



Welcome to our first Dripline for 2015. I hope your Christmas celebrations were happy, and that 2015 will be a healthy and prosperous year for you. Many of our PNDU members share their Christmas stories in this issue, and two of our young members have had a birthday. We read about some of the conferences that PNDU Management Committee members have attended, flying the PNDU flag, especially our own PNDU-run symposia in Auckland, prior to the AuSPEN ASM. Read about our new, updated, travel booklet – a must for HPNers planning a trip – as well as our updated restaurant card and business card. Find out why some of our members live where they do, celebrate with us one of our young member's 'graduation' from pre-school, as well as other informative articles.

Gillian - Editor

ISSUE 10
FEBRUARY
2015

IN THIS ISSUE:

- [OUR MEMBERS' CHRISTMAS STORIES](#)
- [AGM REPORT: WHAT YOUR MANAGEMENT COMMITTEE HAS ACHIEVED IN 2014](#)
- [BIRTHDAY CORNER](#)
- PNDU IN NEW ZEALAND, 2014:
 - [PNDU'S SYMPOSIA AND AUSPEN'S HPNER'S WORKSHOP](#)
 - [PNDU INAUGURAL AWARDS](#)
 - [PNDU AT THE AUSPEN ANNUAL SCIENTIFIC MEETING](#)
- [A VISIT TO BAXTER'S AUCKLAND PHARMACY](#)
- [CHRIS SPEAKS AT THE NATIONAL HOSPITAL PHARMACISTS' CONFERENCE, DARWIN](#)
- [A BREAKTHROUGH ANTI-BACTERIAL GEL](#)
- [GIL AT THE OLEY CONFERENCE, 2014](#)
- [SAM'S PRE-SCHOOL GRADUATION](#)
- [A DAY IN THE LIFE OF AN HPNER](#) – LIVING A DOUBLE LIFE ON HPN
- [FEEL LIKE A HOLIDAY?- PNDU'S UPDATED TRAVEL BOOKLET](#)
- ['I CAN'T EAT A FULL SERVE'](#) – PNDU'S UPDATED RESTAURANT CARD
- ['WHAT DOES SUPER JONNY DO WHEN MUM GETS SICK?' – A CHILDREN'S BOOK](#)
- [WHAT'S IN YOUR BAG: LIPIDS – WHY THEY SHOULDN'T BE FROZEN](#)
- [CONTAMINATED SINK DRAINS](#)
- [LIVING NEAR A HOSPITAL](#)
- [TAUROLIDINE LOCKS](#)
- [COLONOSCOPY HUMOUR](#)
- [LATEST SYDNEY GATHERING, NOVEMBER 2014](#)
- [HPNERS WITHOUT COMPUTERS](#)
- [THANK YOU!](#)



OUR CHRISTMAS STORIES

WORDS BY GILLIAN

I asked our members, on our Googlegroups Forum, what they did for Christmas. The answers were many and varied and show that even those living with Intestinal Failure and their families can find ways to enjoy festivities at this time of the year.

Gillian

I began Christmas celebrations on Christmas Eve, by attending my church's carol service and singing in the choir...attached to my PN. On Christmas day, I got the turkey ready for cooking, and went to church. My dad drove from Gosford and my two children and daughter-in-law came for lunch. We had the turkey, which despite my temperamental oven, cooked well, followed by Christmas pudding and brandy butter. Yum. Luckily I'm able to eat normally, although I don't absorb nutrition from the food. One night, we went for a walk around a local suburb admiring the Christmas lights – Ray carrying my 3kg backpack, me needing to remain close by!

Lynden

Kathy and I enjoyed a peaceful and relaxing Christmas. I am at home, with minimal eating, but enjoying feeling reasonably well. As I'm not eating much, we didn't cook, which is a major departure from our traditional get together! We went to Kathy's son's home for breakfast. They had eggs and bacon etc and I had a small bowl of cornflakes with hot milk, followed by a delicious small portion of home-made trifle. Yum!! Around lunchtime, we returned home and snoozed in the recliners, listening to ABC radio. Late in the afternoon, Kathy's son and daughter arrived with families and stayed the night with 3 of our 5 grandchildren. My 3 children with the other 2 grandchildren were at my son's house in Penguin in Northern Tassie. We really enjoyed a special Christmas with the emphasis on family, rather than food.

Jacqueline

We postponed Christmas until the 26th due to other things happening, but it was special, as we spent our first Christmas with our soon-to-be daughter-in-law, Jan. She and my son arrived mid morning, along with another "orphan" friend of David's and a special surprise visit by Jan's sister and her husband and child. It's the first time in 27 years we had company. Despite a little rain in the morning, the weather was lovely. We had a great time and I managed a few mouthfuls of home-made ice cream...yum

Fay

Our Xmas started with 2 daughters arriving after breakfast with their children. Presents were distributed and all were very happy. After they left around 11am, we went to Teralba to my other daughter's, where grandchildren and great grandchildren were assembled and enjoyed a great Xmas dinner all cooked by my son-in-law in the bbq on the spit (beef, pork, lamb and chicken.) Unfortunately, I was only able to taste a little ham and potato bake, but otherwise I had a lovely day. In the afternoon about 4pm we then travelled to Wallsend to visit Lindsay's sister and mother. His mother is 90 and going great. They were all off to Hobart the next morning to welcome the boats in at the end of the Sydney to Hobart race. (Lindsay's nephew sails in one of the smaller boats.) We then went home to have a quiet night and I had a night off HPN. Wow!

Graeme

We started as usual watching Carols by Candlelight on Christmas Eve, then before going to bed, we left the door of the Coonara open (so Santa could get down the chimney), and the Christmas Tree lights on (so Santa would know where to put the presents).

On Christmas day we went to my sister's place in Bairnsdale, and had a wonderful Christmas dinner with their family. Carol was only able to eat a very small amount, but we shared a wonderful time together.

Monika

I hope everyone had a great Christmas. My Christmas was spent sleeping in until our daughter woke us up so she could open all her presents. She loved everything we got her. After that, we watched a movie as it was too hot to cook or eat. We had our Turkey for dinner. It was nice.

Sal

My Christmas started when we collected my daughter from work, and with my learner driver son at the wheel, we toured the local area looking at Christmas lights. I awoke the kids at 7 on Christmas Day with our dog Pip waking them by jumping on them and licking them! We had Belgian waffles for breakfast, then exchanged gifts, before rushing to church. After church, we raced home to pack the car and cook a salad and head to my parent's place, only to sit in traffic. We got there eventually and had a lovely lunch with my parents, brother and sister, parents and sibling-in-laws and nieces and nephews. The highlight was my Mother almost setting the table alight when she lit the brandy for the Christmas pudding! We had a walk around the block before we had exchanges of gifts. We went home to crash and had a quiet night at home. I got to eat this Christmas, the first in about 4 years. It was yummy.

Jane

I had a lovely day. We began it by visiting our children's church where they all go, so we saw all 6 grandchildren there, too. After

a great service, we all met at our youngest daughter's house. First there were presents, then a swim...for me, the first time for ages. And the swim was fantastic! I put a drainable stoma bag on my CVC and fed it into the bag and stuck the bag down. It worked really well and of course was waterproof. Then a magnificent turkey dinner which I was able to enjoy too...my plate was a small one and I managed to have a small taste of everything with not too much trouble after. A great day, especially with family...and many old friends at church too.

Renee

We do not celebrate Christmas and Channukah is over...but we had a lovely day with friends and our son visiting from Sydney. It was wonderful to simply relax, walk on the beach with the dog, swim - not me, but others - and generally just celebrate the joy of being together.

I can eat (really tough for those who can't!) and am feeling much better than I have for a number of months, so am filled with gratitude and appreciation for this home [in the South Coast NSW] in the midst of such beauty.

Miranda

The kids had their first Christmas tree this year, so we opened some presents in the morning, before heading out to join our extended family and friends, about 40(!) of us, for a picnic by the beach in Balmoral (a 20yr tradition). We had Ariel [aged 4, on enteral feeding, as well as HPN] off her enteral pump most of the day for a special occasion and she was really enjoying and making the most of her freedom. She had a lovely day playing with her cousins, climbed trees and went for a wade in the water as well! We also celebrate Channukah with Dave's family so it has been almost two weeks of festivities!

Karen

My Christmas was very low-key, as I'm still terribly tired from a full year and couldn't cope with even the thought of packing medical luggage again to travel to family. Mum graciously came and stayed with me instead.

I connected up to my PN early on Christmas Eve so we wouldn't be late for the early Christmas Day service at church. Lunch was supposed to be with Mum and my elderly neighbour, however he ended up with a tummy upset so couldn't make it. (Thankfully that was BEFORE he ate my cooking!) I took him a meal to eat later. The turkey took FOREVER to cook - I'm blaming the oven! - but it was still very delicious. [Note to self: next time start cooking it 10hrs before required!] Followed by trifle, it was a meal I could eat and enjoy without problems. And the obligatory apple cider is still very enjoyable even if diluted 1:10 to help prevent excessive dehydration!

Phone calls and messages to and from various family and friends, then it was connecting up to PN early again before spending a wonderful Christmas evening with a small group of friends. Very special and feeling very blessed to be well enough to enjoy the celebrations.

Rosie

I am so happy you all had a lovely Christmas as I did. My 3 children flew home and we had a lovely few days, very low key, focusing more on being together and enjoying each other's company. Our Christmas dinner consisted of oysters, prawns, ham and salads, easy to prepare and I managed to eat a couple of prawns and for desert my daughter insisted we have cheesecake, of which I had a small piece. Last year we had to cancel a planned holiday for Christmas as I got an infected porta-cath and had to go to hospital, so it was wonderful to be well this year.

Shirley (mother of 5 year old Sam, on HPN)

We escaped ClubMed [ie, hospital] at 5 pm on Christmas Eve on the proviso we had Sam pop in for a Christmas IV antibiotic infusion on Christmas Day. We had a fun Christmas morning around the tree laughing, opening gifts and listening to carols. We headed off to family for a late lunch, but Sam missed this as we had to get back to ClubMed. The upside of this was that Santa had left a bag of goodies for Sam in hospital, so Sam had two visits from the jolly red guy! Sam loved his day, being with both his families (real and hospital) and was just the perfect age for being excited and delighted by it all!

Chris (2 grandsons, aged 2 and 6, on HPN)

Christmas 2014, Oh what a joy! We gathered at Brooke & Micks house and were joined by Katie and Brendan. Our Christmas day started with a 6:30 am wakeup call from 3 very excited grandchildren "Nan & Pop, Santa has been, come and see all the presents". The morning was spent learning how to train your dragon, building Lego and playing with assorted planes, trains & automobiles. Pop is still the biggest kid of them all. Dinner was a mixture of ham, salads and seafood (mashed potato and gravy for Logan) enjoyed by all.

2014 was Jordan's 6th Christmas and our first without medical dramas and hospital admissions, so we were able to spend the entire day at home together as a family.

Boxing Day was a picnic in the park with extended family. We chose a park with plenty of play equipment to keep Jordan and Logan occupied and away from the water, while Dylan enjoyed swimming with his cousins.

Another member sadly emailed a few weeks after Christmas that she was sick over Christmas and New Year. We hope that she, and everyone else, will fare better in 2015.

AGM 2014 – CHAIR'S REPORT

WORDS BY KAREN

PNDU is run by volunteers who are themselves living with Intestinal Failure and HPN. As a result, the wheels can turn quite slowly as one or more members of the Management Committee (MC) deal with illness, hospitalisation or simply the busyness of life. In light of this, it has been very encouraging to have a look back at all that has happened in the year to our AGM in November 2014, and all of this on top of our primary purpose of providing opportunities to give and receive support.

1. Over 30 Kiwi and Aussie HPNers represented on our private forums
2. Four editions a year of Dripline – 91 people receive Dripline email with average of 65% clicks
3. 1 HPN member passed away in January – Jessica
4. A couple of new HPN members in Facebook group which was started in May
5. Celebrated our 5th Birthday fairly quietly in January with special edition of Dripline and Birthday email
6. Celebrated the 4th HPN Awareness Week in August with the theme of PNDU being synonymous with HPN support in Australia and NZ
7. PNDU gatherings – 2 in Sydney; Gil and I met Janine, and Sharyn/Steve in Perth, as well as hospital staff; and now another Auckland gathering
8. PNDU symposia held in Auckland over two mornings. Three guests invited to speak as well as Gil and Karen
9. Held 9 MC meetings since last AGM in December 2014
10. Hospital flyer was sent out to 36 HPN reporters, plus all NSW dietetic departments
11. Various articles published:
 - a. stories about members in mainstream media: Kelly, Sal, Shirley, Gil/Lisa
 - b. PNDU articles published in ACCA, Kids Foundation, JGENCA, APA
12. Guidelines developed on information to be used when representing PNDU
13. PNDU Christmas cards 2013
14. New logo
15. Redesigned restaurant card, t-shirts, plus other bits and pieces
16. Medical doll/puppets is a work in progress – available, but seeking funding
17. Website – new format, information updated as necessary, still need work done to combine programs and for someone to keep info up-to-date
18. Poster presentations: NNNG, ESPEN, ASPEN, AuSPEN ASM (ACI poster)
19. 2nd and 3rd member surveys – just over 20 respondents
20. Survey invitation from Auckland City Hospital/Starship re resources to go home on HPN
21. HealthPACT review – individual plus group feedback, stating our support of national approach to IF, areas of concern, what we have achieved and can offer. First 2 surveys sent – 1st survey included in final report published and received August 2014.
22. Involvement in and attendance at inaugural international collaboration meeting in Geneva
23. Speaking opportunities about PNDU/life on HPN down under:
 - a. Chris – Darwin
 - b. Shirley/Karen/Gil – NNNG
 - c. Rachel/Karen – Brisbane/Sydney
24. Baxter liaison – reduced because of tightening of internal and government regulations, in line with findings of HealthPACT report. Hopeful for renewed communication lines. Attempts for another Sydney Baxter tour. Offer from Anica to visit Auckland Pharmacy.
25. AuSPEN liaison – first formal meeting November 2013 – very positive but formal follow up slow or non-existent. Nonetheless, we're encouraged by opportunity to speak about PNDU at AuSPEN consumer workshop. Next formal meeting following workshop. HPN register closed down in Australia due to privacy issues. Goal to continue being positive and sensitive to being a complementary organisation.
26. PNDU Annual Awards – a positive opportunity to acknowledge appreciation of great work by members and professionals
27. Big time-consumers:
 - a. Updated travel booklet – great resource for HPNers and hospitals, incorporates Baxter's new system of organising holidays as well as detail relevant to 'down under'
 - b. Registration and constitution – another labour of love which has required a lot of time in MC meetings and background research. Progress included a temporary move to include HEN until concluding we don't have sufficient resources. Decisions were made to not include hospital PN or hydration-only.

As convenor, I'm very grateful for the work and support of the MC, as able, while I have learned more about the role. There's always room for more assistance. It's a privilege to be able to offer the much-needed support to individuals (phone calls, emails, cards and letters) as well as, as a group (gatherings, programs, resources, forums). PNDU is fulfilling a very-needed role for HPNers and families and I'm looking forward to the year ahead.

24th November 2014

BIRTHDAY CORNER

WORDS BY GILLIAN

Three of our younger members celebrated a birthday during the past 3 months, an exciting milestone for each of them. Ariel turned 4, and both Bryley and Matisse turned 14. Matisse celebrated her special day on Christmas Day - 4 years post bowel transplant and continuing to do really well.

Below we learn more about how Ariel and Bryley celebrated and thank them for sharing their special day with us. Miranda writes:

Thanks so much for the birthday wishes, everyone! Ariel has had a packed day of celebrations, she has been thoroughly spoilt! Here is a picture of her blowing out her 3rd birthday cake of the day J We are having a Peppa Pig party for the girls (Eadie's birthday is on Friday) on Sunday (argh!). Poor Eadie has been suffering today as Ariel has been lording all her presents over her little sister (we are hoping Ariel will soon get the concept of sharing now that she is 4. Hmm fingers crossed!)

Ariel, 4



Bryley writes:

My 14th birthday was lots of fun. I had my 4 Besties over for a sleep over. We stayed up watching DVD's and talking until 4am. Struggled out of bed and then off to a yummy pancake place for breakfast. It was the best!!!!



PNDU'S AUCKLAND SYMPOSIA

WORDS BY KAREN

The last week in November 2014 was a big week for PNDU with lots of organising going on behind the scenes, not only involving symposia preparations, but also travel preparations for those of us who jumped the ditch from Sydney to be at the meetings. Quite a feat in itself, especially for Dave and Miranda travelling for the first time with Ariel on HPN and HEN.

After final preparations the night before, on the Monday morning at the Rose Centre in beautiful Devonport, Auckland, Gil, Lisa, Gillian, Chris, Miranda, Dave and I welcomed a nice size crowd to PNDU's 3rd symposium. It was wonderful for the various Kiwi and Aussie members of PNDU to finally be able to meet in person, after having known each other only through the internet. Lisa and Shirley – how lovely it was to finally meet in person! Moreover, it was wonderful to meet Sharron and Barry as well as Elspeth who cares for a young Kiwi HPNer. We were also very pleased to welcome representatives from Baxter Healthcare, Fresenius Kabi and Biomed (Biomed also generously providing pads and pens) and HPN clinicians.

The day started with Gil presenting the results of our most recent PNDU member survey on the differing set-up procedures HPNers are taught. To highlight the results, Gillian and I then did a mock-up of our own set-up procedures, which couldn't be any more different despite the fact that we began HPN in the same year and in the same city.

Back by popular demand, Prof Patrick Ball then gave an update presentation on filters for PN, showing how, in his expert opinion, filters can benefit PN patients as they will only block when there is particulate matter that needs removing before entering the patient's bloodstream. Despite the ethical inability to do a randomised trial on filters, the evidence is mounting, and various countries, including China and Korea, have mandated the use of filters in public hospitals. To see Patrick's slide presentation, please go to the [Clinical Information](#) page on our website www.parenteralnutritiondownunder.com.

I followed Patrick with a short talk on our newly updated Travel Information Booklet (see [article on page 22](#)) and then we heard from Gil again who presented Dr Kathy Gura's slides on the very relevant topic "To swim or not to swim". This topic is fraught with differing opinions and advice and it was good to hear a balanced, professional presentation on the genuine risks and how these may be mitigated. As Kathy originally presented to a US audience, Gil added information relevant to 'down under' with various beach water quality websites. As with any medical information that PNDU passes on, HPNers/carers were directed to discuss the issues with their medical teams. For Gil/Kathy's presentation, again, go to the [Clinical Information](#) page on our website www.parenteralnutritiondownunder.com.

International HPN consumer collaboration was the penultimate topic for the day in which I outlined what had been taking place to bring about this collaboration, what the purpose and goals are, and what happened at the first meeting held in Geneva in September 2014 which Gil and I attended (see also the article on this topic in our [Aug-Oct 2014](#) edition of Dripline).

We finished up the first morning session by announcing the winners of PNDU's inaugural Professional Awards and presenting the Lifetime Membership Awards (see [article on page 10](#)).

The afternoon was a wonderful time for HPNers and families to mix and mingle. It was great to have Ariel, Eadie, Sam, Candice and Jasmine all together, and to have time to simply relax and chat with others who totally understand life on HPN. All too soon, the day was finished with our AGM and dinner.

The fun continued the next day with another PNDU morning symposium, this time at Skycity Convention Centre in downtown Auckland. PNDU was once again very fortunate and privileged to have an old PNDU friend, Dr Fritz Schwenk, Professor of Paediatric Endocrinology, Mayo Clinic, USA, share his wealth of knowledge on paediatric Intestinal Failure and liver disease in a relaxed and open manner.

This was followed by Miranda's promotion of our updated Travel Information Booklet and Lyn Gillanders' presentation on an interesting international study, which she co-authored, on Quality of Care priorities for clinicians and HPN patients. This was previously presented as a poster at ESPEN 2014.

With Gillian and David welcoming and Chris and Lisa chairing, it was a great team effort and a very successful day and a half for PNDU. We are very thankful to all our speakers for generously sharing their time and expertise with us.

The time for learning wasn't over however! That second afternoon, we all attended AuSPEN's own inaugural HPN workshop for consumers – a full program of presentations by various clinicians covering topics including line infection management, chronic pain, gut adaptation, PN prescriptions, and a heart-warming presentation by young HPNer, Fleur, telling of her own experience on HPN and how, with the support of her medical teams and family, she has been able to transition from paediatric care to functioning as an independent adult. I was also given the opportunity to talk about what PNDU does as a support group, highlighting the importance and great need for support for Aussies and Kiwis living with HPN, how PNDU complements the work of hospital teams, and some of PNDU's activities and projects.

We very much appreciate AuSPEN's efforts to organise their half-day workshop for consumers and the time of all the clinicians who shared their knowledge and expertise with HPNers and families. It was a great initiative and we are very encouraged to hear that, based on the positive feedback received, AuSPEN is hopeful of organising another HPN workshop for consumers alongside AGW2015/AuSPEN ASM in Brisbane in September 2015.

With PNDU's symposia and AuSPEN's HPN consumer workshop, it was a very full 2 days' experience. Importantly, HPNers and families really appreciated the opportunity to learn more about this complex but life-saving treatment that is HPN, and to get to know others 'living with a drip'. PNDU also really values the relationships with industry representatives and clinicians which were strengthened through PNDU's and AuSPEN's consumer seminars and throughout the whole week.

And a very big thank you to our PNDU members who helped to make our 3rd PNDU symposia a great success.



Final discussions and preparations before the big week began, 'Chez Hardy'.

PNDU Symposia – Day 1



Delegates and speakers – Day 1



Our two wonderful chairs, Chris and Lisa



Gillian and Karen's mock-up of their set-up procedures



Patrick's presentation on filters



Time for delegates to mix and chat



Time for delegates to mix and chat



PNDU social afternoon for HPN families



Miranda with Ariel and Eadie, and Shirley with Sam at the PNDU social afternoon for HPN families



Bringing HPNers and carers together



Shirley, Lisa, Candace, Jasmine and Karen watching Sam



Sharron, Karen, Miranda and Gillian

PNDU Symposia—Day 2



Fritz presenting on paediatric Intestinal Failure and liver disease



Lisa presenting Fritz with a thank you gift



Lyn presenting her study on Quality of Care



Chris, Patrick and Fritz

AusPEN HPN Consumer workshop



PNDU AWARDS

WORDS BY KAREN

At our PNDU Symposia in Auckland in November 2014, I had the great privilege to announce the winners of **PNDU's inaugural Professional Awards**. It was a wonderful opportunity to show our appreciation for the great work and care of so many involved in HPN provision in Australia and New Zealand, and our inaugural winners were well-deserving of their awards.

- **Adult PN Professional of the Year** – Kath Angstmann, PN Clinical Nurse Consultant, Royal North Shore Hospital, Sydney
 - **Adult PN – Highly Commended** – Dr Vic Duncombe, Gastroenterologist, Prince of Wales Hospital, Sydney
- **Paediatric PN Professional of the Year** – Karyn Sanson, Clinical Nurse Specialist Liver/Gastroenterology, Starship Children's Hospital, Auckland
- **Company Employee of the Year** – Anna Dionisio, Deputy Team Leader, Baxter Healthcare Pharmacy Services, Melbourne
- And the big one **Outstanding Achievement Award** – Bev Haynes (retired), Baxter Healthcare Homecare Department, Sydney

All winners received glowing nominations from PNDU members, detailing their professionalism and dedication to patient care, often going beyond the 'call of duty' in order to give patients the best quality of care. Thank you to Professors Gil Hardy and Patrick Ball for adjudicating such a high calibre field of nominees.

Understandably, none of the winners were actually attending our HPN consumer symposia, but we were able to present a couple of awards over the next few days at both AuSPEN's HPN consumer workshop and the GastroNZ conference. The other award certificates have been forwarded to their recipients.

Following the PNDU Professional Award announcements, it was then time to also present award certificates together with PNDU's perpetual trophy to the winners of this year's **PNDU Lifetime Membership Awards**, recognising outstanding contribution to PNDU of member(s). The inaugural winners were announced in our [April-June edition](#) of Dripline: Brenda, Jacqueline and Gil, acknowledging the wonderful concept and hard work of all three people in growing the group through its early years. Gil received the award on behalf of all three winners.

Congratulations to all winners of PNDU's inaugural Professional Awards and Lifetime Membership Awards. We thank you for your work and dedication, making a difference in the lives of HPNers in Australia and New Zealand. We look forward to celebrating our PNDU awards and the work of professionals and members again in 2015.



Kath Angstrommann receiving her award from Karen for Adult PN Professional of the Year



Karyn Sanson being congratulated by Karen on winning the Paediatric PN Professional of the Year



Gil with the PNDU perpetual Lifetime Membership Award

PNDU AT AUSPEN AND NZ GASTRO SOCIETY CONFERENCE, 2014 – who, what, where, when, why?

WORDS BY GILLIAN

Last November, four of our NSW PNDU Management Committee (MC) members flew to Auckland for a week's PNDU business. Firstly, we were involved in our PNDU Symposia for HPNers and carers, followed by an HPN Workshop, presented by AuSPEN. These, you can read about in the previous article. The main reason for choosing Auckland as the location for our symposia however, was to also be able to 'fly the flag', so to speak, for PNDU at AuSPEN's Annual Scientific Meeting (ASM).

What is AuSPEN?

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 other responsibilities, look after those of us in Australia and New Zealand who are on HPN (Home Parenteral Nutrition).

When and Where was AuSPEN's ASM?

In 2014, the ASM was held in conjunction with 'Gastro NZ' at SkyCity, Auckland, NZ for three days from 26th to 28th November. AuSPEN Council members were also involved in other prior meetings, including their HPN consumer workshop and an important meeting with members of our MC on the 25th November.

Why do PNDU members attend?

New PNDU members mostly discover the existence of a support organisation for HPNers in Australia and New Zealand in one of two ways: they either stumble on us when they search the internet for information related to parenteral nutrition, or they are told about us by their clinicians. PNDU is very grateful to have been granted a free stand at AuSPEN's ASMs for all but one of the previous 5 years since PNDU's inception, twice in conjunction with Australian Gastroenterology Week. At each meeting, PNDU members 'man' a stand, with pamphlets and relevant information to hand out to these clinicians, so that they are aware of our existence and can pass the information on to their patients.

What was achieved?

- Before the ASM and for the second year running, PNDU's Karen, Gillian, Chris, Miranda and David met with 5 members of AuSPEN's Council, including their president and secretary. Each organisation reported the year's important events for their group, in order to keep each other abreast of their activities. We were able to congratulate AuSPEN on their workshop for HPNers and give positive feedback. It was also a chance to further our relationships with each other, as each time we meet, we get to know each other better. We gratefully thank AuSPEN Council for this opportunity and their time.
- We were given a community stand, at no cost to PNDU, where we could display our banner, our T-shirts, our new updated travel information booklet, our brochure for new HPNers, our anniversary issue of Dripline, our restaurant card, and other relevant handouts. The stand was manned by Karen and Gillian, as well as Lisa, David and Miranda as they were able. We looked great (if I do say so myself) in our new purple and white T-shirts!
- We were able to meet several clinicians, some of whom weren't aware of PNDU's resources and activities, discuss our travel information booklet, which should assist them when helping their patients organise travel, whether it be locally or overseas, and give them our handouts, as well as present another of our PNDU awards in person (see [PNDU Awards article](#) on page 10).
- We met with industry members, either for the first time, or to renew past acquaintances.
 - From Baxter, we had the pleasure of talking again with Hugh Davoren, Nutrition Product Specialist based in Auckland, NZ, who had attended our HPNer symposia, and kindly arranged a tour of the Baxter NZ pharmacy, on the Friday afternoon after the finish of AuSPEN's ASM. As you will read in Lisa's article, it was very interesting and we appreciate Hugh's efforts to organise it. We also had the privilege of meeting Mary Dillon, the new Neonatal and Paediatric Nutrition Manager for Australia and New Zealand, and David dal Pos, Senior Product Manager, Nutrition, based in Melbourne. David kindly volunteered to present our PNDU award for 'Commitment to Care – Company Employee of the Year' to Anna Dionisio, with whom he works. It was great to also briefly meet again with Megan Salon, Marketing Manager.
 - From Biomed, a New Zealand company, we met with Jessica Gordon, who also attended our HPNer symposia, and visited our stall a few times to chat. It was lovely to finally be able to meet Jessica in person, after having received valued support from her and Biomed over the past few years.
 - From Fresenius Kabi (FK), an international company which, along with Baxter, makes PN for hospitals in Australia and NZ, we met again with Charlotte Jamieson, from Sydney, and with Angela McKee, the new

FK representative for New Zealand, who had both also attended our HPNer symposia. It was lovely to be able to meet again with our FK friends.

All industry representatives were very supportive of PNDU as a patient support group, and all indicated a willingness at some stage to potentially sponsor some of our admin costs.

- We met with people representing other community groups and were able to exchange information.
- We received a voucher to obtain a free e-copy of a book written for children to de-mystify hospitals, a press release of which is included in [this issue on page 23](#).

Although it is expensive for our members to assist PNDU exhibit at AuSPEN's ASMs, with the associated costs of flights, taxis, accommodation and food, it is worth it to make contacts with the people whose job it is to care for people on HPN. They will hopefully be convinced of the worth of our patient support group and tell their home patients about us.



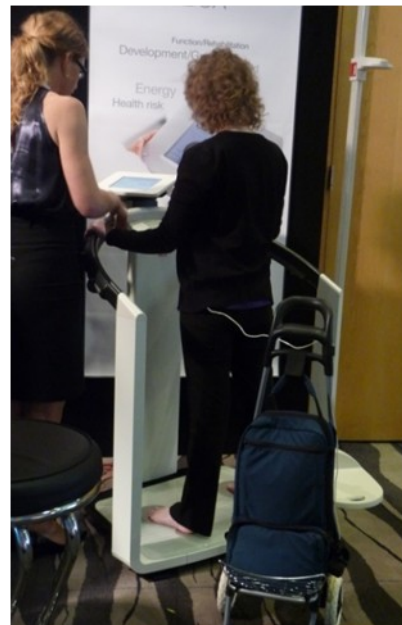
Gillian, Karen and Lisa at our stand



Jessica Gordon from Biomed with Gillian



Mary Dillon, David dal Pos and Hugh Davoren from Baxter



Lisa, trying out a mBCA diagnostic instrument that calculates BMI and prints out nutritional status information.



A well-earned cuppa at the end of a day!

BAXTER PHARMACY VISIT—AUCKLAND

WORDS BY LISA

On the 28th November 2014 I had the privilege of visiting the Baxter Pharmacy in Auckland with Karen and our Mums (Anne and Wendy). Hugh Davoren, Baxter Auckland's Nutrition Product Specialist, was our host. He showed us around and did a superb job at explaining everything that was going on. We were in luck as the pharmacy had just had a big upgrade. I was very impressed with the décor. In particular, there were large beautiful pictures all around with quotes to remind the workers of the importance of their job. This is one: "Our responsibility - what we have in our hands is the lives of our patients." I found this very touching.

First we met the ladies who answer the phones and take my consumable orders. It was lovely to be able to meet them in person. We then moved into the area where the pharmacists are. Meeting Anica, Senior Pharmacist, was a highlight of the trip. I was so excited to see her! She has dealt with any PN issues I have had for many years. She is kind, efficient and I know I can always rely on her.

We then moved into the area where the PN is actually put together. It was truly amazing. Workers were covered from head to foot in white gowns. The process of putting all the ingredients into the bag is done carefully and in very sterile conditions. They also have a "shopping" section. This is where a worker will push a little cart up and down isles and select the required ingredients for that particular patient. It is like shopping in a supermarket, only the ingredients look a little different!

I felt very reassured that great care was being taken to put the PN together. Everyone who works at Baxter genuinely cares about us as patients. They enjoyed our visit as much as we did because they don't often get to see who they are helping. A big thank you to Hugh and Karen for organising the visit and making it happen. It was a very special experience.

Karen and Lisa



Karen, Lisa and Hugh





One of the large posters in the renovated Baxter premises



Anica and Lisa finally meet

CHRIS' DARWIN CONFERENCE

WORDS BY CHRIS

I was invited to speak at "Medicines Management 2014", the 40th SHPA National Conference in Darwin, by good friend of PNDU, Professor Patrick Ball. This is the national congress of the Society of Hospital Pharmacists of Australia, mainly those involved in hospitals and the more clinically orientated of community pharmacists. The theme of the conference was "Broaden your Horizons". My presentation was part of the scientific program "Connecting the Dots".

The focus of the session was about trying to smooth the patient's journey. Everyone knows that it can be pretty difficult here in Australia; we talk about the Darwinian experience as in survival of the fittest.

Patrick was looking for an example that tells the Australian healthcare experience as it is, warts and all and to hear perspectives on what could be done to make it better. What worked, what did not work, what has been paid for, what has NOT been paid for, what was organised properly and prospectively, and what did you have to fight to get etc. The title for my presentation was to be ***'Darwinian Healthcare; If you can find your way to the help you need you are too well to need it.'***

Abstract

'This session will look at coping with serious and long-term conditions in the Australian health system from a consumer/ carer perspective. The presentation will draw on personal experience and the reports of others to demonstrate the difficulties and barriers encountered by consumers when trying to access the help and support to which they are theoretically entitled. Recipients of healthcare in Australia are frequently not referred to support services and have to find out about them by circuitous routes, then visit multiple agencies in multiple locations, completing multiple applications. The problems worsen significantly in situations requiring extension of hospital-type cares into the home, where no Medicare arrangements exist for equipment supply. This involves ongoing federal primary care and state-based hospital care, travel to distant specialists and need for accommodation. If interstate arrangements are required, things are even more complicated.'

Learning objectives

- Understand how challenging the healthcare environment can be from the user's perspective.
- Understand the lack of established arrangements in many places within Australia for 'hospital at home' care especially for rare conditions.
- Understand the need for National specialist centres and seamless care arrangements.

I accepted the invitation to represent PNDU and the Rare Disease community, through my own experiences over the past 15 years caring for 4 family members living with a rare disease, 3 of them HPN dependent. I forwarded the following abstract and 2 nights' accommodation and return airfares to Darwin were booked and paid by the conference organisers, Kaigi.

Darwinian Health Care

Survival of the fittest: a consumer perspective

Charles Darwin has been described as one of the most influential figures in history; Darwin's influence saw analogies of "Survival of the fittest" and the 'Preservation of Favoured Races' introduced into social discourse. The story of my grandchildren for example, began in a Neonatal Intensive Care Unit, with the words of the attending specialist "It would be far better

to place him in a box in the corner and let him perish.” Thankfully we didn’t.

Our government’s instigation of a two-class health system in which the well-off access preferential care from their doctors while the poor face ever higher hurdles, is becoming more entrenched and therefore accepted as normal. In Australia today, it will soon be only the well-off who are also fit! What will be our government’s next solution, Eugenics, or The Malthusian Catastrophe?

Our national anthem speaks of such attributes as courage, sharing, toil, abundance and beauty. Let us learn from Darwin’s remarkable scholarship and put rare diseases under the microscope. Just as Darwin collected specimens and kept meticulous records on his voyage, our government should register Rare Diseases and formulate a National Rare Disease Plan.

End Darwinian Healthcare. Then we will be able to sing, “Advance Australia Fair” and mean it.

The Presentation

Jordan and Logan’s [Chris’ grandsons] story gave me plenty of material to work with as I developed my slide presentation.

*‘Two examples of survival of the fittest within our Darwinian healthcare system are my grandchildren, brothers **Jordan and Logan**, born with the rare disease; x-linked chronic intestinal pseudo obstruction (XCIPO), who both spent the first 12 months of life in hospital undergoing multiple surgical procedures to help stabilise their condition. There is no cure for XCIPO, which renders the intestines unable to absorb nutrients from food, necessitating the use of **Parenteral Nutrition (PN)** by their hospital team. Indeed, when Jordan was born, the family were told it would be far better to let him perish. Thankfully they didn’t and with support from a multidisciplinary team of health professionals, this complex therapy can be managed at home, where it is called **Home Parenteral Nutrition (HPN)**.*

Assembling such a team to care for Jordan and Logan has been difficult and is on-going, now well into its 5th year.’

Rare Diseases and Chronic conditions are rare, but patients are numerous as there are more than 8 000 rare diseases. Many have no formal title and are difficult to diagnose. Collectively, rare diseases are surprisingly common, affecting an estimated 6-8% of the Australian population. This equates to about 1.2 million Australians, 400 000 of them children. Children like Jordan and Logan, who through no fault of their own, were born with a rare disease and simply fall through the cracks of our health system.

I was able to highlight the difficulties in accessing the multidisciplinary services required to care for Jordan and Logan, along with the differences in treatment and services that exist between Hospitals and state health systems, for those who rely on Parenteral Nutrition for survival.

I concluded with

“The overwhelming message is that rare diseases should be viewed as a collective group of diseases, and a National Rare Disease Plan is needed. Consumers have recognised the value in a coordinated approach, leading to the establishment of Rare Voices Australia (RVA). The pressing need for a collective view of, and clear definition for, rare diseases also recently received bipartisan support from the Australian Government House of Representatives. However, without the development of a National Rare Diseases Plan, there is no mechanism by which Australian governments can take a collective view of rare diseases, or promulgate a definition throughout the healthcare system.

“Darwinism gives no moral guidelines about how we should live or how doctors should practice medicine. A Darwinian perspective on medicine can, however, help us understand the evolutionary origins of disease, and this knowledge will profoundly be useful in achieving the legitimate goals of medicine.”

Although I am relating this from my own experiences, through caring for family affected by rare disorders, parts of this problem affects not only our family, but anyone in Australia sick enough to need more than just a visit to the doctor and a prescription to the chemist.

Integrated, healthcare that is seamless for the patient is the only acceptable approach and in my opinion, Australia currently gets ‘1/10 on this’.

Darwin was an unbelievable experience, my presentation went very well. The pyramid effect of interest generated by my presentation continued from midday until well after midnight. The presentation was recorded on Audio and will be used as an educational resource for medical and pharmacy students, along with the associated references to our PNDU support group and PNDU website.

The Rare Voices Australia publication, The Australian experience - living with a rare disease, in which Jordan’s story, along with Sal’s story (another member of PNDU) are published, will now also be used as an online educational resource. Now available on the RVA website www.rarevoices.org as a downloadable pdf file.



Chris in Darwin



Darwin Conference Centre



Gala dinner at Skycity Casino, Darwin



The gala dinner

Adapted from the original Science Daily article.

ScienceDaily[®]
Your source for the latest research news

To read more information about Biofilm and what it is, read the article in the March 2014 issue of Dripline, available on our website, "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

Hospital superbug breakthrough: Antibacterial gel kills *Pseudomonas aeruginosa*, staphylococci and *E.coli* using natural proteins

August 18, 2014 Queen's University, Belfast



Catheter in arm (stock image).

When bacteria attach to surfaces, including medical implants, they produce a jelly-like substance called the biofilm -- a protective layer that is almost impossible for current antibiotics to penetrate.

Credit: © freepeoplea / Fotolia

Scientists at Queen's University, Belfast, have made a breakthrough in the fight against the most resistant hospital superbugs.

The team from the School of Pharmacy at Queen's have developed the first innovative antibacterial gel that acts to kill *Pseudomonas aeruginosa*, staphylococci and *E.coli* using natural proteins.

The gels have the ability to break down the thick jelly-like coating, known as biofilms, which cover bacteria, making them highly resistant to current therapies, while leaving healthy cells unaffected.

Dr Garry Laverty, from the School of Pharmacy at Queen's University, and lead researcher, said: "When bacteria attach to surfaces, including medical implants such as hip replacements and catheters, they produce a jelly-like substance called the biofilm. This protective layer is almost impossible for current antibiotics to penetrate. Therefore bacteria deep within this protective layer are resistant as they remain unexposed to the therapy. They grow and thrive on surfaces to cause infections that are very difficult to treat. The only option is often to remove the medical implant leading to further pain and discomfort for the patient. Our gels would prevent this.

"Our gels are unique as they target and kill the most resistant forms of hospital superbugs. It involves the use of gels composed of the building blocks of natural proteins, called peptides -the same ingredients that form human tissue. These molecules are modified slightly in the laboratory to allow them to form gels that will rapidly kill bacteria. This is further evidence of Queen's research advancing knowledge and changing lives."

The new approach, which was developed as part of an international collaboration between the School of Pharmacy at Queen's and the School of Chemistry at Brandeis University, Waltham, USA, is published in the journal *Biomacromolecules* next month.

The results will form part of a presentation delivered by Dr Laverty at the Academy of Pharmaceutical Sciences, UK PharmSci: The Science of Medicines conference at the University of Hertfordshire on the 8th September 2014.

Journal Reference:

1. Garry Laverty, Alice P. McCloskey, Brendan F. Gilmore, David S. Jones, Jie Zhou, Bing Xu. **Ultrashort Cationic Naphthalene-Derived Self-Assembled Peptides as Antimicrobial Nanomaterials.** *Biomacromolecules*, 2014; 140807094711008 DOI: [10.1021/bm500981y](https://doi.org/10.1021/bm500981y)

HELP ALONG THE WAY: OLEY CONFERENCE REPORT

WORDS BY GIL

The Oley Foundation in USA is a national, independent, non-profit organisation founded in 1983 that enriches the lives of patients dependent on home parenteral nutrition (HPN) and tube or enteral feeding (HEN) through education, outreach, and networking. The Foundation also serves as a resource for consumers' families, clinicians and industry representatives, and other interested parties.

In June 2014 Oley welcomed several hundred people to the 29th Annual Oley Consumer/Clinician Conference at the Renaissance Hotel at SeaWorld Orlando, Florida. HPEN consumers came from near and far to meet and hear experts in the field of nutrition support, to network with one another, and to enjoy the attractions of SeaWorld.

Gil flew in for a couple of days en route from New Zealand to UK, and was asked to make a short informal presentation about PNDU at the Oley Ambassador/Volunteer Workshop on the first day. He showed the Ambassadors some of the

helpful literature produced by and for PNDU members and was accompanied by our mascot Pendoo™. Several of the North American Ambassadors, including Sandy Lacy from Canada (35 years on HPN) were aware of our website and congratulated PNDU on the video clip produced for the 2013 HPN Awareness Week. Presentations were also made by Carolyn and Richard, representing PINNT UK (pictured) and there was a great deal of discussion about the challenges faced when travelling on HPN within the USA and further afield to Europe.

Attendees also learned about the latest HPEN products and services, available from over 30 company exhibitors/sponsors, who in the USA can market directly to patients. Nutricare, one of the HPN service companies, sponsored a social evening at the local golf course and I ended up sitting next to Rob and Tammi Stillion (13 years on HPN with a port) (pictured), old friends of PNDU member, Jodee Reid, who sent their best wishes to Jodee and Matisse.

More than 40 knowledgeable clinicians, including past and present Presidents of ASPEN (American Society of Parenteral Nutrition), presented practical and research based talks and led breakout sessions over the 3 day programme. Topics ranged from a tube-feeding jam session, blenderised diets, workshops on catheter care and infection, medication delivery in Short Bowel/Intestinal Failure, clinical trials, family dynamics, caregiver respite, interpreting lab results and the power of Social Media.

Main session faculty included old friends of Gil's: **Dr Daniel Teitelbaum**, President-Elect of ASPEN, who presented fascinating insights about exciting developments with engineering new bowels in his research laboratory "The Future Care for SBS?" and **Kathy Gura**, Senior Clinical Pharmacist at Boston Children's Hospital, who does not recommend swimming/bathing with a PN catheter, presented a lecture and workshop on the pros and cons of swimming and kindly loaned her slides to help discuss this complicated issue at PNDU's HPN symposium in Auckland last November.

Keynote speech and one of the most exciting and motivational talks was "Advocating for Yourself and/or Your Child" by the incredible **Beth Gore, PhD, MBA**, mother of 6 adopted children, all with special needs, who discussed the need for patients to self-advocate. Manny, her youngest, now 5 years old, has spent a third of his life in hospital with Merosin Deficient Congenital Muscular Dystrophy and is PN dependent. Manny with iPad is pictured below with Beth and siblings Sam and Kaley, after he showed me how to access WiFi in the hotel lobby! Beth's 10 tips for meetings with your hospital team are:

1. Be organised. Document Everything
2. Be on guard
3. Know the chain of command i.e who to talk to.
4. Get decisions into the hospital orders
5. Exchange information. Don't Demand
6. Use your resources well
7. Document and refer team/doctor to documents
8. Be emotionally centred
9. Looks/Appearance matter
10. Don't try to do it all alone.

In addition to Manny, all the 'Oley' children were amazing. Some attended sessions with their parents, dozens joined Oley volunteers in the special childcare centre and participated in the various youth activities including; *Food Fun at Lunch*, with volunteer dietitians wearing badges that invited delegates to "Ask Me, I'm a Dietitian", a *Walk-a-Thon* for all ages, followed by the annual picnic, the silent Oley benefit auction, and a scavenger hunt, followed by the *Jammin Jammies Disco* with DJ and Karaoke. Informal meetings in the lobby or by the pools were great opportunities for attendees to meet one another and talk about life on HPN and/or tube feeding.

Gil, Carolyn and Richard (UK)



Gil with Sandy Lacy
(35yrs on HPN in Canada)



Renaissance Hotel, Orlando





Manny (with ipad), siblings, and mum, Beth Gore (USA)



Rob and Tammi Stillian (American HPNer) with Gil

SAM'S GRADUATION

WORDS BY SHIRLEY

Sam woke up on Wednesday and went to his Kindergarten Christmas party and graduation! He was such a star - he was shepherd and managed to stay focused and do the right things for the duration - no mean feat when there are around 100 kids in various stages of nativity dress-up with a medley of songs. It was truly a delight to see them all in action and I felt quite emotional as he 'graduated'. Such a milestone for our little man and we are so indebted to the love and care of the team at his kindergarten who have nurtured and loved Sam.

I'm afraid the photos aren't great as I forgot my camera and only had my iphone. He is the cute shepherd in the middle!



Again this year he is not in love with the large white bearded fellow, so won't be any cute pictures of him with Santa any time soon. I may try to record his screaming for you!

He is going to have another trial morning at school, before school closes on Thursday.

I leave you with his 'graduation' photo - on the last day of school the child is presented with their graduation cap, which he wore with such pride all day! So he is off on another adventure next year - to a big school, with Ange his faithful carer moving on with him as his Teacher Aide. She truly is a God send and a very dear woman that has become a part of our family and especially Sam's life.

10 days to go before we celebrate the coming of Jesus -we are loving the season and the reason and enjoying being home doing simple things. May you all be able to relax and breathe and enjoy some quiet this Christmas.



Sam with his graduation cap and diploma

LIVING A ‘DOUBLE LIFE’ ON HPN

WORDS BY GRAEME

We had our first taste of being “Grey Nomads” during some extended leave in 1985. We stayed in a caravan park on the Cairns northern beaches, and most of those around us were grey nomads who came for the winter every year. They were having a ball.

Carol was born and raised in Far North Qld, and Graeme in Melbourne. We met and married in Melbourne, then moved to the Latrobe Valley and lived and worked in the country.

In 2002, we were “between jobs” and found ourselves back in Cairns again for several months in a caravan, and then Graeme landed a job in Cairns that had us living there for another 7 years. We bought a unit that was only 200m from the beach, and really enjoyed the Far Northern lifestyle. Our plan was to spend the winters in Cairns (to escape the cold southern winters), and the summers in Victoria (to escape the hot humid summers of northern Australia). Things went well through 2010 when Graeme retired, but in 2011 Carol was put on PN, and spent 4 months in hospital in Melbourne.

We were unable to go north that year, as we were frequently visiting Monash Medical Centre as Carol “eased into” HPN (Home Parenteral Nutrition) . Usually, we spend 5 months in the north and 7 months in the south, as this gives us a clear 6 month period to follow through with any medical issues. Because we lived in Cairns for 7+ years, we have a medical team there as well as in the south.

We have just about everything we need at both places (our clothes are hanging in the wardrobes in both places, and we don’t even need to take our toothbrushes when we travel), except for Carol’s pump. Like most things associated with HPN, it requires planning ahead. Mostly we fly between Cairns and Melbourne, and we travel on the day before HPN delivery. That way, we only have tonight’s HPN plus the spare bag to take, along with a couple of suitcases full of supplies / consumables. Usually, Graeme flies south for a week during the winter stay in Cairns, and picks up another 3 months of consumable supplies, (as well as cutting the grass and cleaning the pool etc on the house in the Latrobe Valley). A couple of times we have driven to Cairns, and this takes a little more planning, as we need to have a HPN delivery along the way. The first time we picked it up at Baxter in Sydney, and the second time we had it delivered to Carol’s sister’s house near Kingaroy. Baxter are fantastic, and we have never had a problem with deliveries.

Not having children, we don’t have any “ties” to keep us in one place, and we are blessed with having close relationships with our church families in both places. It really is like living a double-life, just 6 months about.

This past year, we were only able to spend 3 months in the north, due to some complications with Carol’s health and treatment, but we did miss the coldest months of the winter. Carol’s medical team are supportive of what we do, as she does not cope well with the extremes of hot and cold. We plan for her numerous “check-ups” with her multiple medical specialists when we first return south in October, and then take things from there over the summer, with the aim of having a “stable” treatment regime when we head north in May. So far, this has mostly worked well. Cairns has a well-equipped hospital, which is good for “normal” treatment regimes, but there are just not the specialists needed for managing complicated chronic conditions. We are aware of one other HPN patient in Cairns, and they are administered from a hospital in Brisbane (and for those who are not aware, Melbourne is closer to Brisbane than Cairns is, and by a considerable distance).

All in all, we love the lifestyle, and it is quite workable with a bit of planning, and gives us the best of both worlds.



Yorkey’s Knob – ‘paradise amongst the crocodiles’ in far northern Queensland

FEEL LIKE A HOLIDAY?

WORDS BY KAREN



Travelling with Home Parenteral Nutrition (HPN) has been happening in the northern hemisphere for many years, even decades, but that hasn't been the case 'down under', especially with long-haul international travel. There have been a few intrepid and creative Aussies and Kiwis who never let a drip-stand, cumbersome hospital pump or anything else that's needed for HPN stand in the way of a good holiday, but for the most part, travel for HPNers 'down under' was quite restricted. Realistically, how could anyone suffering Intestinal Failure (IF) travel with so much bulky medical equipment and supplies?

With the introduction of ambulatory pumps nearly 5 years ago however, the tide started turning, slowly at first, but now 'travel' is the new buzz word.



But, why would someone with IF want to embark on something as tiring as travel, especially with the amount of organising it involves? With HPN providing a second chance at life for many of us with IF, while ever well enough, many HPNers will want to pursue the same dreams and aspirations as the rest of humankind. And for many of us, those dreams involve seeing the world or showing our children the world. We all know the value and pleasure that travelling can bring, so if an HPNer is well enough, why not strive to fulfil those travel dreams?

PNDU has just updated our travel information booklet to include much more information relevant to the travel situation 'down under' and incorporating homecare company protocols in this part of the world (ie all travel, whether domestic or overseas, needs to be organised by the HPNer's hospital team, liaising with the homecare company).

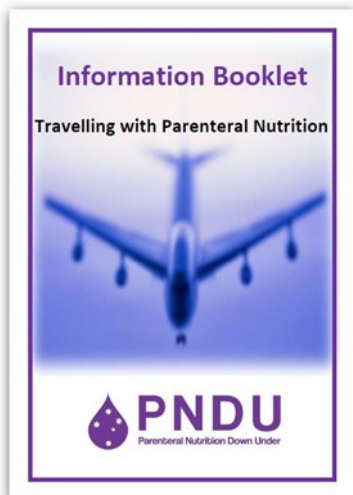
The booklet contains lots of detailed information about what you need to discuss with your hospital/doctor; who is responsible for organising what; various options for your hospital/doctor to consider; what airlines will require; what approvals/documentation you'll need; plus all little things eg what to expect at a security checkpoint, what needs organising at the accommodation, what to take in hand luggage; plus a check-list at the end for both you and your hospital/doctor.

Most importantly, the booklet stresses that no travel bookings should be finalised until it can be ensured that all your HPN needs will be met! It's no use booking a holiday of a lifetime, to then find out you cannot get your PN delivered when/where you were expecting, or the airline won't let you on board the plane as you haven't obtained special approvals!

The booklet is aimed at HPNers and carers, however it is also an invaluable resource for hospitals to be able to understand the whole process involved and assist their HPN patients to organise a safe holiday.

Travel with HPN involves a lot more planning and consideration than that of the average tourist, but with the advice and assistance of your hospital team, doctor and homecare company, as well as the information in this booklet, the opportunities to travel are certain to bring great rewards and pleasure.

If you are an HPNer or carer, or a medical professional with patients on HPN and would like a soft or hard copy of PNDU's Travel Information Booklet for yourself and/or your patients, please contact us at contactpndu@gmail.com.



Contents

Thinking about travel

1. Consult your doctor and hospital team	2
2. Domestic travel	2
3. Cruising	3
4. Overseas travel	3
5. Network with other travellers	4

Planning & organising your trip

6. Your homecare provider	5
7. PN Solution options	5
8. Provision of your PN Solution	6
9. Consumables	9
10. Your infusion pump	10
11. Travel insurance	11
12. What your doctor needs to provide	12
13. Travel folder and other documentation	14
14. Accommodation & transport	15
15. Flying	15
16. Emergencies	20

Nearly ready to go?

17. Preparing for transportation of your HPN supplies	21
18. Preparing to fly	22
19. More useful information	23

Off we go ... (travelling)

20. At the airport	24
One last word	27
Glossary of terms	27
Acknowledgements	27
Appendix – Resources and Final Checklist	28
My contacts	33
About PNDU	34

When Auckland mother of four, Simone Colwill was diagnosed with Crohn's Disease life changed. "All of a sudden I found myself in the sub-world of the chronically ill." She says. "Hospital admissions, medications, and on-going monitoring." A radiographer by profession, Simone went looking for a book to teach her children about hospitals AND empower them to help. Unable to find one, she wrote Super Jonny. "I was having trouble finding an angle to tell the story", She explains, "Then one day, my youngest son came to the hospital dressed in his superhero suit. 'Super Jonny' is his story.



"Kids come up to the hospital, and simply don't know what to do," explains Simone. "My book helps them find their role."

Synopsis

Super Jonny is a story about a little superhero. His Mum is sick. How can he help? Join Jonny and Bear as they go to the hospital to investigate. Learn who the staff working in the hospital are and what they do. Discover Jonny's secret weapon.

Curriculum links

Recognising that teachers often have a child in their class with a sick relative, Simone decided to make the book suitable for classroom use. The list of questions at the rear of the book help children to consider how they could help a sick loved one. These link to the national curriculums in New Zealand and England. Themes include persistence, problem solving, critical thinking and empathy. Because of the subject matter, teachers recommend this book for children aged 2-9 years.

Helping the chronically ill

Some sick people need regular hospital help. With this in mind, Simone included a page in the book entitled: Preparing for a hospital admission: 5 tips for chronically ill mums. This is a simple list of supplies, for when her children visit. This list can also be actioned by any adult wanting to support a sick mum.

Healthcare professionals recommend Super Jonny as a simple way for children to learn about how hospitals work. Mum does not have a diagnosis. **This means the book is suitable for all mums who are admitted for any reason.**

Super Jonny has received favourable reviews across three sectors

1. From New Zealand Doctors magazine
2. From Barbara Murison (New Zealand children's literature expert).
3. From Marineke Goodwin, curriculum advisor (early childhood) at Auckland University College of Education.

About

This book is available as either a hardcopy, or as an ebook. (Ebook from the usual platforms).

Hardcopy: a 38 page picture book. (21.59cm x 27.94cm). (A4 size). Full colour with bleeds to the edge of the page. ISBN 978-0-9941127-2-9 UK Version (available in UK and US versions).

For ordering information and new releases please sign up for our newsletter, at www.sickmom.org

Available from Wheelers Online

WHAT'S IN YOUR BAG: LIPIDS—WHY THEY SHOULDN'T BE FROZEN

WORDS BY GIL

Editor's Note: 'What's in Your Bag' is a semi-regular article; the previous article in this series can be found in our April 2014 issue and covers an overview of 'Nutrients, Trace Elements and Vitamins'.

Question: I got my PN from the fridge this morning – middle shelf, not even near the freezer part – and found the creamy section hard to touch. What damage if any will this do? Is it okay to use tonight?

Answer: The creamy section is a lipid (fat) emulsion that must not be frozen. Freezing breaks the emulsion with a danger of infusing large fat particles that can block your lungs. Authorities, like AuSPEN, recommend that PN bags should be stored in a refrigerator set at 4-8C. Most hospital pharmacies monitor the temperature of their fridges to ensure that the contents stay within this temperature range and that freezing (or heating) does not occur. I would therefore recommend installing an inexpensive maximum-minimum thermometer in your fridge at home.

Intravenous Lipid Emulsions (IVLE): manufacture and storage

Lipids (fats or oils) are an important source of essential fatty acids (EFA) and concentrated energy, providing more than double the calories (kilojoules) of sugars like glucose. Their incorporation into paediatric and adult parenteral nutrition (PN) regimens has revolutionised nutrition therapy (NT). However, their clinical use has not been without risk, and will continue to remain so, because of their (intravenous) route of administration. Modern lipid products, based on Olive oil, Coconut oil and/or Fish oils, have demonstrable formulation and clinical benefits over traditional Soybean oil IVLE and, when combined in the new multi-chamber bags (MCB), can also offer improvements in stability and safety.

The large particle size of oils means they cannot be safely infused intravenously. They must first be converted into a creamy looking oil-in-water emulsion and then sterilised. An IVLE is formed by a long period of homogenisation of one or more of these oils, with water and phospholipid emulsifier, usually egg lecithin, to form a very fine emulsion (a bit like making your own egg mayonnaise). Each small emulsion particle is kept separate by the negative charges of the phospholipid around its surface. This electrostatic charge repulsion maintains the IVLE in a stable state.

The safe average emulsion particle size is between 0.2 - 0.4 micron, minute enough to pass through the smallest capillaries in the body.

Lipid particles, greater than 5 micron in size, can potentially obstruct the capillaries of the pulmonary microvasculature, in our lungs. Lipids are normally broken down in the liver to produce the EFA required by the body and by our immune cells, for energy and cell growth. However, animal studies suggest that enlarged lipid or oil particles, from an unstable emulsion, can cause oxidative stress and may injure the liver and other organs. So the essential requirement of any IVLE after being added to a PN mixture is that the overall particle size does not increase, to the extent that it might produce these adverse effects.

The main destabilizers of IVLE in a PN regimen, are temperature, excessive acidity and inappropriate electrolyte content. In addition, some trace elements, vitamins, amino acids, drugs, the PN bag material, oxygen and light exposure, can all affect stability. Unfortunately, the essential electrolytes, such as Sodium, Potassium and Calcium, are all positively charged and can neutralise the negative surface charges of the emulsion, causing formation of aggregates. High temperatures and/or freezing can have the same destabilising effect. Since oil is lighter than water, these aggregates tend to float to the surface and form a "cream" layer (just like the top of full cream milk).

IVLE instability occurs in three phases: Creaming, Coalescence and Cracking:

Creaming is the movement of emulsion droplets under the action of gravity and manifests itself as a dens white layer at the top of the PN container. It can occur slowly without a significant change in stability and if the cream layer is first dispersed by gentle shaking then the PN bag can be safely administered. [pic]

Coalescence is the next transient stage after creaming, before cracking, when the electrostatic barriers are failing and aggregation of small droplets into larger fat globules occurs. Coalescence is difficult to see, but as it continues, the number and surface area of large fat aggregates increases until oil begins to separate

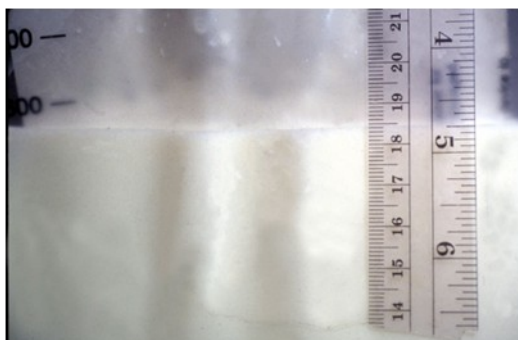
Cracking: At this point, both the mechanical and electrostatic barriers have been irreversibly broken, the emulsion breaks and is said to be "cracked". This results in a potentially dangerous formulation that releases free oil into the mixture. (See pictures below)

In practice, it requires relatively large concentrations of electrolytes to significantly reduce the emulsion surface charges. But the more highly charged electrolytes, such as Calcium or Magnesium, are much more efficient charge neutralisers, and consequently more influential on stability. More importantly, if an IVLE is subjected to extremes of temperature, by either freezing or heating above 25-30C, the creamy aggregates start to coalesce, then the emulsion breaks or cracks to form large free oil globules, which can be hazardous.

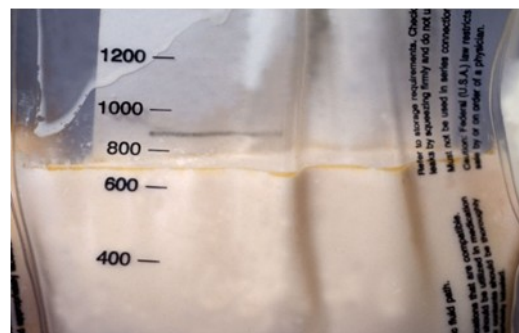
PN with a cracked IVLE should never be infused.

The human body is remarkably resilient and any untoward clinical events with IVLE are usually transient. In over 50 years usage of IVLE, adverse reactions have rarely been directly associated with variability in lipid droplet size. Nevertheless, it is important for PN compounders to appreciate the various pharmaceutical factors influencing stability, and for HPN consumers to follow the recommendations for correct storage, inspection before use and administration of their PN bags.

PN Bag with cream layer



PN Bag with cracked emulsion and free oil at surface



CONTAMINATED SINK DRAINS LINKED TO INFECTION OUTBREAKS

Summarised by Gil Hardy PhD FRSC from a report by Nancy A. Melville at Medscape Medical News, December 2014

A perplexing string of infections caused by *Pseudomonas aeruginosa* (Pae-MBL) has been linked to an unexpected, but possibly common source — a contaminated sink drain.

"In our hospital, this is a new focus," said investigator Anna Stjarne Aspelund, MD, from the Department of Infection Control in Region Skåne, in Lund and Malmö, Sweden. "I believe this is a commonly overlooked source of bacteria."

In her presentation at the Healthcare Infection Society (HIS) International Conference in November 2014 at Lyon, France, Dr. Aspelund and her team cultured 121 sink drains in three wards, and searched patient records for positive cultures of Pae-MBL. Ten drains, all in hand-washing sinks in patient bathrooms, tested positive for Pae-MBL. In the record search, 12 patients were found to have had Pae-MBL-positive cultures, all but one of whom were in wards with a contaminated sink.

We have to consider the way we handle sinks.

Relatively simple treatment with acetic acid (vinegar) followed by boiling water once a week, and flushing two times daily, has been largely successful, and cultures have been negative for 4 months, Dr. Aspelund reported. "The acetic acid treatment seems to be effective, but the contamination might not be limited to Pae-MBL", she pointed out. "The resistant strains get our attention, but if they can spread this way, other bacteria probably can too."

These findings should serve as a wake-up call for hospitals. "We have to consider the way we handle sinks. We have to implement good practices for healthcare workers and cleaning personnel, give the right instructions to the patients, and build our hospitals with well designed sinks," Dr. Aspelund explained.

Reservoirs for Bacteria

A previously reported experience with an outbreak traced to sink drains was described in 2012 by Allison McGeer, MD, from Mount Sinai Hospital in Toronto, Canada (*Emerg Infect Dis.* 2012;18:1242-1247). In all, 66 patients were infected with *Klebsiella oxytoca*. The bacterium was found in cultures from hand-washing sinks in the intensive care unit (ICU). An intervention, in which sinks were cleaned three times a day, sink drains modified, and an antimicrobial stewardship program, when implemented, appeared to prevent further infections.

Dr McGeer pointed out that sink drains have been implicated in an increasing number of outbreaks in the past decade, and speculated that the trend might be an unexpected consequence of efforts to improve hand sanitation in hospitals. The issue of potential sink drain contamination should be prominent in discussions of hospital safety and appropriate and safe ICU design, Dr. McGeer said. "The first thing hospitals need to be aware of is that sinks can be potential reservoirs for bacteria," she explained.

HOW MICROBIOLOGICALLY CLEAN ARE YOUR SINK AND DRAIN AT HOME?

LIVING NEAR YOUR HOSPITAL

WORDS BY GILLIAN

One of our members posted a question on our Googlegroups Forum asking, 'Just out of interest, how many people have moved, or choose to live where they do, because of proximity to their hospital?' Here are the responses, which are quite varied.

- We're moving to the city. We are currently 160 km out, but do the drive twice a week on average. When we move we'll only be 10 mins from the hospital instead of 2 hrs each way (if the traffic's not too bad!!!)
- My decision to stay in the city while the rest of my family is in rural NSW is primarily based on proximity to my hospital, as well as climate (where they live is freezing in winter and boiling in summer and I just don't cope well with that anymore!).
- It was a necessity for us for [our child] to relocate - we were living in the north of the city, which took 30 mins with no traffic, or 1 hour 15 min in peak hour. With her numerous hospital stays, visits to her doctors and therapists meant that living as close to the hospital would make the medical schedule bearable (so we could feel like we can still have a life!). We live 2 mins drive/10 mins walk to the hospital which means that dashing out for supplies is pretty convenient and also gives us peace of mind for emergencies. Also, because of our proximity to the hospital, we have been able to reduce the length of our admissions on some occasions (returning for specific tests as out-patients, or having the nurse visit us at home afterwards).
- I've lived in this area for nearly 50 years, and I'm about 12 min drive to my hospital, but then you have to factor in parking, so I allow about 25 min all up. When we moved last year about 3 min from our last home, it was certainly a consideration to stay in the area, but not the only one.

- We live 35 mins from our hospital. We recently put our house on the market as we want to be within 10 mins of hospital. Also our family support is located in [this city] and we want to be closer to them. We would not be looking to relocate from our beautiful beachside home if I didn't have [my current health problems].
- I can but dream of living closer to the hospital - it's still half an hour away in good traffic, but we can't afford the area.
- We definitely moved to be closer to the hospital four years ago. The main problem is the septic shock I have a habit of getting and a few times don't remember anything until waking up several days later. But it's also for [my husband], as after he visits me in the hospital at night, he has to drive home.
- Well I am definitely going against the trend here! When we were in Sydney, we lived about twenty minutes from the hospital, more in traffic, and it was very easy. I also had a system where I could get priority review in emergency. We made the decision to move to Jervis Bay on the South Coast, which is three and a quarter hours from [my hospital] where I am treated. In an emergency I can go to the nearby hospital (about 30 mins) and have a local gastro-enterologist who works with my Sydney gastro and the PN team. There is also a local infectious diseases specialist and I have a very conscientious GP. Fortunately I have had no emergencies since we moved and still go to Sydney for regular checkups/tests. It was a big decision, but we opted for the quality of life we wanted. I would not have been brave enough to make this move the first year I was on HPN, but am obviously more confident now and also know I have great backup from my team on the phone at any time.
- If I had a child on HPN, I would definitely want to be close to the hospital, but having dealt with illness for close to 50 years, I am fairly philosophical about my situation....what will be, will be. In the meantime I am following my heart and loving it.
- We live about 45 mins from my hospital, but need our leafy suburb!! We certainly chose to be reasonably close to [my hospital] because of HPN.
- I have moved from a mining town, which was a 13 hour drive to see my specialist. So we decided to move to the coast, which is now only just under an hour's drive. I know how hard it is to drive to a hospital.

As you can see, while proximity is desirable, it isn't always possible, or the best solution. Lifestyle, family support and cost are also important factors in making this decision.

Taurolidine lock is superior to heparin lock in the prevention of catheter related bloodstream infections and occlusions

E. Olthof¹, M. Versleijen², G. Huisman-de Waal^{1,3}, T. Feuth⁴, W. Kievit⁴, G. Wanten¹. ¹Intestinal Failure Unit, Department of Gastroenterology and Hepatology, Radboud University Medical Center, Nijmegen, ²Department of Nuclear Medicine, Netherlands Cancer Institute Antoni van Leeuwenhoek, Amsterdam, ³Scientific Institute for Quality of Healthcare, ⁴Department of Health Evidence, Radboud University Medical Center, Nijmegen, Netherlands

Rationale: Patients on home parenteral nutrition (HPN) are at risk for catheter-related complications. We have previously shown that catheter locking with taurolidine dramatically reduced re-infections when compared with low dose (150 U/ml) heparin. Our HPN population therefore switched from heparin to taurolidine in 2008. The aim of our study was to compare long-term effects of this catheter lock strategy on the occurrence of catheter-related complications in HPN patients.

Methods: Data of catheter-related complications were retrospectively collected from 212 patients who received HPN between January 2000 and November 2011, comprising 545 and 200 catheters during catheter lock therapy with heparin and taurolidine, respectively. We evaluated catheter-related bloodstream infection- and occlusion incidence rates using Poisson-normal regression analysis. Incidence rate ratios were calculated by dividing incidence rates of heparin by those of taurolidine, adjusting for confounders. Data of adverse events and hospital admission were also collected.

Results: Bloodstream infection incidence rates were 1.1/year for heparin and 0.2/year for taurolidine locked catheters. Occlusion incidence rates were 0.2/year for heparin and 0.1/year for taurolidine locked catheters. Adjusted incidence ratios of heparin compared to taurolidine were 5.9 (95% CI, 3.9 8.7) for bloodstream infections and 1.9 (95% CI, 1.1 3.1) for occlusions. The ratio of hospital admission days per catheter day, decreased by 60% from 0.055 in two pretaurolidine years to 0.022 in 2011. Seven percent of patients reported adverse events possibly related to the use of taurolidine.

Conclusion: Given that no other procedural changes than the catheter lock strategy were implemented, these data strongly suggest that taurolidine decreases catheter-related complications in HPN patients compared with heparin.

ABSTRACT PP226-SUN from ESPEN ANNUAL SCIENTIFIC MEETING in GENEVA 2014 (published in Clinical Nutrition 2014;33; Supp 1. S104-105)

COLONOSCOPY HUMOUR

PREFACE BY GILLIAN

Our Canadian HPN friend, Laurie, who heads up the British Columbia HPN group, sent this email to PNDU. If laughter is the best medicine, then I'm sure this will at least give you a chuckle – especially those of you who have had the experience. The article was credited to Dave Barry, a Pulitzer Prize-winning humour columnist for the Miami Herald.

Colonoscopy Journal:

I called my friend Andy Sable, a gastroenterologist, to make an appointment for a colonoscopy. A few days later, in his office, Andy showed me a colour diagram of the colon, a lengthy organ that appears to go all over the place, at one point passing briefly through Minneapolis.

Then Andy explained the colonoscopy procedure to me in a thorough, reassuring and patient manner. I nodded thoughtfully, but I didn't really hear anything he said, because my brain was shrieking, *'HE'S GOING TO STICK A TUBE 17,000 FEET UP YOUR BEHIND!'*

I left Andy's office with some written instructions, and a prescription for a product called 'MoviPrep,' which comes in a box large enough to hold a microwave oven. I will discuss MoviPrep in detail later; for now suffice it to say that we must never allow it to fall into the hands of America's enemies.

I spent the next several days productively sitting around being nervous. Then, on the day before my colonoscopy, I began my preparation. In accordance with my instructions, I didn't eat any solid food that day; all I had was chicken broth, which is basically water, only with less flavour.

Then, in the evening, I took the MoviPrep. You mix two packets of powder together in a one-litre plastic jug, then you fill it with lukewarm water. (For those unfamiliar with the metric system, a litre is about 32 gallons). Then you have to drink the whole jug. This takes about an hour, because MoviPrep tastes - and here I am being kind - like a mixture of goat spit and urinal cleanser, with just a hint of lemon.

The instructions for MoviPrep, clearly written by somebody with a great sense of humour, state that after you drink it, 'a loose, watery bowel movement may result.' This is kind of like saying that after you jump off your roof, you may experience contact with the ground.

MoviPrep is a nuclear laxative. I don't want to be too graphic, here, but, have you ever seen a space-shuttle launch? This is pretty much the MoviPrep experience, with you as the shuttle. There are times when you wish the commode had a seat belt. You spend several hours pretty much confined to the bathroom, spurting violently. You eliminate everything. And then, when you figure you must be totally empty, you have to drink another litre of MoviPrep, at which point, as far as I can tell, your bowels travel into the future and start eliminating food that you have not even eaten yet.

After an action-packed evening, I finally got to sleep. The next morning my wife drove me to the clinic. I was very nervous. Not only was I worried about the procedure, but I had been experiencing occasional return bouts of MoviPrep spurtage. I was thinking, 'What if I spurt on Andy?' How do you apologize to a friend for something like that? Flowers would not be enough.

At the clinic I had to sign many forms acknowledging that I understood and totally agreed with whatever the heck the forms said. Then they led me to a room full of other colonoscopy people, where I went inside a little curtained space and took off my clothes and put on one of those hospital garments designed by sadist perverts, the kind that, when you put it on, makes you feel even more naked than when you are actually naked.

Then a nurse named Eddie put a little needle in a vein in my left hand. Ordinarily I would have fainted, but Eddie was very good, and I was already lying down. Eddie also told me that some people put vodka in their MoviPrep.

At first I was ticked off that I hadn't thought of this, but then I pondered what would happen if you got yourself too tipsy to make it to the bathroom, so you were staggering around in full Fire Hose Mode. You would have no choice but to burn your house.

When everything was ready, Eddie wheeled me into the procedure room, where Andy was waiting with a nurse and an anaesthesiologist. I did not see the 17,000-foot tube, but I knew Andy had it hidden around there somewhere. I was seriously nervous at this point.

Andy had me roll over on my left side, and the anaesthesiologist began hooking something up to the needle in my hand. There was music playing in the room, and I realized that the song was 'Dancing Queen' by ABBA. I remarked to Andy that, of all the songs that could be playing during this particular procedure, 'Dancing Queen' had to be the least appropriate.

'You want me to turn it up?' said Andy, from somewhere behind me... 'Ha ha,' I said. And then it was time, the moment I had been dreading for more than a decade. If you are squeamish, prepare yourself, because I am going to tell you, in explicit detail, exactly what it was like.

I have no idea. Really. I slept through it. One moment, ABBA was yelling 'Dancing Queen, feel the beat of the tambourine,' and the next moment, I was back in the other room, waking up in a very mellow mood.

Andy was looking down at me and asking me how I felt. I felt excellent. I felt even more excellent when Andy told me that IT was all over, and that my colon had passed with flying colours. I have never been prouder of an internal organ.

NOVEMBER SYDNEY GATHERING

WORDS BY GILLIAN

November 15th 2014 saw our most recent Sydney get-together, this time held at Jane's home in Hornsby. Many thanks to Jane and Neil for their hospitality, beautiful garden, and for Neil's great coffee! There were 9 HPNers, aged between under 6 and over 60, as well as family members.

Dave and Miranda were there with Ariel, aged 4 (HPN) and Eadie; Mel and Malcolm with Emily, aged 5 (HPN) and baby Phoebe; Tanya and Chris were there with grandsons Logan, aged 2 (HPN) and Jordan, aged 5 (HPN) and Dylan, aged 7, along with their parents Brooke and Mick; Gillian (HPN) was there with Ray; Sal (HPN), Karen (HPN) and Emma (HPN); and our hosts Jane (HPN) and Neil.

It was wonderful to meet Emma, who flew from Tasmania for the weekend and managed to see the ballet on the Friday night before our lunch on Saturday. And it was great that the whole gang (Chris, Tanya, Brooke, Mick, Dylan, Jordan and Logan) were well and able to make the trip from Newcastle, allowing us to meet some of them for the first time.

Unfortunately, 2 other NSW HPNers had planned to come, but both ended up in hospital! Hopefully they will be able to make the trip for our next get-together around March 2015.

The children had a ball and got on well together, while the adults caught up on the latest happenings in our lives. We wish both Emily and Jordan all the best as they both commence kindergarten at their local schools this year.

Please email us at contactpndu@gmail.com for details of the next Sydney gathering, or if you'd like us to help organise one in your area.



Neil, Malcolm, Mel with Phoebe, and Jane



The whole gang in Jane and Neil's beautiful garden



Sal, Miranda with Eadie, Dave with Ariel, Emma



Dave, Emma, Gillian, Jane, Ray, Sal, Neil, Mel, Mal

Our PNDU T-shirts –hot off the press!



Gillian, Chris, Tanya, Brooke with Logan, Mick, Sal, Jane



Logan having fun on a swing



Tanya, Brooke and Mel with
Phoebe



Nurses Jordan, Ariel and Emily,
helping patient, Bear

WHAT ABOUT HPNERS WITHOUT A COMPUTER?

WORDS BY KAREN

As many would be aware, the age range of those living with HPN is great – from the littlest child to our more senior citizens. This can mean that there are those on the older end of the spectrum, and their carers, living with Intestinal Failure and HPN, who have never had a computer or struggle to use one. As a result, in this digital age where so much happens ‘on-line’, the ability for these HPNers and their carers to ‘chat’ with others who understand what life is like living with HPN is very limited.

PNDU offers the opportunity 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.

THANK YOU

\$30 coin donations in the Altra Nursery donation box

\$2 from donation box in Rose Centre Auckland

\$100 from A Lesser

We are very grateful for these donations.

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.



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.parenteralnutritiondownunder.com

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

Additional Committee Members: Jacqueline, Jodee, Kelly

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

DISCLAIMER: PNDU has made every reasonable effort to ensure that the content of this newsletter is accurate, but accepts no responsibility for any errors or omissions. The views expressed are not necessarily those of PNDU and no reference to any product or service is intended as a recommendation or endorsement. You should always seek advice from your own team of healthcare professionals in relation to your specific needs/treatment.

Designer: Sal