DRIPLINE

PARENTERAL NUTRITION DOWN UNDER

Parenteral Nutrition - Down Under™

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5TH ANNIVERSARY BUMPER EDITION

Welcome to our 5th anniversary edition of Drip Line. Five years ago, on January 7th 2009, PN-DU was formed to provide moral support for people living with Home Parental Nutrition in New Zealand and Australia as well as raise awareness and understanding and advocate for best practice in this part of the world. It began with a handful of members and has gradually grown to over 160 website members. Technology has greatly assisted us, as many come to know about us through our web-site. Our Management Committee, with representatives in both countries, as well as several states in Australia, uses Skype for our meetings. Our private HPNer chat forum and our newsletter rely on email; and when we want to meet up in a huge park in Sydney, a mobile phone is often useful to find people's whereabouts. As you will read, from small beginnings PN-DU has made several significant achievements. This progress is particularly remarkable, considering the relatively small number of HPN patients in our two countries (200 at the most), and the fact that many living with HPN are either carers of children with great needs, or have periods of illness themselves.

Sadly, over the 5 years, some of our members have lost their battle with health problems, and have passed away, leaving family and friends desolate, but with wonderful memories of love, strength and courage. They are remembered with love in Karen's tribute.

One of our members is in hospital as we read, having undergone a liver and intestinal transplant at the Royal Children's Hospital in Melbourne. At almost 6 years of age, he is the 3rd and youngest transplant patient to have this operation in Australia, and after Matisse from New Zealand in December 2011, is the second of our PN-DU members to have a successful transplant. We all wish Talon a smooth recovery, and share his parents' joy as well as the grief of the donor family. We will hopefully hear more about Talon's remarkable journey in our next issue.

Gillian, Editor

IN THIS ISSUE

PRECIOUS LIVES, PRECIOUS MEMORIES

WORDS BY *KAREN*

Over the 5 years of PN-DU's existence, we have been reminded of the fragility of life, especially for those with Intestinal Failure. Sadly, PN-DU has shared with family and friends in saying good-bye to five precious loved ones who have passed away, but who have also left wonderful memories of love, strength and courage. In this 5 year anniversary edition, we remember those precious lives and gratefully thank the families who have graciously continued to be involved with PN-DU and share their knowledge and experience with other families:

Hebe - 3 January 2008 aged 2½ years (Hebe passed away before PN-DU existed, but her parents are founding members of PN-DU and we greatly appreciate their continued involvement)

Pauline - 29th April 2011 aged 38 years

Aria - 20th June 2011 aged 5 years

Tynesha Rose - 29th October 2012 aged 5 years

Jessica – 24th January 2014 aged 20 years

May the cherished memories of these dear ones never fade.

THE BIRTH OF PN-DU (PARENTERAL NUTRITION DOWN UNDER FOR AUSTRALIA AND NEW ZEALAND CONSUMERS)

WORDS BY *BRENDA.*

REPRODUCED FROM OUR INAUGURAL JUNE 2012 EDITION OF DRIP LINE

The support group came about after years of personal isolation within New Zealand. I knew of, and had belonged to, Oley, [the USA support group, for Enteral and Parenteral users] since 2001, as well as another patient support group, the Gastroparesis Yahoo Group. Initially I felt that it would be best that the Health provider caring for the HPNer should play a part in the support group, but after four years of broken promises, and getting to hear of other HPNers in the same situation, the desire to get something off the ground and onto the internet exploded, or imploded, and took off.

I had met Gil Hardy [member of our Management Committee, our treasurer, and Professor of Clinical Nutrition at Massey University in New Zealand] in 2008, and with his encouragement and inside knowledge of PINNT, the UK support group, I had the green light needed to get underway.

First the name, which came to me after a long day at work, about 1.30 am whilst driving home. I wanted to have the down under theme, as that belongs to both Australia and NZ. After a few kilometres spent thinking, PN-DU seemed good and so I stopped and scribbled it on a piece of note paper.

Next day, the name still seemed good, and there were no more thoughts in the bucket. I then made up the Google groups forum and wrote my first introduction, what our aims were and what it was meant to do.

Later that day I sent the name and email address to Gil and said we were ready to go. Those whom I knew who were on HPN were notified, and I asked them to notify anyone else they knew. Jodee had her list from her own blog site and by the end of the month we had over 5 members.

We did discuss the need for an emblem, an identity as being a small group; and so on a trip back home to England, and with the artistic skills of his grandsons, Gil came up with the simple sketch of the PENDOO. That then led to meeting a soft toy manufacturer and the making of a very exclusive and rare animal. We were in existence! Our colours were simply the gold and green of Australia mixed with the black and silver of New Zealand.

I am hot on our privacy and the need to be able to vent, feel emotion both negative and positive, and not have it back lash. And so it was that the website was then formed, with public access but with a private 'members only' interactive section. Due to poor knowledge on my behalf, I registered it with a fairly long name; this has actually been to our advantage as we are not likely to be spammed, jammed and whatever! Go to any search engine and type in at least 3 of our words in the name and up we come. So easy to find if you are looking for us.

Jodee baptised the site with a great over view of children's care and the journey to being on the transplant list. Karen said yes, she'd help, having no idea that my computer doesn't talk to the website ones, and landed up with the job of setting up the site, which she did very well, and also being PN-DU's secretary.

We are now linked to PINNT and Oley, so we are truly part of the international scene.It is what was hoped for two years ago, a family of folk bonded by their complex treatment, making it simpler and safer for those who have to live with it.

WHAT PN-DU MEANS TO ITS MEMBERS

WORDS BY *GILLIAN*

When you are the only person that you know with a medical problem, sometimes the only person whom your hospital monitors, it's wonderful to be able to connect with others who have similar issues happening in their lives. While our medical teams – doctors, nurses, dieticians and pharmacists – can provide us with medical support, they don't really understand what our everyday lives are like. For that kind of understanding, you need to speak to someone who is walking the same path. I asked our Kiwi and Aussie HPNers to share their thoughts about the opportunities that PN-DU provides to connect with others living with Intestinal Failure and HPN. Gillian.

Karen writes:

With such an unusual and complex medical treatment, for me PN-DU's existence has been a precious gift. In the four and a half years since becoming a member, I've learnt so much more about my own treatment, but more than that, I've connected and made friends with an incredible bunch of inspirational families and individuals. PN-DU is very caring and supportive, - sharing the highs and lows of HPN, knowing that we all 'get it'. And believe me, when HPN is so rare in this part of the world, knowing others travelling the same road is invaluable. Moreover, these PN-DU friendships are very precious to me. Being a bit of a social butterfly, I love being able to catch up in person with PN-DU friends, as well as meeting new members.

As current convenor, I'm also greatly encouraged by what has been achieved over the years since PN-DU's inception, to increase awareness and understanding of HPN, and to strive for the highest level of care standards across Australia and New Zealand. I very much look forward to seeing even more progress in the years ahead.

My heart-felt thanks go to Brenda, who with Prof. Gil Hardy's support, began PN-DU 5 years ago. Our numbers and activities have gradually grown from those humble beginnings, but PN-DU's heart and raison d'être remain the same.

Recently I met amazing Rosie, who has been on HPN for over 20 years, infuses approximately 20 hours a day, and continues to enjoy life in rural NSW. Amazing woman!

Rosie (left) and Karen

Sal writes:
Since joining PN-DU, I have come to know I am not alone and have been supported by those who understand what it's like to live and survive on parenteral nutrition. I have met and gotten to know some amazing and courageous people who have inspired and encouraged me to battle on. I have been able to share my journey and be listened to and heard. Wisdom, advice and ideas shared among us have also been helpful. I consider myself truly blessed to be part of such a wonderful group of awesome people.

Shirley writes
As carers of a 4 year old boy on HPN, learning about PN-DU only a year ago has opened our world up. No longer is all our advice and input medical, but it has a human face filled with wisdom and care from those with a similar experience. We don't feel isolated or weird anymore, but know that there are people who understand our world that we can interact with.

David and Miranda write:
PN-DU is an extended family who genuinely care about each other and who just "get it". The group is a collection of real people living or caring for someone on PN to whom we can always turn to for some practical advice on what can be an overwhelming medical routine. PN-DU is a loudspeaker through which we can voice our concerns on issues that impact our lives and it is a place where we can share the peaks and troughs of our journey and know that we are understood wholeheartedly.
Lisa writes:
For me, PN-DU is a place to connect to others who understand the daily challenges of living on HPN. The practical and emotional support has made a huge difference to my life.

Renee writes:
PN-DU is simply a wonderful support, a place where I know I can ask questions I need answered and where I will be understood. It makes a huge difference speaking to others on HPN, sharing ideas and having the opportunity to offer support too. I have met fabulous people whom I would not have met had it not been for HPN!!
Above all it is a space in which we can walk the journey together, knowing we will be heard with love, wisdom and understanding. Many thanks to you all.

Gillian writes:
PN-DU is a group of individuals who are kind, caring, helpful, and understanding of what life is like on HPN. If you have a concern or problem, someone will usually have an idea to help, and even if they don't, you usually receive many sympathetic responses from people who really care. When something goes well for us, everyone is happy for us. PN-DU complements my medical team in supporting me live my life on HPN

Chris writes:
2014 will be our families' 12th year dealing with Home Parental Nutrition in two Australian states and four major hospitals.
During this time we always felt like we were doing it alone, that we were the only family in this position.
In a way perhaps we are unique, having had three members of our family on HPN.
Where do you turn for support when facing the many issues that surround the administration of HPN? When our family and friends, social workers, even State and Federal Government, just don't understand the frustration you can face each day? The many differences between health systems in each state and hospital only add to the many frustrations we endure.
All the time thinking we are on our own.
In April 2013, I joined PN-DU. We now feel like we have an extended HPN family, a group of people who genuinely understand what we deal with on a daily basis, a group who endure the same or similar ordeals.
Not just an online community, a group who are willing to meet and discuss the multitude of issues we all face. A proactive group who carry our message and advocate for all HPNers.
Yes a group who really do "Get It"

Thank you PN-DU

CENTRAL VENOUS CATHETERS, BIOFILM, AND THROMBOSIS

Adapted with permission by Patrick Ball from an article by Marcia Ryder, PhD, MS, RN published in the Oley Foundation Newsletter (Lifeline Letter Sept/Oct 2013). The original article was adapted from a breakout session Dr.Ryder gave at the 2013 Oley Conference.

Microorganisms (or bacteria) are everywhere. About one-hundredth the width of a human hair, they were the first living cells on Earth. They have had to adapt to survive over this vast time span. Ancient, invisible and powerful, bacteria cause catheter-related infections.

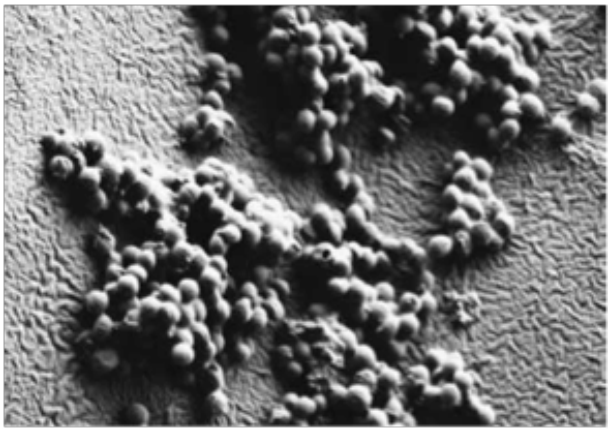
Bacteria's Lifestyles

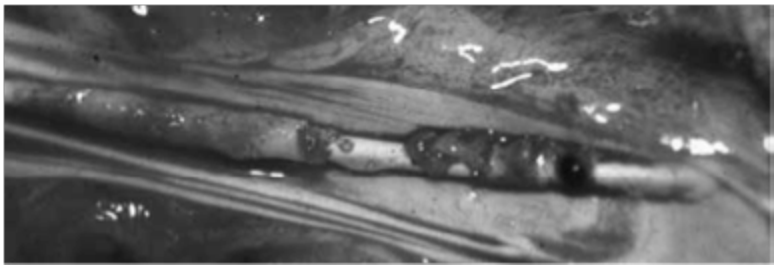
In 1683, Anthony van Leeuwenhoek developed the first microscope powerful enough to visualise bacteria. He didn't know what he was seeing, but observed something alive and moving. Modern devices such as a "confocal laser" microscope can take real-time pictures. Whilst previously it was thought bacteria only existed as single cells, we now know there are two types of lifestyle for them.

Bacteria live as independent, single cells (called "planktonic") floating in liquids, but more often they live in a biofilm, as a community of microorganisms attached to each other on a surface. The cells in a biofilm are physiologically distinct from planktonic cells.

Biofilm

Biofilm is all around us—on showerheads, tooth brushes, water systems, in our bodies. Some of the biofilms that live with us are good for us. We have over seven hundred species of bacteria in our mouth, and in the bowel, hundreds of thousands of bacteria help digest food and absorb nutrients. All of these have practical functions that help us be healthy. Conversely biofilms on central venous access devices (CVAD) shed cells into the circulatory system, and these can be harmful.





Left: Biofilm on the intraluminal surface of a catheter hub.Right: Central venous catheter with fibrinous conditioning layer and thrombus formation. Photos: Marcia Ryder, all rights reserved

How do biofilms develop? When bacteria make contact with a surface—such as a catheter—the cells produce a substance that allows them to stick to the surface. They then release messenger substances that communicate with other cells, triggering them to produce a material that envelopes them in a cluster. This is a survival technique: in biofilm, the cells are protected from attack by white blood cells.

Bacteria that switch into this biofilm mode—where they are cooperating and communicating with one another—change their DNA structure and how they live. For example, they can down-regulate their activity, like an animal hibernating through harsh conditions. Each cell becomes almost a completely different organism from where it started. In this state, the bacteria are not harmful; they are dormant, quietly ticking over in a microscopic community. When the biofilm reaches a mature state, however, cells are released in order to colonize new surfaces. Release of small numbers is quickly mopped up by the white cells of the immune system, but if enough biofilm releases sufficient cells, an infection results.

Resistance

Bacteria in biofilm are well protected. They are protected from host defences (your white blood cells and antibodies) and to all antibiotics and antiseptics at the normal therapeutic doses we use. In order to kill biofilm cells, they need to be exposed to around 100-1000 times the concentrations of antibiotic that are typically found in blood after the doses we use. Cells within biofilm can also rapidly develop anti-microbial resistance because they transfer genes between the community that makes them resistant to antibiotics. They stick strongly to the surface. A lot of friction and mechanical scrubbing is required to remove them.

Infection and Thrombosis

When a catheter is placed through the skin and into the body, it provides a path for the entry of microorganisms. It also causes vessel

injury as it puts a puncture through the wall and stays in place. The presence of the catheter also causes some slowing of blood flow. This makes patients potentially vulnerable to both infection (sepsis) and blood clotting around the catheter - thrombosis. We'll discuss each individually, then address the connection between them.

Bacteria can attach to the inside (intraluminal) and outside (extraluminal) surface of a catheter, from sources along your infusion set and the hub itself. Considering first the outside; when a catheter is placed, it passes through the skin and the tissue beneath the skin, and then into the bloodstream. About 250 species of bacteria and other microorganisms live on our skin. They help maintain the skin as a barrier. Before a catheter is inserted, the clinician swabs the skin with an antiseptic to reduce the number of bacteria on the skin. The bacteria that live in hair follicles and the deeper layers of the skin, however, can't be reached, and can attach to the catheter surface. Within hours, these deeper bacteria return around the hair follicles and sebaceous glands and recolonize the skin.

The open wound around the catheter cannot heal; there will always be a space around the foreign body (catheter) going through it. This provides opportunities for the bacteria to travel down the subcutaneous tract, and enter the bloodstream. This is why care of your insertion site as specified by your hospital team is so important.

When do infections typically occur?

Researching clinicians have looked at all of the central-line–associated bloodstream infections (CLABSI) that were reported in the US state of Pennsylvania in 2010. They recorded each one to the day that the infection occurred. They found that 54 of the 653 infections happened on the fifth day after the catheter was placed. These they classified as early-onset, and the early-onset infections are due to insertion and mostly the result of bacteria on the outside of the catheter.

What about the later infections?

Those are primarily from bacteria inside the catheter. Seventy-one percent of infections happened later, during routine use of the catheter.

How do bacteria get inside the catheter?

They can enter through a stopcock-hub, an injection port, a needleless connector, or the catheter hub itself. This is why it is crucial to carefully prepare these surfaces as instructed by your hospital, before infusing. You are to a large extent, masters of your own destiny here.

Thrombosis

When a catheter goes through the skin, it enters the subcutaneous levels and the vessel wall. The most vulnerable time for bacteria to become attached to the outside is during insertion. Bacteria on the inside of the catheter come into blood vessels through the catheter hub. The body responds by sending white blood cells to the area to protect it and to begin to heal the wound. This triggers local inflammation to warm the area and make the body defences more efficient.

When the catheter enters the bloodstream, proteins in the blood stick to the catheter surface. They touch the surface, and 'recognise' it as foreign material and turn into a solid layer on the catheter, and begin to entrap some of the white blood cells and platelets, creating a 'conditioning layer.' This causes blood platelets to activate, and this in turn causes the protein fibrin to begin to build up around the conditioning layer, keeping the red and white blood cells together in a sheath or clot around the catheter surface. This is the blood's normal reaction to any foreign object inside a vessel. The industry is working to develop catheter materials that won't allow this to happen, but we are not there yet. This fibrin sheath can vary from being a thin layer over the catheter to being quite large, partially or rarely wholly blocking the blood vessel. We do not understand what makes it one or the other. If the vessel becomes occluded, a "thrombus" may form. This is a blood clot within a blood vessel. Clots can also form on the vessel wall due to damage to the inner lining of the vein wall by the catheter.

The Connection

Infection and thrombosis are distinct, but related problems. If bacteria are present, they will form a biofilm within any or all of the conditioning layer, fibrin, or thrombus. These now provide added protection for the biofilm. For the bacteria community this is a very healthy area; plenty of nutrition in the blood vessels and relatively safe from immune-system attack. Bacteria have receptor structures on their outer walls with a particular affinity (liking) for attaching to fibrin.

The catheter goes through the skin, then into a subcutaneous layer, and then into the blood vessel. Fibrin can develop in the subcutaneous space as well as in the bloodstream. It can create a tube of fibrin that progressively grows along the catheter, through the tissue and into the vein. If bacteria penetrate that tube, they have the potential to spread through the subcutaneous tissue and into the blood. Infection of a sheath is not inevitable; not all sheaths become colonised. It appears that bacteria don't spontaneously invade the sheath, they have to be transported there. This is where catheter care techniques are vitally important, and should be practised exactly as you were taught by your unit, so that no bacteria are deposited.

Intraluminal Issues

How does biofilm get inside the catheter? In a study, some needleless connectors were examined after they had been used by patients. They were examined under a scanning electron microscope and revealed the bacteria staphylococcus spp (very commonly found on our skin) in a very thick biofilm all over the top of the connector.

Biofilm can develop on anything; and if you don't clean the biofilm off before you inject, bacteria will be flushed into the catheter. Inside the catheter, if they touch any part of the catheter lumen or the inside of the connector hub they are likely to stick to it and produce more biofilm.. Any bacteria that don't stick go directly into the blood.

The study also examined the hub of the connector, which was also found to be coated with biofilm cells. When the hub is colonised, again, if these cells are infused, the effects are the same as above. Following your line care protocol is essential for success.

Drawing blood through the catheter

Most units try to minimize blood sampling through the catheter. In most units it is only done in an emergency if there is no alternative. When blood comes in contact with the inside of the catheter, the processes that lead to formation of fibrin on the outside of the catheter, can occur on the inside. Plasma proteins will stick and form a conditioning layer. This of itself, rarely affects catheter function in the short term but any bacteria that pass this layer are likely to colonise it.

The other problem with pulling blood into catheters is clotting, especially if the catheter is not flushed correctly after a blood draw. Sometimes fibrin can collect at the tip of the catheter, even though blood is flowing around it. A clot inside the catheter can mean that the catheter will become blocked.

Helping yourself

Rigorous attention to detail and carefully following the procedure taught to you by your hospital is your best protection from line infections. Make sure you maintain adequate stocks and don't run out of anything. Be particularly careful if you are tired. Most people will have experienced at least one line infection. Know the signs and if you think you are developing an infection seek professional help promptly.

Conclusion

Vascular catheters or CVAD are life-saving and life-sustaining, but they also come with risks. It is important to know the risks and how they may occur. Understanding how to care for your catheter is an important part of your nutrition support plan. The industry is working hard to bring us newer and better products but this is the best we have for the present.

Paraphrased and updated for Australia and New Zealand by Prof Patrick A. Ball. Charles Darwin University, Australia.

A DAY IN THE LIFE OF A HPNER

WORDS BY *GAIL*

Holidays in our caravan have always been an integral part of our life since Bryley was born. As a family, we needed to have something to look forward to, to regroup and refresh us enough that whatever would come our way in the future, we could handle it. There was always that niggling fear that Bryley would go into hospital just before we would be due to go, though. Twelve years down the track that fear is still with us, but we have had some amazing holidays.

This is one of our more memorable holidays for all the wrong reasons!!!!!

Idea: let's take the caravan to Northern NSW and then on to South East Queensland to catch up with the kids Grandparents.

So off we went. Bryley was 3 at the time and on 4 nights a week of PN, so it allowed us some flexibility in hooking her up. We always had a letter from her consultant, made sure that we weren't far from major hospitals and had our exit plans if the unthinkable happened and we needed a hospital fast.

We arrived at our destination and started our holiday. Took a trip down to Byron Bay, walked up to the lighthouse, went swimming in the ocean and generally started to relax.

About 4 days into the holiday and after hooking her up a couple of times with no problems, we decided a day at the beach was in order. Matt, our 9 year old son, wanted to boogie board, and Bryley wanted to play in the water and make sandcastles.

All of a sudden, Matt came out complaining that he was stinging everywhere. We had a look and sure enough there were welts all across his back. Looked like the blue stingers had got to him. We started to panic at this stage and came across a lifesaver and asked what we should do. He said just to go and put vinegar on it and hopefully it should calm down. Matt is extremely allergic to peanuts, and as this hadn't happened before, we hoped he wasn't going to have a bad reaction to this as well. Thank goodness it didn't get any worse and after a few hours he was getting back to normal again. Back to enjoying our holiday.

It was hook up night for Bryley, and Matt wanted to go and play bingo with all the other kids from the caravan park, so off we went. Around 7.30pm I decided it was time to get Bryley on her lines. Left Matt playing and I went back to the caravan.

Scrubbed up, got everything ready, flushed her line, hooked her up and within minutes, she started to shiver very badly. She looked extremely unwell and I knew that she had had a 'septic shower'. She started to vomit and her temp was high. Decided we needed to call an ambulance. We got taken to the nearest hospital but not a major one. They called a paediatrician in, got IV access and started pumping fluid into her. I asked them to call her consultant in Melbourne, but they were reluctant to do it for whatever reason. I told them that they needed to take blood cultures and start antibiotics and asked if they had the antibiotics that she required. His reply was 'of course they did, after all they were a hospital' and when I asked when we would get transferred to a more major hospital, I was told 'they could handle it'. My confidence at that moment with this doctor started to diminish. He got a nurse from ICU to come down, who sat there with a big reference book on Paediatric Medicine. The stress levels were becoming unbearable. I think I was going into some sort of shock. In between bouts of vomiting and diarrhoea, I kept telling them they needed to have her transferred. The nurse with the Big Book told me in uncertain terms, "to calm down and sit there, they are doing all that they can." She was treating me like a mum who was over-reacting. But I had had enough experience to realise this was an extremely serious. Anyway, by this time my husband and son had arrived at the hospital. The hospital still hadn't contacted her consultant, so I decided to do it myself on my own phone. Once I reached her and told her what had happened, she immediately wanted to speak to the doctor. Once that happened, they contacted the ICU Retrieval Team from a large Brisbane hospital to come and get her. They were going to get a helicopter in, but it was diverted to another patient. I told my husband to go back to the caravan, as I would be going to the hospital with Bryley.

When the ICU team arrived, a huge sense of relief flooded my body. They took control of the situation, did their own tests and proceeded to get her ready for the trip in the Ambulance.

All ready to be transferred, I was then informed by the ambulance driver that there wasn't enough room for me to go with her. I couldn't believe it. As hard as the ICU team tried, the driver would not take me.

I had to call my husband back who had just arrived at the caravan (after a 45 minute trip) to come and get me as they couldn't take me. Bryley went off in the ambulance and I waited for Mark. We decided to go back to the caravan and try and get a bit of sleep and I would head up to Brisbane in the morning.

Arrived at ICU and found Bryley double the size she normally is due to all the fluid that had been pumped into her. I sat beside her having a little cry. She asked me what was wrong. I told her I was sad and she said she knew what would fix me up. "An orange juice". How could that not bring a smile to my face?

The doctors wanted to take her line out. It was so very difficult to deal with a hospital that doesn't know her or me. And on top of that, the stress and lack of sleep didn't help. It's all a bit of a blur but I can remember asking them to ring her surgeon in Melbourne. Don't know if they did or not, but anyway the line came out. I can remember talking to Bryley's Gastro Consult and told her that they took her line out. I can still hear her disbelief. "They took her line out…" That comment has been forever etched into my brain.

Anyway, she was admitted to a ward, given a couple of days of antibiotics and we flew back on a domestic flight back to RCH in Melbourne.

Mark and Matt had to then pack up the van and drive back home without us.

I must admit it took "the wind out of our sails" for awhile, but it didn't take long to get our confidence back and go on another holiday. And we have had lots since then.

Editor's note: Swimming with a central line is something that needs to be discussed with your medical team.

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LETTING THE WHOLE WORLD KNOW ABOUT US

WORDS BY *KAREN*

PN-DU was afforded a couple of great opportunities in October and November 2013, not only to use our fantastic new pull-up banner, but also to raise our profile and inform clinicians of our existence and what we offer to Aussie and Kiwi HPNers. Hopefully, with more clinicians knowing about us, more HPNers will have our information passed on to them enabling them to join us.

AGW in Melbourne

The first opportunity was at the huge conference – Australian Gastroenterology Week (AGW) 2013 – for which I travelled to Melbourne in October. We are very grateful to the Gastroenterological Society of Australia for once again allowing us to exhibit. Sadly due to the fact that AuSPEN and all things nutrition were holding their conference separately last year, rather than jointly with AGW, not as many clinicians working with intestinal failure and PN patients attended AGW and therefore we didn't receive as much interest as in previous years. That aside, it was still a brilliant opportunity to network with other support groups, from whom we have learnt so much, and meet various clinicians and industry representatives.

AuSPEN meeting and conference in Sydney

The big conference event of 2013 for PN-DU however was the much smaller AuSPEN Annual Scientific Meeting in Sydney in November.

Miranda, Dave, Gil and I were given the opportunity to meet with members of AuSPEN Council and the HPN Working Group before the conference started. This was PN-DU's first official meeting with AuSPEN and we were greatly encouraged by the meeting. Being the clinical body overseeing HPN care in Australia and New Zealand, we consider it important for PN-DU members and all Aussie and Kiwi HPNers that we work with AuSPEN towards the same goals. A very big thank you to AuSPEN Council and the HPN Working Group for making the time to meet with us for what was a positive and productive meeting.

Following that meeting, Miranda, Gil and I exhibited at the AuSPEN conference and again, we are very grateful to AuSPEN for allowing us to exhibit. There was a lot of interest from clinicians with PN patients and we also appreciated the opportunity to meet with Baxter, Fresensius Kabi and REM Systems representatives.

Karen with Ibolya Nyulasi, AuSPEN President

Karen, Miranda and Gil exhibiting at the AuSPEN conference in Sydney

Karen with Linda Lanham of REM Systems showing the new and updated Bodyguard pump, at the AuSPEN conference in Sydney

CONGRATULATIONS GIL!

PN-DU's very own Prof Gil Hardy is the recipient of a prestigious international award in recognition for his outstanding services to clinical nutrition therapy in USA, Latin America, Europe and Australasia.

The American Society for **Parenteral and Enteral Nutrition (A.S.P.E.N.)** selected Gil for its 2014 **Distinguished International Nutrition Support Service Award.** Founded in 1976, A.S.P.E.N has more than 5,500 members, making it the leading worldwide interdisciplinary organisation for dietitians, nurses, pharmacists, physicians, scientists and other health professionals, involved in every facet of clinical nutrition, including **parenteral and enteral nutrition (PN and EN)** therapies.

Gil is **PN-DU's current Treasurer** and one of our founding members. He has just retired from his position as Professor of Pharmaceutical Nutrition at The University of Auckland, but continues as **Professor of Clinical Nutrition at Massey University in New Zealand.** He is also a founder and trustee of **The IPaNEMA Charitable Trust** and has published over 200 research and review papers in the field of clinical nutrition and served on the Research, Publications and Membership Committees of A.S.P.E.N. A.S.P.E.N is dedicated to improving patient care by advancing the science and practice of clinical nutrition and metabolism. The society presents annual awards to outstanding members who have contributed to clinical nutrition by showcasing exceptional expertise in clinical practice, research, education and advocacy.

The award was formally presented to Gil by the A.S.P.E.N President, Dr Ainsley Malone at the Dudrick Research Symposium at Clinical Nutrition Week in January 2014 in Savannah Georgia USA.

We congratulate Gil on this wonderful award and thank him for his many years of work and dedication in the field of clinical nutrition as well as his invaluable support and involvement in PN-DU.

ROYAL TREATMENT

WORDS BY *CHRIS AND TANYA WALKER*

Having two grandchildren born with a rare disease, spending 4 years in hospital caring for them 24/7, Royal Treatment is only a dream.

Two of our three grandchildren were born with the rare disease XCIPO (X-Linked Chronic Intestinal Pseudo Obstruction) which affects the gastro intestinal tract and its ability to absorb or propel food and nutrients, so as a direct result the two brothers can't eat or drink, and are totally dependent on PN (Parental Nutrition) in order to survive. Both boys have drainage tubes through the length of their small intestine, which protrude each side of their abdomen: Jejunostomy and Colostomy. We have an extensive care program that uses many products, some from the Coloplast company.

I received an Email from our wonderful support group, PN-DU Parental Nutrition Down Under, advising that the Coloplast company were running a competition where you could win a Royal Treatment package, just log onto the Coloplast website and tell them in 25 words or less why you deserve some Royal treatment. I submitted the following "Having two grandchildren born with a rare disease, spending 4 years in hospital caring for them 24/7, Royal Treatment is only a dream", believing it was only a dream, that I couldn't win

a raffle if I had the only ticket.

To my surprise, I received a phone call from Heidi at Coloplast. “Congratulations, you’re a winner.”

“Dear Chris,

On behalf of Coloplast, it is with great pleasure that I announce that you are one of the lucky winners of the Coloplast competition to see the Danish Crown Prince Couple at the Sydney opera house on Monday, 28th October, 2013.

The Danish royal couple, HRH Crown Prince Frederick and HRH Crown Princess Mary, are visiting Sydney as patrons of the 40th anniversary of the Sydney Opera House. On Monday, 28th October they will celebrate at the iconic opera house with an awards show in their name. Featuring a variety of live performances from Danish and Australian artists, this is the first time that the awards show will take place outside of Denmark. This event will be televised live.

The prize includes dinner for you and your wife, Tanya, at Pullman Sydney Hyde Park Hotel, 2 tickets to the awards show and 1 night’s accommodation (including breakfast on Tuesday 29th October) plus air travel both ways.

Dress code: Black Tie Formal.”

I was speechless, I had finally won something.

Telling my wife Tanya, I was overjoyed with excitement. Then reality set in:- how do we make this work with our busy schedule, Jordan and Logan were in Westmead undergoing surgery, Tanya would be in Westmead as a carer, their brother Dylan would be at home with me, Black Tie formal- I don’t have a Tux. But, with a major reschedule, a couple of extra trips to and from Sydney, and we decided we could make this dream happen.

On Monday 28th October, we headed to Newcastle airport for our flight to Sydney aboard REX airlines, then took the train to Museum station, followed by a short walk across Hyde Park to Pullmans Hyde Park Hotel - a 5 star hotel with valet service to our room. We settled in with two hours to spare and ready ourselves for the evening ahead.

All spruced up in Tux and evening gown, we headed down to Pullmans Windows on the Park Restaurant, where we were greeted by the Coloplast Representatives and were treated to an extensive buffet meal with an amazing selection of fine food and desserts, washed down with an excellent selection of red wine for myself, diet coke for Tanya.

Much to our surprise, during the formal dinner speeches from Coloplast, our story was read out as it had touched the management of Coloplast.

Then we were onto the bus and off to the Opera House.

We walked the red carpet into the Opera House along with the celebrities, in front of all the photographers and television cameras and were ushered to our seats ready for the evening of entertainment and awards.

The show was hosted by Julia Zemiro (SBS Rockwiz) and Nikolaj Koppel.

The Crown Prince Couple arrived, greeted the audience, and were seated. A truly amazing couple, how humble and appreciative they were to the reception they received.

The Crown Prince couple of Denmark presented:-

The Crown Prince Couples award of DKK 500,000 given to a significant Danish or Greenlandic artist or group of artists with international potential.

The Crown Prince Couples Social award of DKK 500,000 given to a ground breaking social project or initiative in Denmark or Greenland.

Two Rising Star awards of DKK 50,000 given to young, talented artists from Denmark or Greenland. This year’s Rising Stars are violinist Rune Tonsgaard Sorenson and singer MO.

We were treated to performances from these two artists and previous winner OH Land from Denmark. Australian artists Diesel and Gurrumul also performed.

The show concluded with the Danish artists’ rendition of Waltzing Matilda. It truly was a magnificent evening.
Unfortunately, we didn’t get to meet the Crown Prince couple.

The Sydney Opera House invited Denmark to participate in the 40th Anniversary celebrations of the Opera House, designed by Danish architect Jorn Utzon. The evening belonged to the Danish people and underlined the enduring links between Australia and Denmark, first forged by the Opera House.

Back on the bus to Pullmans Hotel, a nightcap or two, and off to bed in luxury.

The morning began with an excellent buffet breakfast, as good as, if not better than, last night's dinner. Check out at 10 am and off for some sight -seeing around Circular Quay, before heading to the airport for the trip home.

The flight home was the most turbulent flight I have ever been on, better than any roller coaster I have ridden. Tanya no longer wants to fly, and I can't blame her - it was rough.

The total Royal Treatment package was an awesome experience. Thank you to the people of Coloplast, a Danish company.

A very big Thank You to PN-DU because without your email re. the Coloplast competition, this experience would not have happened.

Above: The Crown Prince Couple; image by Jakob Boserup
Right: Chris and Tanya, both looking gorgeous!

PRINCIPLES OF NUTRITIONAL MANAGEMENT OF CHILDREN WITH CHRONIC LIVER DISEASE

Reproduced with permission of the author and the Centre for Research On Nutrition Support Systems, publisher of Nutrition In Disease Management, New Delhi, India (Update Series 58 April 2013)

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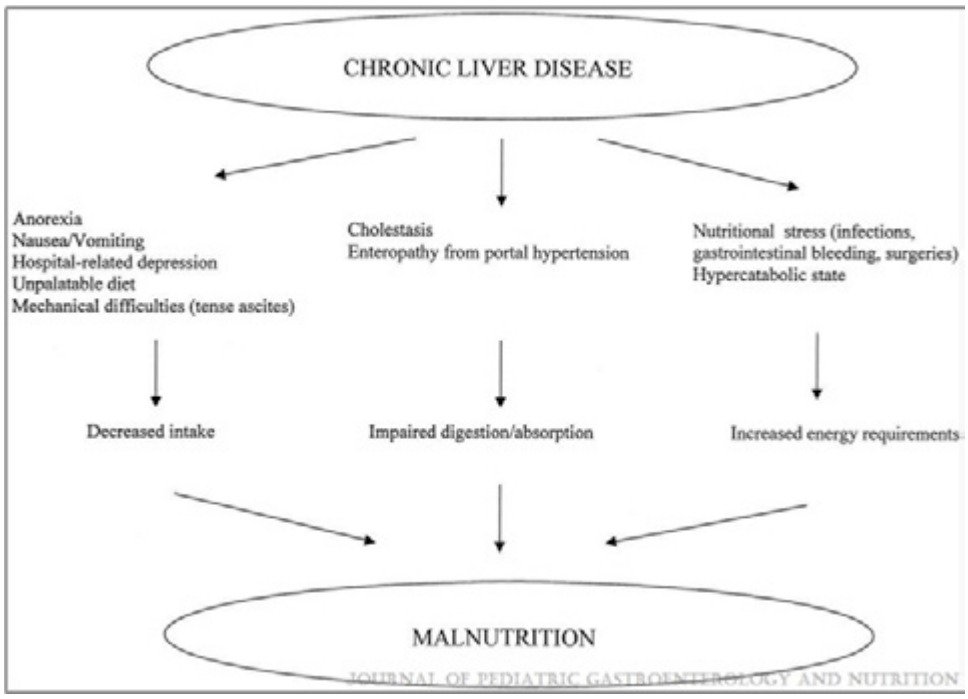
Chronic liver disease (CLD) is a complex multi-system disorder with a propensity to affect, sometimes severely the nutritional status and wellbeing of children. Malnutrition is a multifactorial process in children with CLD and carries an independent risk of morbidity and mortality. A thorough nutritional assessment is needed to determine the degree of malnutrition present and to tailor the nutritional intervention. With the advent and success of pediatric liver transplantation (LT), it has become paramount that the nutritional status of children be optimized prior to LT. Studies have conclusively proved that pre-transplant nutritional status affects post transplant outcomes.

Causes of malnutrition and multivitamin deficiency in CLD

The etiology of malnutrition in CLD is complex. The following figure is a lucid line diagram which shows the process in children with CLD.

The severity of malnutrition may not correlate with the degree of vitamin or trace mineral deficiency or the degree of hepatic dysfunction.

Adapted from: Ramaccioni, Valeria; Soriano, Humberto E.; Arumugam, Ramalingam; Klish, William J.Journal of Pediatric Gastroenterology and Nutrition. 30(4):361-367, April 2000.



Assessment of nutritional status in a child with CLD

A number of obstacles complicate the ability to accurately assess the nutritional status of a child with liver disease. Body weight may be deceptive because organomegaly from an enlarged liver or spleen, edema or ascites can mask weight loss and actually increase or falsely inflate the weight. Height may be a better indicator of malnutrition in these children and can be a reliable tool to determine chronic malnutrition. A decrease in height for age percentile may be indicative of the duration of malnutrition. Triceps skinfold and arm circumference measurements provide a sensitive indicator of nutritional status in children with chronic liver disease. As lower extremities are more prone to peripheral edema and fluid retention than upper extremities, upper extremity measurements may be a better indicator of body fat stores and muscle mass.

Reduced fat fold thickness and mid upper arm circumference have been observed in children prior to weight or height reductions. In children, early reduction in fat and muscle stores reflects the preferential utilization of fat stores to conserve protein stores for energy in the malnourished state. To optimize the accuracy of anthropometric measurements, it is prudent that the same observer take serial measurements using a standard technique. Measurement of plasma proteins including albumin, transferrin, prealbumin, and retinol-binding protein actually reflect the severity of liver disease, rather than the nutritional status of the child. Similarly, immune status and nitrogen balance studies cannot be used as proxy markers of the nutritional status. Dual energy x-ray absorptiometry (DEXA scan) is a non-invasive method with minimal radiation that provides accurate measurement of body composition and bone density. This has emerged as a reliable tool in centres where it is available.

Nutritional Measures to be taken in a child with CLD

For reasons mentioned previously in the text, the daily caloric intake of the child is often lower than the daily recommended intake. However, due to increased resting energy expenditure (due to the CLD) the caloric intake should be increased. The aim is therefore to reach a caloric intake of 130 % of recommended daily caloric intake for age. If this goal is not achieved by oral feeding, nasogastric feeding should be started, supplying sufficient amount to reach 150 Kcal/kg/day. These measures should be initiated as soon as abnormal weight gain is observed, or even anticipated. Once malnutrition becomes established, it becomes increasingly difficult to restore body mass. It is important to emphasize, that children with CLD require 2.5-3g/kg of protein daily. Protein intake need not be entirely restricted in patients with hepatic encephalopathy.

Fat

Steatorrhea is frequently observed in patients with cirrhosis and/or chronic cholestasis. There is a poor correlation between the degree of biliary obstruction and the amount of fat excreted in the stools. Intraluminal bile salt concentrations are below the critical micellar concentration such that intraluminal products of lipolysis cannot form micellar solutions. A prolonged prothrombin time is seen often which corrects with parenteral vitamin K administration pointing to poor fat-soluble vitamin absorption.

Treatment with a low fat diet supplemented with medium chain triglyceride (MCT) (C8-C12 fatty acids) containing formulas or MCT oil helps to decrease the degree of steatorrhea and may help to improve the nutritional status of the child. MCT-enhanced diets can also improve energy intake in older children with cholestasis. MCT does not require intraluminal bile salts for micellar formation in order to be absorbed in the intestinal lumen. They are relatively water soluble and directly absorbed into the portal circulation. Essential fatty acids (linolenic, linoleic and arachidonic acid) also need to be supplemented especially in neonatal cholestasis. Corn oil or safflower oil containing linoleic acid can be added to food or to MCT containing preparations.

Carbohydrate

Carbohydrate intake should equal 60% of the daily caloric intake of the child. If there is any evidence of lactose intolerance, the diet should be tailored accordingly.

Fat soluble vitamins and minerals

Bile acids in the intestinal lumen are not only important for fat absorption from the lumen but also for fat-soluble vitamin absorption. Vitamins A, D, E and K are all dependent upon intraluminal bile acid concentration. When the intraluminal bile acid concentration falls below a critical micellar concentration (1.5-2.0 mM), malabsorption of fat-soluble vitamins ensues. Bile acid binding resins (Cholestyramine), may deplete enteral bile acids and interfere with fat-soluble vitamin absorption from the intestines. Vitamins A and E in addition, require hydrolysis by an intestinal esterase that is bile acid dependent prior to intestinal absorption.

In infants, cholestasis leads to rapid depletion of body stores of fat-soluble vitamins with both biochemical and clinical features of deficiency evident unless adequate supplementation is utilized. Evaluation for fat-soluble vitamin deficiency, supplementation and monitoring are all necessary for infants and children with cholestasis. In order to alleviate the malabsorption of fat- soluble vitamins in chronic liver disease, a doubling of the daily dose of an aqueous preparation of vitamins A, D, E and K may be utilized as a starting dose.

Vitamin E, in the form of D-α-tocopherol polyethylene glycol-1000 succinate (TPGS), is the only fat-soluble vitamin that comes in an oral water-soluble formulation. Serum levels of vitamin E should be monitored (600 to 1400 μg/dl), and the ratio Vitamin E (μg/dl) / Total lipids (mg/dl) should be kept above 0.6.

Hypocalcemia, due to dietary calcium deficiency or malabsorption, can lead to resultant rickets. Large doses of vitamin D supplements (5-20,000 IU/day) may be required to correct this condition. Zinc deficiency is common in cholestasis. Zinc is a common cofactor of various enzymatic systems, and deficiency may affect liver metabolism such as for example ammonium metabolism and urea cycle. Iron deficiency may be observed and is most often associated to occult or overt GI bleeding. Thus, both zinc and iron need to be supplemented in children with cholestasis.

The exact details are given in Table 1.

Table 1: Vitamin and mineral requirements in CLD

Nutrient	Oral formulation	Oral dose	Parenteral formulation	Parenteral dose	Monitoring
Vitamin A	Available	5000-25000 IU/day	Intramuscular injection	50000 IU/month	Serum level between 400-500µg/L
Vitamin D	25 OH fat soluble	2-4µg/kg/d	Intramuscular injection	100000IU/6 weekly	Serum level between 25-30ng/ml
Vitamin E	Water soluble TPGS	25IU/kg/d	Intramuscular injection	10mg/kg every 2 weekly	Serum level between 5-15mg/L
Vitamin K	Fat soluble vitamin K	2.4-15mg/d	Intramuscular or intravenous injection	10mg every 2 weekly	Prothrombin time
Zinc	oral	1mg/kg/d			Zinc level, ALP
Water soluble Multivitamins	Oral formulation	2 X RDA			-

Malnutrition and multivitamin deficiencies in children can thus be circumvented in children with adequate nutritional support. This endeavour, will not only blunt the disease progression, but will make the child a suitable candidate for liver transplantation, if and when the need arises.

Suggested Reading:

1. Sibal A, Gupta S, Bhatia V, Kapoor A, Wadhawan M. Liver transplant for children: Indian scenario. Indian Journal of Transplantation. 2011;5(2):53-5.
2. Sokal EM, Goldstein D, Ciocca M, Lewindon P, Ni YH, Silveira T, et al. End-stage liver disease and liver transplant: current situation and key issues. J Pediatr Gastroenterol Nutr. 2008;47(2):239-46. Epub 2008/07/31.
3. Kelly DA, Sibal A. Liver transplantation in children. Indian Pediatr. 2006;43(5):389-91. Epub 2006/06/01.
4. Ramaccioni, Valeria; Soriano, Humberto E.; Arumugam, Ramalingam; Klish, William J. Nutritional Aspects of Chronic Liver Disease and Liver Transplantation In Children. Journal of Pediatric Gastroenterology and Nutrition. 30(4):361-367, April 2000.

GATHERINGS

WORDS BY *KAREN*

As we celebrate PN-DU's 5th year of existence, it's encouraging to look back over our many gatherings so far and to see how we have grown in such a short time. As all our members testify, there is overwhelming benefit and value to consumers and carers in being able to meet and have contact with others in similar circumstances, as well as increasing our knowledge and understanding of this complex treatment for Intestinal Failure.

• Our inaugural PN-DU gathering took place in Christchurch in the first year of PN-DU's existence, in November 2009, alongside AuSPEN's Annual Scientific Meeting. Three HPNers/carers and a number of supportive clinicians attended from Australia, New Zealand and Denmark. An exciting start to a bright future for PN-DU.

• In October 2010 we aimed high and held our own PN-DU satellite symposium in conjunction with Australian Gastroenterology Week and AuSPEN's ASM at the Gold Coast, Queensland. The one day symposium was open to clinicians as well as HPN consumers/carers and included various highly qualified international and local HPN experts, with open forums included in the programme. We had PN-DU members travelling from New Zealand, Tasmania, Melbourne, Sydney and Newcastle for the symposium and the opportunity to meet with other members. Every member who attended has fond memories of that special event.

• In November 2011 we held a mini-symposium in Sydney, again with various speakers and question/answer time, but aimed just at HPNers and carers. It was a great event to welcome new PN-DU members.

• With an increasing number of PN-DU members in Sydney, in 2012 we began holding social picnics in Sydney for HPNers, carers and families. These wonderful events have continued every 6 months.

• In September 2013 Auckland joined in the fun and hosted PN-DU's first social gathering for Kiwi members and we're hoping for many more to follow.

• Likewise in November 2013 the first member gathering took place in Tasmania.

In the years ahead, PN-DU looks forward to providing more of these opportunities for HPNers, carers and their families to meet, whether it's simply to talk and share stories or also to learn and gather information from HPN experts.

Left: Christchurch, New Zealand
Bottom Left: Gold Coast, Queensland
Bottom Right: Sydney: Miranda, David, Gil and Fay

Left: Sydney
Bottom Left: Hobart: Ray, Gillian, Jacqueline and David
Bottom Right: Auckland: Gil, Lisa, Sam, Shirley, Candace

APPLE ISLE GET-TOGETHER

WORDS BY *GILLIAN*

Ray, Gillian, Jacqueline and David with (I think) Hugo the dog.

In November, Ray and I took three weeks of my Long Service Leave and toured around Tasmania. As we were planning to spend a week based in Hobart, it seemed a great chance to meet up with Jacqueline and put faces to names. Unfortunately, we weren't in the north long enough to suggest a meeting with our other Tassie PN-DU member.

Jacqueline and her husband, David, very kindly invited us to dinner, so we set off and headed for their home at the base of Mt Wellington. Unfortunately it was an overcast, rainy evening, with such low cloud that the looming mountain at the rear of their property couldn't be seen! It also meant that it was too wet to explore their lovely garden.

Jacqueline and David share their home with three friendly rescue dogs – two Golden Retrievers, and one Airedale. These are dogs who, for whatever reason, people no longer want, and over the years they have had many such dogs.

Having read many comments that Jacqueline has written about her home, about the gaps in the stone, and how cold it can get, it was lovely to see that the renovations are finished (at least as much as houses are ever 'finished') and they have a delightful, comfortable home. David did a wonderful job fitting out their kitchen.

After a delicious meal, we sat and chatted around the fire for a couple of hours and learnt a bit more about each other and our health issues. It is so much easier to listen and talk to people, than to type and read a conversation. I would strongly recommend meeting up with other HPNers when the opportunity arises.

Thanks so much, Jacqueline and David, for your warm welcome – one day we might be able to reciprocate in Sydney!

LOOK WHAT WE'VE DONE! (PN-DU ACHIEVEMENTS)

WORDS BY *RACHEL*

The past 5 years have been busy for PN-DU. In addition to our foundation goals of providing support and information within our membership, PN-DU has also recently increased its role in advocacy and awareness-raising.
During 2012 and 2013 alone we have:

• Conducted two member surveys: (1) to build baseline information about perceptions of hospital compliance with clinical guidelines published by AuSPEN; and (2) to better understand the costs and financial impost facing HPN consumers.
• Presented the findings of our first survey at the 3rd national conference for Nutrition & Hydration in Melbourne in 2012, and the British Association of Parenteral & Enteral Nutrition southern regional conference in Southampton UK in 2013.
• Submitted an organisational response to, and provided individual member input into, the HealthPACT review of Australian and New Zealand Intestinal Failure and HPN services. Our submission highlighted the systemic issues identified within our membership and was well received by the reviewers, who sought permission to reproduce the findings of our first survey, in full, in their final report. Our submission contained three key recommendations:

1. establishing a nationwide IF and HPN service in Australia;
2. improving practical supports for HPN patients and carers to help them cope at home; and
3. strengthening consumer participation in IF and HPN policy and planning initiatives, including establishing a formal mechanism to facilitate consumer input involving health care providers, AuSPEN and consumers.

• Contributed to the production of a patient factsheet on PN for NSW hospital inpatients and their families (presented as a poster at AuSPEN ASM October 2013)

Tanya Hazlewood of Agency for Clinical Innovation, Suzie Daniells, dietitian, and Karen with the poster presentation of the patient PN factsheet project at AuSPEN ASM 2013.

• Expanded domestic and international travel options for members by instigating the approval for operation of the Bodyguard® infusion pump throughout flight on all Qantas airlines.
• Produced several publications including 6 quarterly 'Drip Line' newsletters containing member stories and interesting clinical articles, and booklets containing travel information and general non-medical tips.
• Promoted an annual HPN Awareness Week in collaboration with the Oley Foundation (USA) and other overseas support groups.
• Exhibited and attended Australian Gastroenterology Week (and AuSPEN conferences when they combined) to raise awareness about intestinal failure and HPN.
• Initiated contact and discussion with Baxter Healthcare, organised site visits of their pharmacy department and agreed on the

format and procedure to be followed for reporting HPN quality issues.
• Continued a private email forum providing information and peer support for consumers and carers and a website offering public information relevant for HPN in Australia and New Zealand.
• Organised social get-togethers for consumers, carers and families in Auckland, Brisbane and Sydney.

Future directions and emerging issues

Over the next twelve months, PN-DU intends to:
• share and stimulate discussion about the findings of our survey on consumer costs associated with HPN dependence;
• seek early input into the implementation of recommendations arising from last year's HealthPACT review of IF and HPN services in Australia and New Zealand;
• strengthen links with AuSPEN and seek to facilitate consumer input into the development of the new Australasian HPN clinical practice guidelines;
• strengthen international links with Oley (USA), PINNT (UK), Italian, Polish and other European patient support groups through ESPEN/ASPEN;
• work towards establishing a committee comprising clinicians, industry and consumers to review new and existing product designs etc, modelled on overseas examples such as the UK LITRE Committee;
• register PN-DU as an incorporated association in NSW (with a view to additional registration as an Australian Registered Body) and obtain deductible gift recipient status to commence operation as a formal non-profit organisation as soon as possible;
• seek to gain sponsorship to send a PN-DU representative to future Oley Conferences to strengthen our links to overseas HPN support groups; and
• celebrate our 5 year anniversary throughout 2014.

Our ongoing advocacy work will highlight a number of concerning issues affecting our members, including:

• Resisting attempts in some Australian jurisdictions to shift costs to HPN consumers for costly items such as: HPN solution; sterile HPN single-use giving sets; and sterile single-use consumables needed to care for a central venous access device at home. We consider this trend to be very alarming. If it continues, HPN therapy in Australia would be beyond all but the richest families in our society, and would jeopardise patient safety if patients were in a position of sourcing their own consumables and rationing their use of items that need to be discarded without hesitation in the event of contamination or expiry.
• Encouraging improved compliance by HPN centres with the AuSPEN HPN Clinical Guidelines. On our private member forum, issues continue to arise that reflect the serious patient safety issues identified in our 2012 pilot survey eg the need for timely triage and early treatment of potential central line infections.
• Advocating for local adoption of systems and products used overseas that make life on HPN safer and simpler for patients.

PN-DU CHRISTMAS CARDS

WORDS BY *GIL*

For Christmas 2013 we decided to produce a PN-DU Christmas Card for members to purchase and send to family and friends.

Carla produced a delightful Christmas tree design and we found a lady in Auckland who prints cards as a hobby.

Five hundred cards were printed (at a total cost , including P&P, of NZD724) and were all purchased by 14 members in Australia and New Zealand. This made us a small profit of NZD134.

Questions to members for next year:

• Should we repeat the exercise or are more and more people using E-cards?
• Should we still aim to make a profit?
• If so, how can we increase sales (and profit)?
• Can we publicise outside of PN-DU?
• Do we change the design and wording each year?

PN-DU HOSTS OLEY'S REPRESENTATIVE IN THE HARBOUR CITY

WORDS BY *KAREN*

Following on from Dave and Miranda's trip to Oley conference 2013 in the USA, they were able to return the warm welcome shown to them when Darlene Kelly MD PhD FACP, Oley's Science and Medicine Adviser, made a flying visit to Sydney in January 2014. Sydney's harbour managed to sparkle in between grey clouds drifting across the sky,and a visit to Taronga Zoo provided opportunity to see the beautiful harbour views as well as some unique Aussie animals.

Darlene also kindly allowed time to meet with a couple of PN-DU representatives. It was a wonderful opportunity for Karen and Gillian, along with Miranda, Dave and little Ariel to meet with Darlene, putting faces to names and discussing all manner of things HPN and support groups.

As distance and travel restrict the amount of 'in person' contact we have with other support groups, we really appreciated Darlene's generosity of time, enabling this gathering to happen. We look forward to working more closely with Oley as well as other overseas support groups as together we seek to support those families living with HPN and advocate for best practice.

L-R: Miranda, Karen, Gillian and Darlene

ANOTHER SYDNEY GET-TOGETHER

WORDS BY *GILLIAN*

Our last Sydney picnic for HPNers and their families was on Sunday 3rd November 2013. It was lovely to see some familiar faces, as well as welcome new ones. It was a pleasure to meet Debbie, who heard about the picnic in the flyer sent with her PN delivery, and her daughter Jessica. Chris and Tanya showed up just before everyone left – they had been with Jordan and Logan, their grandsons both on HPN, who were in hospital in Sydney, and came to pick up some vests that one of our members gave to them to adapt for the boys.

Our next HPNer picnic will be on Sunday 9th March, any time after 12:30pm. It will again be at Riverside Park, Silverwater . Bring blanket/chairs, food, umbrella for shade and the family. (In case of bad weather, ring Karen on 0413 715 187 for location.) We hope to meet even more new friends.

Sadly, since this gathering, young Jessica has passed away. Our thoughts and prayers go to her family and friends as they grieve her passing. We are very grateful to have met this beautiful young woman and are really pleased we will continue to have contact with her mum, Debbie.

raising children network
the australian parenting website

www.raisingchildren.net.au

We include the following information, which may be of interest to some of our Australian parents of children on HPN.
Managing a child or children with different disabilities, including chronic illness can be very challenging.
We know the stress it can have on the entire family unit. We often receive questions from parents on where they can go to for additional support.
The Raising Children Network shows a video on where to start for respite care when dealing with children with disabilities. They also offer advice for siblings, ways to look after yourself and managing stress at home for the entire family.

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

On-line donations:
PayPal via our website www.parenteralnutritiondownunder.com
Or direct deposit (New Zealand dollars only) to IPANEMA's bank account with the notation "PN-DU":
NBNZ 22 06 0273 0308 799

COMMITTEE MEMBERS

Convenor: Karen
Minute Secretary: Gillian
Treasurer: Gil
Regional Reps; QLD: Rachel, NSW: Gillian/Karen, TAS: Jacqueline, NZ: Jodee, US affiliate: Jodee
Paediatric Coordinator/Advocate: Rachel, Kelly
Adult Coordinator/Advocate: Karen, Gillian
Incorporation/Registration: Miranda
Webhost: Jodee
Newsletter Editor: Gillian
More about our other committee members in future newsletters.

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.parenteralnutritiondownunder.com**

Designer: Carla