winter school holidays, Ray and I took our caravan for a few nights' break to a lovely caravan park at Merimbula. Our en-suite site had fabulous views overlooking the water, as well as being in a lovely part of NSW to explore.

Unfortunately, the weather was very cold, and I just couldn't seem to get warm. During the days it wasn't so bad, as we'd drive somewhere and go for a walk and the activity seemed to help. However, at nights, trying to sleep, I needed our electric blanket on, with two extra woollen blankets, plus my warm winter dressing gown as well. It's very difficult to get a good night's sleep when you can't get warm enough.

It wasn't until I was home in my own warm house and bed that the truth hit me…I had a line infection! It was, in fact, the fourth line infection that I'd had since beginning HPN (for the first 5 years I seemed to average one a year – my statistics have improved over the last two years), so I was foolish not to recognise the symptoms; it was the coincidence of it happening just as I was on holidays, in winter, in a caravan, that must have blinded Ray and me to that possibility. When I was home, it was obvious that the inability to get warm and the shivering (rigor) pointed to infection. When I realised that, I took my temperature, and sure enough, it was high.

Naturally, this discovery happened on a Sunday night, which meant that my hospital team wasn't there to alert them. If they had been there, they would have let the triage nurse in emergency know to expect me, and to call them when I arrived. I went to the emergency department (ED), explained the situation, and was seen fairly quickly. However, the doctor in charge who makes the final decision as to whether to admit or not, decided that without evidence of a 'bug' he wouldn't admit me and commence the usual protocols which my hospital uses to disinfect a line. I was sent home, quite annoyed, as I knew I'd be back soon. I was right – four days later the symptoms returned during the day at school where I work, and this time I could contact my team. They told me to come straight in, I was admitted quickly and decontamination began.

Lesson learnt? To ***always*** take a copy of my hospital's own central line decontamination protocols along with me to emergency – it has the hospital's Intensive Care Department's own logo on the top of the page. This has worked in one or two subsequent occasions when an infection strikes on a weekend. Other HPNers have different letters, but basically a letter from your hospital team addressed to any Emergency Department with information about your central line, the seriousness/risk of a central line infection and instructions on what to do. A couple of other ideas to assist the ED experience, whether on holidays or at home:

- have your own details, including your doctor details, emergency contact details, medical conditions, major surgeries, medications, a copy of your PN prescription and latest blood tests all in a document or on a USB stick, carried with you at all times. Oley Foundation has a pro-forma for this: "Packet for Travel and Hospital Admissions" in the Resources section of their website www.oley.org or you can email us at contactpndu@gmail.com for a copy.
- take with you a record of your temperature readings in the lead-up to your arrival at ED. This will hopefully assist staff to understand what's been happening. And it goes without saying, to always have a thermometer with you when you go away.

Ray and I returned to the same caravan park earlier this month and had a wonderful time in this lovely coastal town.

Get-Togethers

Editor's Note: *There have been several PNDU member get-togethers over the past few months, official, and privately organised. Find out more.*

PNDU Easter Get Together in Auckland

WORDS BY *GIL*

On a beautiful sunny Maunday Thursday afternoon, seven PNDU members gathered together at Gil's house in Auckland. As Aucklanders, Lisa and her mum, Anne are regular visitors to Devonport and had cheerfully ventured across the harbour bridge, in the heavy pre-Easter traffic to be the first to arrive, bearing calorific sweetmeats for their host.

They were later joined by Sharron and Barry, relatively new members of PNDU, who we had first met at the HPN workshops in November 2014. The Walkers had travelled over 1500 km from the old gold mining town of Alexandra, in the South Island, reputedly known as the richest, hottest, driest and coldest place in New Zealand! They had first stopped off at their daughter's in Hamilton for sustenance and to restock with PN supplies before venturing further north into stranger foreign parts. They successfully negotiated customs and immigration controls to enter the independent republic of Devonport on the warm and sunny north shore of JAFAland.

Finally, two even more intrepid travellers, Jacqueline and David in their trusted campervan, with a delicious apple crumble cake, also found us in time for afternoon tea. Their journey, of over 2400km, from Hobart, Tasmania had been uneventful, and, apart from one or two courier hiccups, delivery of Jacqueline's PN bags and accessories from Baxter NZ had preceded their arrival in Devonport.

During the afternoon, there was lively discussion with exchange of experiences, especially between Jacqueline, Lisa, and Sharron, about HPN regimens, pumps, accessories and trolley adaptations. Baxter was also complimented on the excellent overall PN delivery service in NZ. The annoying Aussie pastime of sledging and beating the Kiwis at cricket was not discussed.

Barry being also a collector of old things (not me of course, Sharron was heard to mutter with a smile), examined some of the antique scales and balances, belonging to Gil, who was able to demonstrate that, despite rumours to the contrary, he does at least have one scruple (see pic)!

With the obligatory group photographs taken (group pic), the visitors began leaving. Jacqueline was then able to hook up with her Kiwi HPN, while Gil and David loaded the campervan with her two weeks supplies. Hopefully everyone again successfully battled the Auckland holiday traffic to all points North and South. All in all, a very enjoyable get-together - despite the fact that the cakes, hot cross buns and sweeties were left behind to further enlarge Gil's waistline.

David and Jacqueline (HPNer) from Tassie, Lisa (HPNer) and her mum Anne from Auckland and Sharron (HPNer) and husband Barry (standing on right) from South Island NZ

Gil's Scruple

PNDU friendships

WORDS BY *KAREN*

I'm not sure what it is about those living with HPN, but they all seem to be such lovely people! One of the things I like most about being part of PNDU is getting to know these wonderful people and the treasured friendships that have resulted. I feel very blessed.

Sometimes these friendships develop over the internet, others over the phone. And from time to time, some of us are able to meet up in person. These opportunities are very special and I thoroughly enjoy time spent with PNDU members.

In February this year I was blessed to stay with PNDU members Renee and Mervyn (and their very loved kelpie, Alex) on the beautiful NSW south coast for 3 nights. I'd briefly visited the general vicinity some 30 years ago, but really couldn't remember it. What a stunning part of Australia!! It really is a slice of paradise! Renee and Mervyn couldn't have been more generous hosts and it was a really fun, relaxing and enjoyable few days together. We visited a few of the beautiful beaches, caught up with some of their friends, ate out on the local café strip, and took in a movie at the very quaint local independent cinema. And as I'm sure you can guess – there was loads of chatting, laughing, sharing!

One of the lovely benefits of staying with another HPNer is that you know they understand your needs! There is no apprehension about being able to do HPN set-up and disconnection in a suitable environment; or that your PN is going to be received and stored suitably! And of course, holiday PN delivery is a breeze for Baxter when it's going to an existing HPNer's residence!

Thanks so much for the great holiday Renee, Mervyn and Alex – it really was a relaxing and enjoyable time and I look forward to visiting your little corner of paradise again.

Sydney Get Together

WORDS BY *GILLIAN*

Sunday 8th March saw 6 six of us gathering at Miranda and Dave's beautiful house in Randwick. With a central location and a child-friendly back yard, it was a great place to meet. Unfortunately, a few regulars couldn't make it, but it was great that Fay and Lindsay from the Lake Macquarie area were able to join us. Dave and Miranda provided us with a delicious selection of food for lunch, and together with food that others brought, we were spoilt for choice. Rather ironic for a group where half the members are dependent on HPN for nutrition and either don't eat at all, or only small amounts!

One of the culinary delights on offer was a platter of crumbed cauliflower and dip. It was so popular that I thought as something different, I would include Miranda's recipe.

Crispy Cauliflower

Ingredients

- 1 smallish head of cauliflower, trimmed, cored and cut into florets
- 3 eggs
- 1 cup panko breadcrumbs (you can buy there Japanese style crumbs at big supermarkets or at an Asian grocery store)
- 1 cup finely grated pecorino or parmesan cheese
- oil for drizzling

Directions

Preheat oven to 200C and line a baking sheet with baking paper. Drizzle the baking paper with a little oil. Place the eggs in a bowl and beat. In another bowl, mix the breadcrumbs and cheese. Dip each floret into the egg making sure to coat it (the crumbs won't stick at all otherwise). Then roll in the crumb dip and place on the prepared tray. Drizzle lightly with some more oil. Bake for 20 minutes until golden. Turn over and bake, adding a little extra oil if needed. Serve with aioli or Ranch sauce.

Crispy Cauliflower and Ranch sauce

"Ranch" Sauce

Ingredients

- 6 tbs mayonnaise
- 1tsp sweet chilli sauce
- 1tsp Dijon mustard
- ¼ tsp paprika
- Salt and pepper
- 1 tbsp chopped chives
- Mix all the ingredients together…..voila!

Back: Lindsay, Fay, Miranda, Ray, Jane.
Front: Gillian, Karen, Eadie, Dave with Ariel

Tasmanian Get Together

WORDS BY *JACQUELINE*

31st January 2015 saw Gil Hardy in Tasmania with some friends of his and that was the catalyst for the Tasmanian PNDU members to have a get-together. It was really the first official get together, although David and I had travelled to the north of the island last year and met up with Ann.

In true Tasmanian summer style, the rain gods took control and brought with them low lying clouds and persistent rain, but our chosen venue, the Royal Tasmanian Botanical Gardens, has a cafe so the gods didn't beat us. Emma came along and was joined by myself and my husband David and of course, our special guest Gil.

It was the first time Emma and Gil had met in person so there was a lot of catching up to do. We talked for two hours on a range of topics, including our own personal stories and our social interests.

The time went quickly and it was 4 o'clock before we knew it. Because the cafe closes at 4pm and the rain hadn't given up and gone away, we decided to take a slow walk out to our cars and say goodbye.

Unfortunately, there were a few others members who were unable to join us, but we're hoping they'll be able to next time. The plan for our next Tasmanian gathering is to hold it about half way up the island to hopefully enable more people to attend.

Gil, presenting Jacqueline with her Lifetime Membership Award, and Emma

David, Emma (HPN), Jacqueline (HPN) and Gil

Birthday Corner

WORDS BY *MEL*

Thank you so much everyone for Emily's birthday wishes! Emily had a wonderful party on the weekend, complete with a fabulous magician! Today she has gone off to school complete with flower cupcakes! I can't believe my baby is 6!!! Take that mid-gut volvulous!! And thank you Lord for Amazing HPN!!!

Logan (HPNer), Jordan (HPNer) and Dylan

WORDS BY *CHRIS*

Logan had a great 3rd birthday. The day started early with the excitement of the Easter Bunny- an assortment of chocolate eggs had mysteriously appeared overnight and older brother Dylan had everyone awake by 6:30am, to join in his “chocolate feast”.

By mid-morning, the Egg-citement gave way to the birthday celebrations. Three little friends, Aleisha, Chloe and Jayden arrived and transformed the lounge room into toyworld, six very excited children enjoyed playing together for several hours. Logan received new dinosaurs, trucks and tractors, but the hit of the day were the various Lego Duplo block sets, which even kept the adults entertained.

The weather was unkind and kept us confined to the house for the day; the planned BBQ menu was quickly changed to chicken, coleslaw and bread rolls as a few family and friends joined us for lunch. Logan enjoyed his Dinosaur birthday cake, baked by Auntie Katie. It was a great joy to see both Logan and Jordan eating cake and chocolate, even if it was only a bite or 2 of each.

Logan would like to thank all his friends from PNDU for the wonderful birthday card he received.

How much sleep do you need?

***Editor’s note:** The following are comments from our Google Groups email chat forum discussion about sleep. As people didn’t know their comments would be used, I have made it anonymous.*

“Both boys seem to sleep between 10-12 hours each night, when they are well. The 5 year old no longer has an afternoon nap, but the 2 year old has a power nap of about an hour each afternoon. If their sleep is disrupted or their activity level is higher than normal, they seem to tire early in the afternoon and require a nap.”

“My uncle was in his 40’s when on HPN and would sleep at least 10 hours each day, including an afternoon nap.”

“Some days I need an afternoon nap – those times I get into bed, sleep for about an hour or a bit more, then generally wake up refreshed. Sometimes I find getting to sleep that night takes a while, sometimes not. I find I get less tired when I’m able to regularly walk in the mornings. I go for half an hour, but maybe people could try a 10 or 15 min walk and see if that helps. I go in the morning before breakfast as a) I have the time, and I’m not as yet tired from the day, b) it’s not busy – I have the streets almost to myself, and c) it becomes routine and doesn’t get forgotten or swept aside in the busy-ness of the day. I have to get up half an hour earlier than I normally would, which takes will power.”

“As for sleep...I'm very lucky in a way...because my kidneys are not good, I don't have to get up to go to the toilet in the night. I do get a broken sleep though, as I have to take my blood sugar several times in the night and titrate the rate of PN, but don't actually have to get out of bed, which is great.”

“I need a large amount of sleep, usually 10-12hrs, especially if I've worked.”

“Sleep....I do get pretty tired and need about eight hours a night, preferably with a sleep in the day when that is possible. When I am not well it can be much more.”

“I know others get up to the loo frequently at night, so have broken and reduced quality sleep like me. I am in such a routine with my PN nights that I wake up often on my non-PN nights as well, when I don't need to get up to the loo. I need 8 hours minimum, but usually only get 7. I need my nanna naps every day if possible and finding I am getting into a deep sleep rather than a quick 10 minute power nap, which makes me feel more tired. I wonder if I need a long sleep in the afternoon because I am too tired at the moment. My muscles fatigue really easily too."

"I get about 4 to 6 hours' sleep as I am up every 2 hours to go to the toilet and then I am up at 6.00am. I do get tired, but I don't sleep during the day. I do fall asleep watching TV early."

Setting up in Small Spaces

WORDS BY *GILLIAN*

Holidays can still be enjoyed by people on HPN(Home Parenteral Nutrition); it just takes a bit more thought and planning so that deliveries make it to the correct address on the correct dates, and that enough supplies are taken to last the duration. (Detailed information about preparing for travelling can be found in PNDU's information booklet 'Travelling with Parenteral Nutrition'.) Sometimes people are nervous about setting up in unknown places – whether there will be enough space to set up and remain sterile, and whether there are power points nearby for the pump if it doesn't last overnight.

Since commencing on HPN 9 years ago, Ray and I have had many holidays in our caravans (our current, small caravan is pictured to the left), as well as apartments, motel rooms, relatives' houses, B&Bs, cabins and a very small cabin on the Murray Princess. All are different, with their access to water and bench space for setting up unpredictable. But with careful thought, setting up can be completed successfully without compromising sterility virtually anywhere. As can be seen in the picture, the dressing pack is very close to the sink, so I have to be very careful to wash carefully without splashing water. When a place has no sink handy for priming the line into, then I use a bowl. If a place has traditional taps that need to be twisted off, then either the water has to continue running after washing until setting up is complete, or another person has to be on-hand to turn it off for you. If you have travelled on a plane, and therefore don't have Chlorhexidine with you due to flight restrictions, then methylated spirits, which you can purchase at your destination at just about any supermarket, can be substituted (check this with your hospital team for approval or alternate suggestions). Take soap-on-tap and paper towels with your supplies. If your pump needs to have an electrical supply during the night, then take an extension lead with you in case there isn't a power point close to the bed.

If you are unsure of how things will go away from home, try staying away for just one night before venturing further afield for longer. Don't be put off by the unknown – talk with your doctor/hospital team, plan and prepare well, then go for it!!

Editor's Note: *Intestinal Failure (IF) is, in itself, a rare condition, and thus PNDU and Rare Voices Australia have similar aims.*

Rare Diseases Summit, 2015

A National Plan for Rare Diseases – Driving Collaboration, Driving Action - March 27-28, Melbourne Australia

WORDS BY *CHRIS*

Rare Voices Australia (RVA) recently held the inaugural Rare Disease Summit at the Novotel in St Kilda, Melbourne. PNDU were invited by RVA to have a representative attend the Summit, and join together with all the various rare disease stakeholders for conversation, input and ongoing dialogue to drive 'A National Plan for Rare Diseases'. The PNDU Management Committee accepted the request of Chris Walker to represent PNDU and all Australians living with the rare condition, 'Intestinal Failure requiring Parenteral Nutrition'. Travel sponsorship and accommodation were arranged by RVA; PNDU would like to acknowledge the advocacy work of RVA, the unified voice of all Australians living with a rare disease and thank RVA for their generosity and invitation to the inaugural Rare Disease Summit.

The overarching goal of a National Plan is to drive coordinated and collaborative action to address important, common needs and concerns of people living with a rare disease. The Rare Disease Summit brings together opinion leaders from patient, healthcare, research, government and industry organisations to share knowledge and insights for future action.

Intestinal Failure (IF) requiring Parenteral Nutrition (PN) for survival is an extremely rare condition, affecting approx. 5 people per million of population. Across Australia and New Zealand this equates to about 200 Home PN patients. Parenteral Nutrition Down Under (PNDU) exists to support, research and inform consumers, carers and providers of Parenteral Nutrition for Intestinal Failure. Responses to PNDU surveys, feedback from the PNDU online forum and the tireless work of the PNDU Management Committee, have highlighted inequality in the delivery of healthcare services for Intestinal Failure that exist across Australia.

Five key areas were identified to progress a National Plan for Rare Diseases, the same five areas all relate to the treatment and management of Intestinal failure requiring Parenteral Nutrition.

1. Data Collection
2. Coordinated care
3. Equitable access to health services
4. Diagnostics and treatments/equitable access
5. Research

Intestinal Failure already has documented optimal models of care for paediatric and adult patients. DLA Piper was commissioned in 2013 by the Health Policy Advisory Committee on Technology, HealthPACT, to deliver a report on Intestinal Failure in Australia and New Zealand, highlighting current services, gap analysis and service planning guidelines. This was completed and the report circulated in August 2014. HealthPACT is a sub-committee of the Australian Health Ministers' Advisory Council (AHMAC).

The Australasian Society of Parenteral and Enteral Nutrition, AuSPEN, is the professional society which has developed best practice guidelines for Parenteral Nutrition, including Home PN in Australasia, as well as an HPN registry in both Australia and New Zealand, which has been compiled and reported annually since 2005. The Australian HPN registry was stopped in 2013, however PNDU is very encouraged that AuSPEN intends to restart this vital resource in Australia by the end of this year.

These models of care and best practice guidelines for Intestinal Failure and Parenteral Nutrition are wonderful tools to ensure equitable access to healthcare, but only if they can be implemented in every hospital and local area health district. They are of little use without implementation across both Australia and New Zealand, ensuring we all receive the same gold standard principles/practices and access to healthcare.

I felt a sense of pride in our support group PNDU, when during the workshops I was able to use the resources and information PNDU has published and gathered. PNDU made a genuine contribution to the summit by adding the *collective voice* of all Aussies (and Kiwis), living with the rare condition of Intestinal Failure, to the *unified voice* of all Australians living with a rare disease.

"Every voice has a right to be heard by our leaders. The voices of people with rare diseases are no exception. These people are our fellow citizens and deserve equality in healthcare and research. These voices appeal to human love for one another. We should respond." The Hon Michael Kirby AC, CMG, Founding Patron Rare Voices Australia

A very comprehensive, informative and productive 2 days, working towards a National Plan for Rare Diseases. A credit to all the organisers, presenters and 120 delegates, from politicians, medical professionals, patient groups and many others. Everyone worked together for the one goal, developing a communiqué, to be presented to the federal government, to communicate key messages, pathways and commitments to drive collaborative and co-ordinated action on rare diseases. Informing the Government is a first step in developing a national plan

Day one was a full day of presentations on each of the summit themes, to share knowledge and insights, models and approaches, and opportunities for coordinated and joint action.

Session 1: Insights on progressing a National Rare Disease Plan for Australia

- This first session presented the key findings of the Rare Voices Australia RVA National Roadshow (RVA undertook a national roadshow in 2014 to progress a national plan for rare diseases). The roadshow involved round table discussions with representatives from patient, healthcare, research, government and industry organisations with sessions in QLD, SA, NSW, and WA. The discussions focussed on the needs, barriers and drivers for coordinated action on rare diseases. Presented by Megan Fookes, Executive Director RVA and author of "The Australian experience of Living with a Rare Disease" (Jordan, Logan & Sal, appear in this publication).
- The Australian Rare Disease Survey findings – Children, presented by, A/Prof Yvonne Zurynski Australian Paediatric Surveillance Unit APSU.
- The Australian Rare Disease Survey findings – Adults, presented by Ms Caron Molster, Dept. Health, WA.
- Over the past 2 years I have had the opportunity to attend workshops, presentations and Parliamentary events held by both RVA and APSU. I was humbled to find out the information provided on Jordan and Logan's story, was used as the case study for the McKell Institute "Funding Rare Disease Therapies in Australia" report, presented by Sam Crosby from the McKell Institute.

Session 2: Models for Data Collection and use

Session 3: Models of care to better meet patient needs

Session 4: Equitable access to diagnostics, therapeutics and services

Sessions 2, 3 & 4 gave presentations from both Australian and international models, which gave the perspectives of gaps, needs and opportunities from patients, patient organisations, clinicians, industry, researchers, and Department of Health.

This set the context for participation and deliberation in the workshops on day 2. Four concurrent workshops were planned:

1. Data collection
2. Coordinated Care & Equitable access to Health Services (I joined this workshop)
   We were able to highlight the need for better communication between specialists, GP's, allied health services and patient organisations and to combine their collective information; a need to have someone responsible to coordinate a patient's care; a need for gold standard principles/practices; the need for multi-disciplinary clinics; with the use of modern technology a virtual centre of excellence which could be used as a national resource for GP's; and better use of existing services/up-skilling of existing services.
3. Diagnostics and treatments
4. Research

The data, recommendations and outcomes of the workshops will be refined into a communique (due in May) at which time PNDU will have the opportunity to endorse the communique.

For further information on the resources used at the summit, please follow the links below.

The Australian Experience of Living with a Rare Disease
https://www.rarevoices.org.au/page/14/living-with-a-rare-disease

The Australian Paediatric Surveillance Unit APSU
http://www.apsu.org.au/research

The McKell Institute funding rare disease therapies in Australia
https://www.rarevoices.org.au/news/2049/the-mckell-institute-funding-rare-diease-therapies-in-australia-report

Megan Fookes, executive director RVA, opening the summit

Chris (left) in a workshop

Editor's Note: *AuSPEN is the Australasian Society for Parenteral and Enteral Nutrition, focusing on clinical nutrition. The membership includes physicians, surgeons, intensivists, dieticians, pharmacists, nurses and scientists. In other words, the people who, amongst their other responsibilities, look after those of us in Australia and New Zealand who are on HPN (Home Parenteral Nutrition). One of AuSPEN's activities is to research and write guidelines as a reference for clinicians. Below are highlights from the recently updated AuSPEN guidelines for trace elements in adult PN. The full document was published in Asia Pac J Clin Nutr 2014;23(4):545-554 and is available from AuSPEN (admin@auspen.org.au) or PNDU (contactpndu@gmail.com). PNDU supports and encourages AuSPEN's great work which benefits all of us living 'down under' with Intestinal Failure and HPN.*

Australasian Society for Parenteral and Enteral Nutrition...

...guidelines for supplementation of trace elements during parenteral nutrition

Authors: Emma J Osland MPhil AdvAPD, Azmat Ali AdvAPD, Elizabeth Isenring PhD, AdvAPD, Patrick Ball PhD, RP, Melvyn Davis PhC, FSHP, Lyn Gillanders NZRD

Background

This work represents the first part of a progressive review of AuSPEN's 1999 Guidelines for Provision of Micronutrient Supplementation in Adult Patients receiving Parenteral Nutrition, in recognition of the developments in the literature on this topic since that time.

Methods

A systematic literature review was undertaken and recommendations were made based on the available evidence and with consideration to specific elements of the Australian and New Zealand practice environment. The strength of evidence underpinning each recommendation was assessed. External reviewers provided feedback on the guidelines using the AGREE II tool.

Results

Reduced doses of manganese, copper, chromium and molybdenum, and an increased dose of selenium are recommended when compared with the 1999 guidelines. Currently the composition of available multi-trace element formulations is recognised as an obstacle to aligning these guidelines with practice. A paucity of available literature and limitations with currently available methods of monitoring trace element status are acknowledged. The currently unknown clinical impact of changes to trace element contamination of parenteral solutions with contemporary practices highlights need for research and clinical vigilance in this area of nutrition support practice.

Conclusions

Trace elements are essential and should be provided daily to patients receiving parenteral nutrition. Monitoring is generally only required in longer term parenteral nutrition, however should be determined on an individual basis. Industry is encouraged to modify existing multi-trace element solutions available in Australia and New Zealand to reflect changes in the literature outlined in these guidelines. Areas requiring research are highlighted.

RECOMMENDATIONS FOR CLINICIANS

1. TEs are essential components of human nutrition and should be provided daily with PN provision from the time of commencement as standard practice in short, longer term and HPN provision.
2. Biochemical assessments of TE are expensive and many TEs do not have reliable biochemical tests available at the present time. Unless otherwise clinically indicated, monitoring of TE levels should be reserved for clinically stable, longer-term PN or HPN patients. Unless otherwise clinically indicated, annual TE monitoring should be sufficient.
3. In cases where monitoring is being performed in patients with acute issues, a CRP level in which to provide context to the level of inflammation or presence of APR that should be performed.

RECOMMENDATIONS FOR INDUSTRY

To support safe and evidence based clinical care, new multi-TE products that reflect the present recommendations are required to be available on the Australian and NZ market. Specifically:

1. Mn provision decreased to 1 µmol (55 µg)/day
2. Cu provision decreased to 5 µmol (315 µg)/day
3. Se provision increased to the higher end of the recommendations (~1.2 µmol (~100 µg)/day)

RECOMMENDATIONS FOR RESEARCH

These guidelines highlight the need for further research in PN provision. These include but are not limited to:

1. Investigation into the TE contamination profile associated with contemporary PN packaging practices;
2. Surveillance of changes to TE deficiency and toxicity patterns in longer term and HPN patients with the changes to storage and handling of PN components;
3. Development of reliable methods to facilitate TE assessment and monitoring in longer term and HPN patients; and
4. Validation of earlier poor quality studies into safe and adequate provision of TE in short, longer term and HPN patients.

HPN Awareness Week 2-8 August 2015

WORDS BY *KAREN*

It's a few months away yet, but we have begun planning for the 2015 international HPN Awareness Week in August. HPN Awareness Week is a great opportunity to highlight amongst family, friends, clinicians and the public in general, this highly specialised and complex home therapy. With just over 200 of us in Australia and New Zealand dependent on HPN for life, this week is very special. Many of us sustained by HPN look well, and people may be reticent to ask questions or simply have trouble understanding. HPN Awareness Week is the perfect opportunity to tell our stories and to invite questions. Furthermore, let's spread the word about the wonderful support offered by PNDU for those living with Intestinal Failure and HPN!

If you are an HPNer or HPN clinician at a hospital that may be interested in joining the HPN Awareness Week celebrations, please contact us at contactpndu@gmail.com and we will be very glad to assist in whatever way we can.

AuSPEN consumer workshop and PNDU social gathering – can you come?

WORDS BY *KAREN*

Following on from the success of AuSPEN's inaugural HPN consumer workshop last November in Auckland (see Dripline issue 10), we are excited to let Aussie and Kiwi consumers and carers know that another one is being planned to coincide with Gastro2015 at the end of September/early October in Brisbane. We applaud AuSPEN for this invaluable event and thank them for all the hard work they do.

Details are yet to be finalised, but if you are interested in attending or know of any HPN consumers/carers who would be interested, please get in touch with us for more details as they come to hand.

Alongside AuSPEN's consumer workshop, PNDU is planning to hold a HPN consumer and carer social gathering. So once again, look out for the details as the event is organised.

AuSPEN's inaugural HPN Consumer Workshop, Auckland, November 2014

Travel Sponsorships on offer

In order to assist members to travel to these great events, PNDU will be offering two $500 travel sponsorships for Aussie or Kiwi HPN consumers/carers who will be attending the AuSPEN consumer workshop and PNDU social gathering for the first time. Applicants should not be receiving any other financial assistance for travel and/or accommodation expenses related to attending the workshop/social gathering. Travel sponsorships are limited to one per family.

Qualified workshop/social gathering attendees should write two paragraphs describing how they believe attending the workshop will affect their life and submit them to contactpndu@gmail.com. Travel must be completed and receipts received by PNDU before reimbursement can be made.

PNDU's HPN Consumer Social Gathering, Auckland, November

Thank You

We received $33 in donations from the Altra Nursery donation box. Many thanks to Altra Nursery, Depot Rd, Mortdale, for assisting PNDU in this way.

Our Private forums for Aussie and Kiwi HPN-ers and carers

Any Aussie or Kiwi HPNers or carers who would like to join one or both of our private forums (Googlegroups email forum and/or closed Facebook page) where you can chat with others living with HPN, please email us at contactpndu@gmail.com, telling us about yourself.

HPNers without a computer

PNDU also offers the opportunity for Aussie and Kiwi HPNers and carers to correspond the 'good old-fashioned way' – by letter or card – with one of our members. If you are interested or have a 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.

Donations

If you feel able to contribute to our support group, you may wish to make a donation. Donations are currently only tax deductible in New Zealand. We are grateful to our sister charity IPANEMA (Charities Commission Registration CC21178) which receives donations on our behalf.

NZ cash, NZ cheques or International Money Orders made payable to:

"IPANEMA TRUST" and sent to:
PN-DU Treasurer, c/o G Hardy, Massey University, Private Bag 102 904, Auckland 0745 New Zealand

Online donations:

PayPal via our website www.pndu.org

Or direct deposit (New Zealand dollars only) to IPANEMA's bank account with the notation "PNDU":

Bank: ANZ
Account name: IPANEMA
Payment ref: IPANEMA "PNDU"
A/c No: 0602730308799-00
SWIFT code for foreign payments: ANZBNZ22

Committee members

Convenor: Karen
Minute Secretary: Gillian
Treasurer: Gil/Chris
Incorporation/Registration: Miranda
Newsletter Editor: Gillian

Contact us

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

Visit the website at www.pndu.org

Designer: Sal