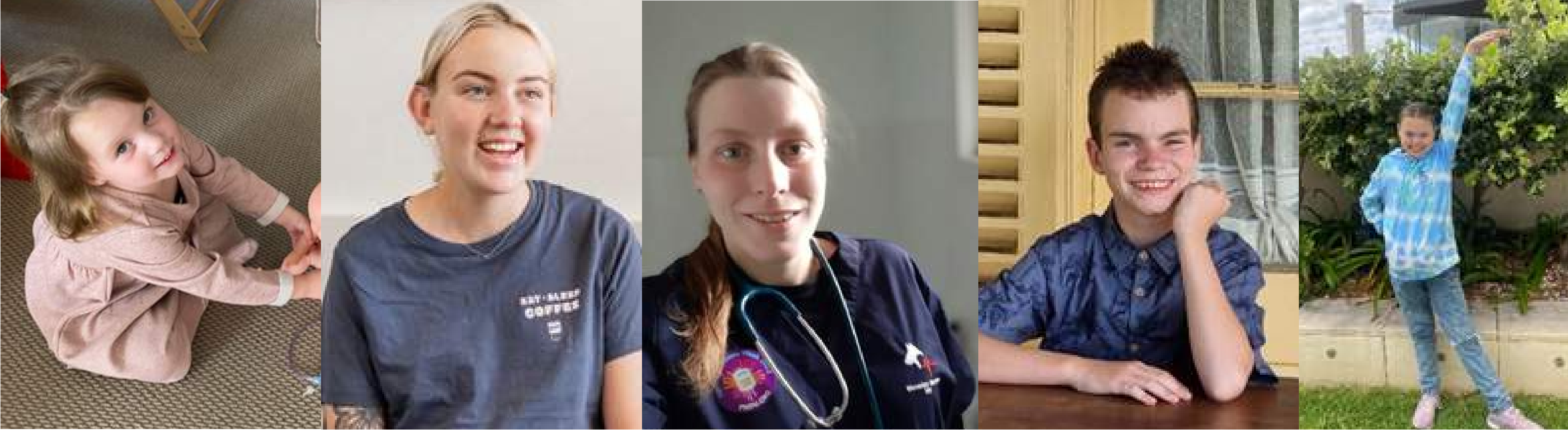


DRIPLINE

PNDU
Parenteral Nutrition Down Under

ISSUE 41
AUG-OCT
2022

This is a huge issue, packed with information about HPN Awareness Week activities and how HPNers are ably supported by their support group, PNDU, and by their PN providers. Read about, and see photos of, the pharmacy tours; see some of the Instagram and Facebook posts telling how being on HPN doesn't stop enjoyment of activities; in fact, HPN: Our Life – it gives us the ability to enjoy our lives. Read about a tour from the perspective of one of our 13yr old members; discover medically appropriate toys and books for paediatric HPNers; learn about the upcoming AuSPEN Consumers' Workshop and register – for either in-person or streaming attendance; and where to join the PNDU Social Gathering! Also read about PNDU president, Chris', visit to Canberra; and discover how buying books from Book Depository for Christmas can help PNDU financially. I hope you make time and enjoy the read,

Gillian
Editor

Contents

Finding representation in books and toys for young HPN kids

By Julia

As we were raising our family, which includes seven children we adopted who had been born in Korea, Taiwan, India and Papua New Guinea, I knew it was important that children see themselves represented in the books, toys and entertainment around them. It wasn't easy, but over the years I found many great resources for our kids.

Our older nine kids had grown up by the time our youngest, Syena, joined our family nearly three and a half years ago. She was born with Vanishing Gastroschisis and lost most of her small intestine and her ascending colon, resulting in Ultra Short Gut Syndrome. Now that she is a busy and social four-year-old, we are preparing for preschool next year.

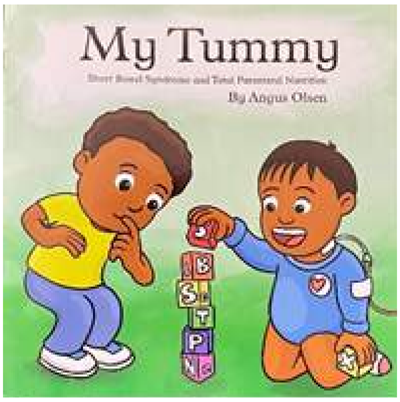
Since Syena was a baby, I've looked for toys and books to show she is not alone in her life with HPN. Despite the internet bringing the world within reach, this has been much more challenging than the job I had gathering suitable toys and books for our older kids. There simply aren't as many toys and books available that normalise life for kids who use HPN.

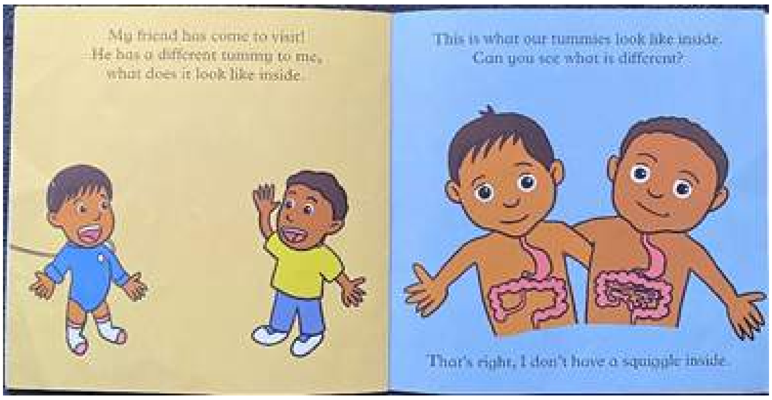
When we joined PNDU, we were delighted to receive a little doll that was customised to reflect Syena's medical devices at that time … a central line and a Mic-Key gastric button.

There are also people online who customise dolls at various sites including Etsy. I also found a wonderful organisation in the US called "Tubie Friends", whose volunteer surgeons "operate" on a soft toy the child can pick from several options, to mirror the child's own medical equipment. Our beloved puppy was provided to Syena free of charge, with us just paying for his shipping.

Through chats on various Facebook groups, as well as many searches of online bookstores, I found some fabulous children's books. Ours are aimed at children from maybe 3 years old through to around 10 or so. I love that all of them could be shared with a child's preschool or school class to better their understanding of the various ways you can eat.

My favourite simple book for little ones is "My Tummy" by Angus Olsen. Angus is an Aussie who was an illustrator for Disney when his small daughter was diagnosed with cancer. Through this harrowing personal experience, he found that hospital kids lacked books that talked of their reality. He has written many fabulous little books for children that relate to their medical lives and the illustrations are both simple and delightful. Angus has a Facebook group and a website, both called "I draw childhood cancer", where you can find all his books, many of which can be downloaded as pdfs free of charge.

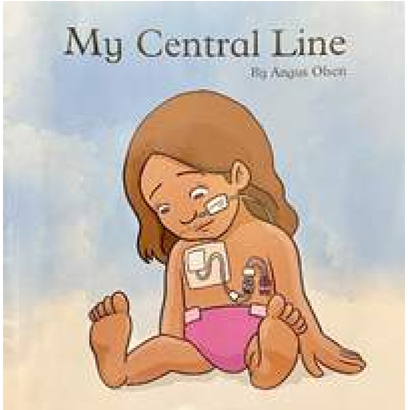


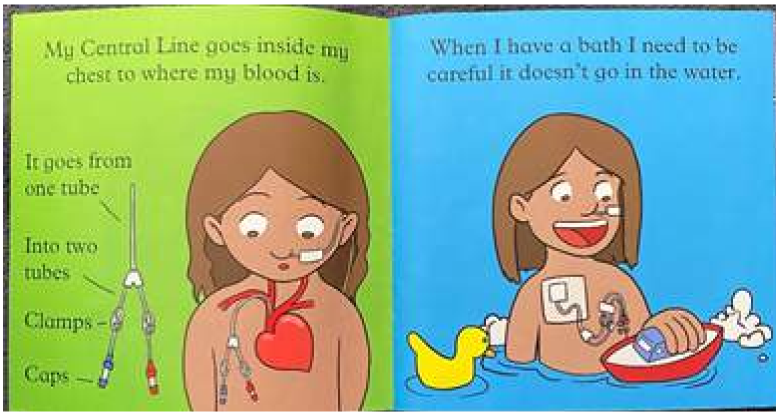


My friend has come to visit!
He has a different tummy to me,
what does it look like inside.

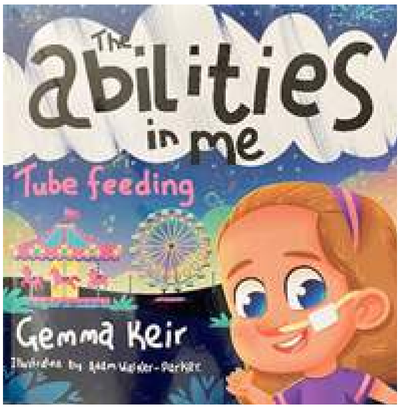
This is what our tummies look like inside.
Can you see what is different?

That's right, I don't have a squiggle inside.

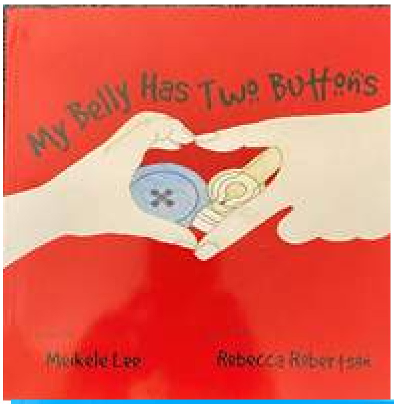


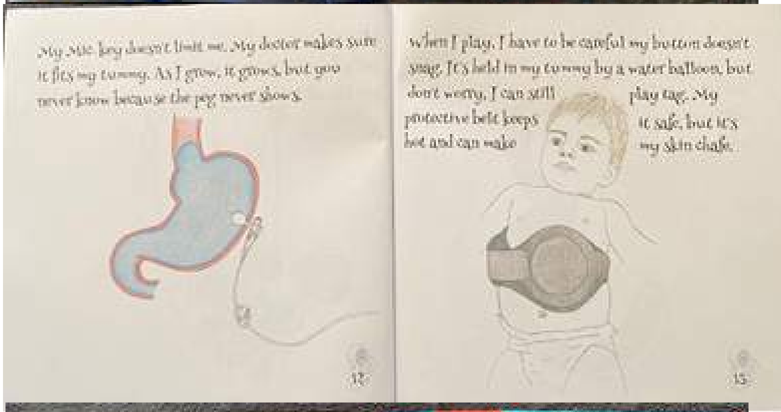

My Central Line goes inside my chest to where my blood is.

When I have a bath I need to be careful it doesn't go in the water.

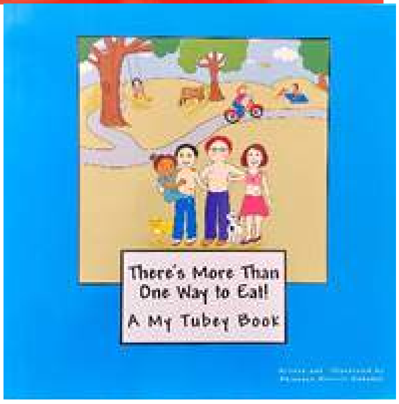


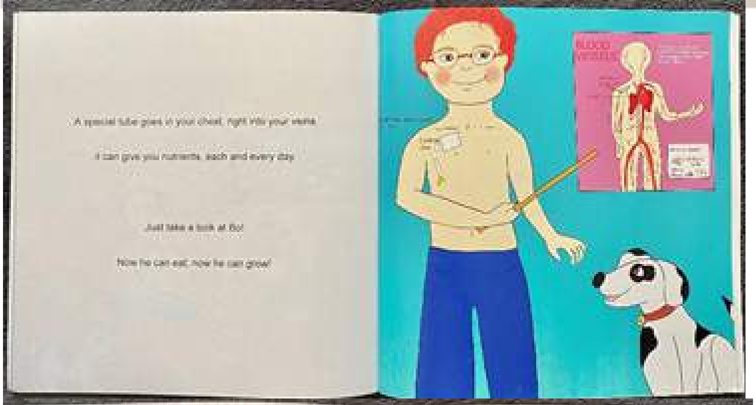

I've had four types of tube feeds:
The NJ, NG and PEG,
and then came the Mic Key button
which has helped me feed instead.




My Mic key doesn't limit me. My doctor makes sure it fits my tummy. As I grow, it grows, but you never know because the peg never shows.

When I play, I have to be careful my button doesn't snag. It's held in my tummy by a water balloon, but don't worry, I can still play tag. My protective belt keeps it safe, but it's hot and can make my skin chafe.

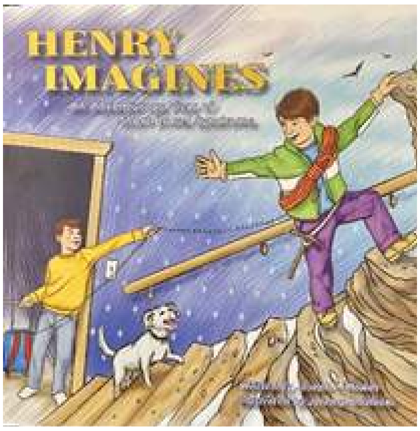



A special tube goes in your chest, right into your veins

It can give you nutrients, each and every day

Just take a look at Bo!

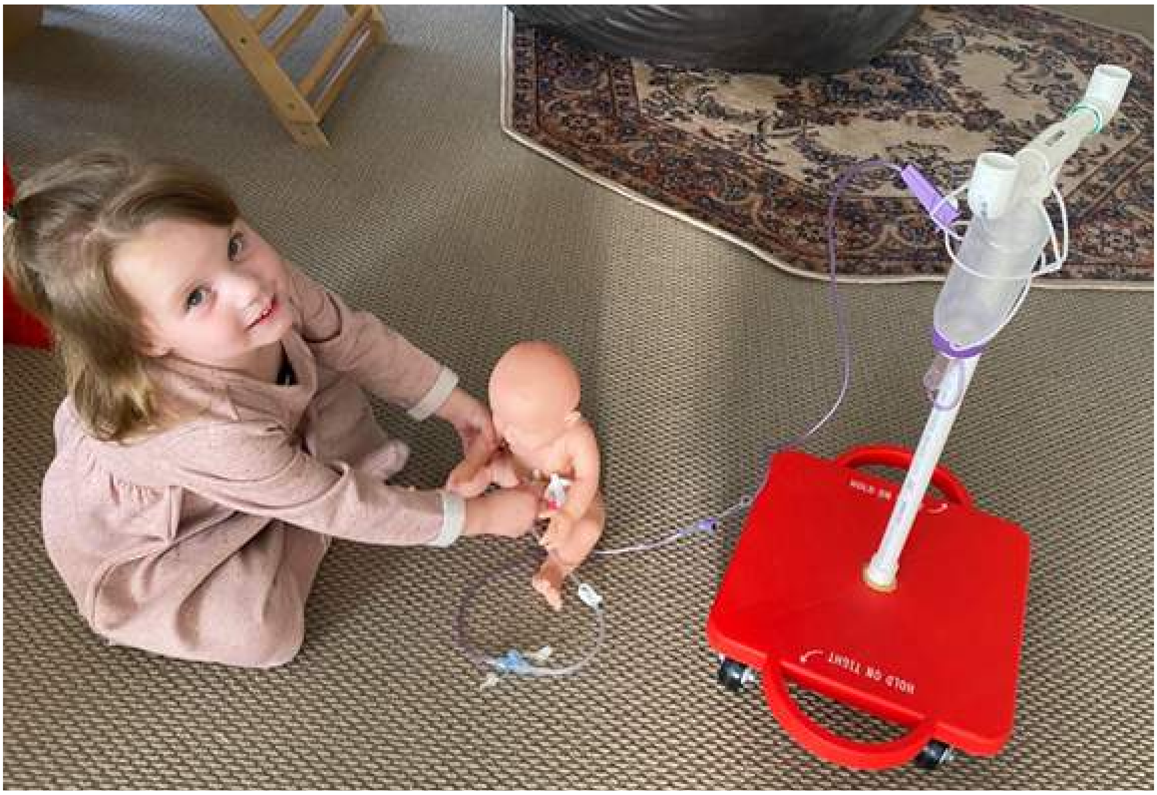
Now he can eat, now he can grow!




Henry has a central line

Henry's TPN goes through a line in his chest. He needs to keep his line from being pulled.

We have had toy doctor sets, but I wanted Syena's play to be able to also include lines and stands, so I made her a simple toy IV pole and attached a hanging bottle and gastric feed line. She hooks up her doll and puppy's gastric buttons to her play IV pole.



When her 4th birthday was nearing, I was happy to hear that a toy company called Our Generation were bringing out a hospital room, complete with accessories including an IV bag and line, light-up x-ray display and an oxygen mask. Although they aren't cheap, she has delighted in playing with this pretty much every day since she's received it. Pretty quickly, the doctor doll was relegated to the role of the second patient and Syena took over as the doctor.

As none of these resources could be found in our local toy shops or bookstores, I thought other parents may be interested in looking at some of the things we've gathered. I would love to hear about any books or toys you've found for your own little warriors.

How to Make Syena's Dripstand

Medical play is a big part of play time in our home, for our little girl as well as any visiting children. If anyone is interested in making a toy IV pole for a child in their life, here's how I made ours.

The red wheelie base was bought for $12 from Kmart in the toy section, near children's bikes and skateboards. An alternative would be a wheeled base for large pot plants but the Kmart toy had the advantage of already having a hole in the centre. I then bought a length of PVC pipe from Bunnings plumbing section, along with a T-joint to fix the crossbars to the upright bars, and two corner joints to go on the end of the crossbars to stop her "feeds" from sliding off. PVC pipe is easily cut to size and it slides into the joints - and a dab of glue will hold it secure. You can make the IV pole as tall as you like, but shorter is more stable for play.

We then hung inverted baby bottles for her pretend enteral feeds and expired IV fluid bags for play HPN, with a cut down silver cover bag to make it look the part. Pumps were fun to make out of suitably sized small boxes covered with paper and then decorated to suit.

HPN Awareness Week 2022

HPN: Our Life

The biggest event on the PNDU Calendar is HPN Awareness Week, a time for our members to engage with the wider community and help bring about a better understanding of what life is like living with Intestinal Failure (IF) requiring Home Parenteral Nutrition (HPN).

HPN Awareness Week is a week-long celebration of Home Parenteral Nutrition (HPN). Put simply, our patient community would simply not be here without Parenteral Nutrition, which has enabled us to thrive and live our lives outside of the hospital environment. For many patients with Intestinal Failure, this has been a rocky rollercoaster of infections and surgeries and hospital admissions, but it has not dimmed the light that comes with having "**LIFE**" and time to spend with our families, friends and doing the things we love to do. We are very thankful for HPN, and to the wide circle of carers, clinicians and health industry workers that make administering this treatment at home possible.

HPN Awareness Week 2022 (AW22) kicked off on the 9th of October with the release of the PNDU AW22 Video, another wonderful concept by PNDU Secretary Miranda, with the help of her amazing family and PNDU members, Julia and Phillip. The video was produced by Delgrecodigital. PNDU is very grateful for the efforts Miranda and her team put in each year producing this invaluable resource.

The link to the video can be found on the PNDU website www.pndu.org; this link will take you to the PNDU YouTube channel, where you will find all the amazing HPN Awareness Week videos. To stay up to date with PNDU, you can to subscribe to our channel.

To watch & share on YouTube:
https://youtube.com/shorts/gtEsGDUM5X0?feature=share

To watch & share on Instagram:
https://www.instagram.com/reel/Cjd_38FAFCB/?igshid=NzNkNDdiOGI=

To help our members and friends engage with the wider community during HPN Awareness Week, PNDU provides various informative resources free of charge, including posters, "What is HPN?" flyers and our favourite, the AW Stickers. We ask everyone to please wear these stickers with pride. Reach out and connect with others, be ready to start a conversation about what HPN is and how it keeps a very rare and special little group of Kiwi's and Aussies alive. If we give stickers to others, we ask them to do the same i.e., wear them during the week and be ready to talk to others about what being on **HPN: "Our Life"** really means to us.

PNDU is always encouraged by the positive feedback and wonderful photos our members and friends share with us.

Sal

I'm Sal and here I am at work today. Able to be here because of the HPN that has kept me going for over 10 years. It has also meant I could watch all 4 of my children complete school, 2 get married and I will get to see my 2nd child graduate from uni soon. I feel incredibly blessed that, despite living with Autoimmune Autonomic Neuropathy that has caused me severe gastroparesis and colonic paresis, I still live a fulfilling life. Previously famous for my cakes, gardening is my latest hobby, apart from escaping in our 1950's Clipper coach that we restored.

Thanks, PNDU for being part of my story too. #hpnlife

Meags

This week I've been spreading HPN awareness to not only my staff members but clients that come in with their pets too.

A little about my journey with HPN.

At 16 I had been going through periods of extreme bloating and vomiting. Eventually I had X rays done and I was sent to have emergency surgery, to remove 34cm of my large intestine. After 2 months in hospital, I was diagnosed with Chronic Idiopathic Pseudo Obstruction (CIPO). In just the 1st 2 weeks I had lost 15kgs and was weighing 40kgs, so I was put onto HPN. I got out of hospital a month later. Unfortunately, as I'd missed a lot of school, I needed to repeat most of my year 11 subjects. 9 months later I was able to come off PN. I had 8 good years, where I was able to travel, date and complete a bachelor in veterinary biosciences. Then one day I had so much pain and distention that my small intestine flipped and again I required emergency surgery. This time they removed 72cm but during the surgery my body went into shock and the Dr's put me into an induced coma.

They decided that I would again need to be on HPN and 3 years later I still depend on it.

I'm now a qualified veterinary nurse and love my job. I appreciate all my friends and family and especially my wonderful boyfriend.

Stickered

PNDU is very grateful for the support of our hospital teams

During HPN Awareness Week PNDU reaches out to our treating hospitals, inviting HPN teams to join in awareness week activities. PNDU appreciates the time and effort our teams devote to improving HPN: Our Life and thank you for your support. Here is some feedback from our hospitals.

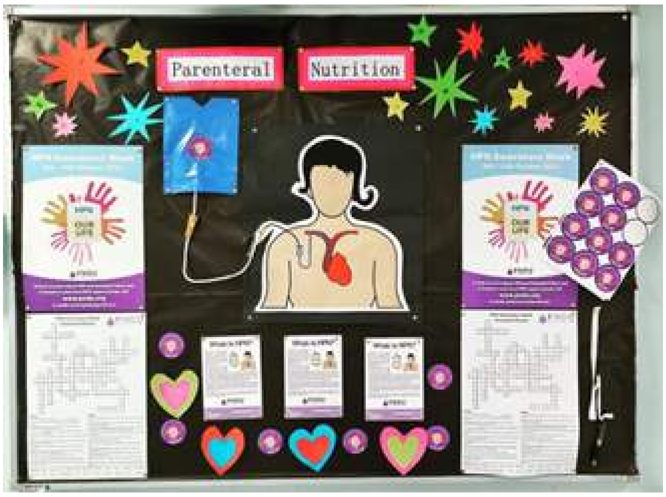
Queensland Children's Hospital

Thanks for your support of us in promoting HPN awareness week!

We used all the resources, had a PN team morning tea, and said 'thanks' to our babies' ward nursing team for their support and care of our babies on long-term PN (and their families) via a poster & treats. This ward really becomes a 'home away from home' for these babies and their families!

In the below photo we have our PN team (from left): Pharmacist Zara, myself, dietitian Julia, Dr Looi, Karen, and dietitian Ming. We are privileged to care for a group of babies/children and their families, who inspire us every day.

Royal Brisbane and Women's Hospital



Specialised Nutrition Support Team.

Happy HPN awareness week!

Shout out to the brilliant crew on 9AN for their display helping patients, visitors and staff understand #HPNlife a little better.

QLD HPN Steering Committee

PNDU appreciates the opportunity provided by the QLD HPN Steering Committee to have a patient representative attend their meetings and be able to provide the patient perspective. Thank you for your support.

Emma Osland, (Chair QLD HPN SC) Great resources as always! Thanks, PNDU

I love this video!!! I shared it on our SNST Instagram page and my twitter account, as well as sending it far and wide this morning to our nutrition and gastro departments. Thanks for the great work you do during HPN awareness week as well as the rest of the year.

Gold Coast University Hospital

Home PN Awareness Week 2022 was a hit at GCUH. Staff participated in a quiz testing their knowledge on all things Home PN (with Jacquie and Scott winning the coffee voucher prizes). We also celebrated our Home PN patients with an afternoon tea and game of Home PN bingo on C2E on Wednesday. Thanks so much to everyone who got involved. Kind Regards Mel

The Royal Melbourne Hospital

During the past week, we spread the news around the hospital by hanging posters and distributing flyers and stickers to staff. During the week we had two inpatients receiving HPN training which was a great opportunity for raising awareness about the impact it can have in improving QOL.

We would like to thank you for your continued efforts in supporting and raising awareness for people on HPN. Many Thanks, Jess Collins.

Social Media

The world of social media provides platforms that enable PNDU, our members and friends to share their stories of HPN Our Life far and wide during HPN Awareness Week. PNDU maintains 2 closed forum groups for our members, an email forum and a facebook page, a place for our members to engage with each other and share their journey's of HPN Our Life.

PNDU would like to thank all of our members and friends who shared stories of HPN Our Life on social media during the week. It's great to have the support of Rare Voices Australia (RVA), Rare Disorders New Zealand (RDNZ), AuSPEN, National Intestinal Failure and Rehabilitation Service New Zealand (NIFRSNZ)

Hi! My name is Emily!

I have been on TPN for over 11 years! I love living life to the fullest and go to school full time when I can. I love all forms of dancing, but contemporary is my favourite. I play the violin and piano and love hanging out with my family and friends.

Happy TPN week everyone!

Jordan: HPNer 13 Years

Jordan has required HPN since Birth

Connected to HPN for 15 Hours every night

When not connected to HPN

Jordan enjoys riding bikes &

scooters, playing video games

and fishing with pop.

#HPNlife

Happy TPN week everyone!

Jodie

Hi everyone,

This is our family, made possible thanks to HPN!

Jodie has been on HPN for around 25 years (I lose count!) due to CIPO. This not so little (now 10 years old!) miracle boy was only possible because of HPN.

These days Jodie enjoys hitting the gym, going to uni, English tutoring and writing. Ryan

Sydney Local Health District: Community and Events

Paige

"I wouldn't wish for another life – I enjoy my life and I get to do a lot."

At six weeks of age, Paige Simpson was diagnosed with hollow viscous myopathy; a rare chronic digestive disorder that affects her gut's ability to absorb food. In the past, her illness has caused severe weight loss and necessitated multiple surgeries to remove parts of her bowel.

Now aged 26, Paige lives a full life and runs her own takeaway coffee business in her hometown of Dubbo, in western NSW. With the support of the Intestinal Failure Team at RPA Hospital, she manages her condition with Home Parenteral Nutrition (HPN), which enables her to get nutrients through a Hickman line into a vein near to her heart. RPA cares for the highest number of HPN patients in Australia, with specialists including a gastroenterologist, gastrointestinal surgeon, specialist nutrition nurse and dietitian. Paige says she has built a strong bond with the team that cares for her at RPA.

"I'm really grateful for everything that's been done for me and my quality of life," she said.

This week is Home Parenteral Nutrition Awareness Week, which highlights patients like Paige and the specialists such as those at RPA who work to treat and support them.

PNDU utilises Instagram for our public engagements. During AW22, PNDU members Logan, Renee, Naomi and Gillian shared a glimpse of HPN Our Life with the following posts.

@ pndownunder

Hpn: Our life.

LOGAN

HPNer 10yrs,

I have a rare genetic condition XCIPO which causes intestinal failure requiring HPN. I'm connected to HPN for 15hrs a day. I enjoy boat rides and fishing trips with Pop, playing oz-tag and soccer, climbing, and going to the skatepark.

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

Logan

Naomi

on HPN (almost) 4 years

I was put on PN almost 4 years ago due to digestive tract paralysis.

My family and friends are very important to me and I enjoy spending time with them whenever I can. My faith is also a very important part of my life.

I love animals, science and baking for the people I love! HPN has given me the strength back to start living life again.

Gillian

on HPN 16.5 years

I enjoy my family, gardening, road trip holidays, church activities and PNDU MC related work, such as putting Dripline together quarterly. The years from age 52 to 68 are all thanks to wonderful HPN!

Renee

on HPN 11 years

This photo is taken on Iluka Beach near where my husband Mervyn and I retired eight and a half years ago.

This photo epitomises what I love to do with my life - working with wonderful community groups to achieve social justice and care for the most vulnerable in society.

I feel very blessed to live in such a peaceful and beautiful environment. This is certainly good for my health!

Across Australia and New Zealand there are 3 providers of HPN, Biomed, Fresenius Kabi and Baxter.

All generously open the doors of their HPN compounding facilities for guided tours and welcome HPNers, family and carers to share their stories of HPN Our Life, with the dedicated staff who manufacture and supply our HPN and consumables. A heartfelt thank you to all our HPNers, family and carers who attended the pharmacy tours and openly shared their stories, you have all contributed to bring about a better understanding of HPN Our Life.

PNDU would like to thank our industry friends for this wonderful opportunity to see how our HPN is manufactured and the attention to detail that ensures the safe delivery of our life saving solution that is HPN.

This afternoon myself and our son Markques attended Baxter facility in Canning Vale Perth. I am Absolutely gobsmacked on what goes into making our son's, and many others, life line. Yes, I do the hook up, but never took into account what the actual process was as we just double check the big bag against the orders. Thank you, Chris, and more so Baxter in Perth; the feedback was amazing for the "team " to meet our son and understand what PN means to us as a family. Markques loved getting gowned up with the Baxter team. Just WOW! Everyone should reach out and if possible, attend this great opportunity. Thanks, Leah

Just wanted to do a shout out to PNDU for organising the awareness week activities. I have just had a personalised tour of the Christchurch compounding facility where they actually made one of my bags while I was watching...I thought I had an understanding of the complex process but boy, I really had no concept of just how much goes into making those lifesaving bags for us. I feel super privileged to have been able to go and meet them, and put faces to names and voices I have been communicating with over the past 15 months or so since I've been on Home PN.... I really encourage those of you who maybe were a bit shy this year (as I was, Chris really had to encourage me to go), that it's well worth it if you get another opportunity next year. Felicia

BAXTER Tours

Put together by Katie Barovs

Old Toongabbie, Sydney

During the week, Baxter ANZ celebrated Home Parenteral Nutrition Awareness Week with a series of events and activities across Australia and New Zealand.

For the first time since 2019, members and friends of Parenteral Nutrition Down Under (PNDU) were welcomed on site, to tour our compounding facilities around Australia and New Zealand. For the first time ever, we had attendees at each of our 7 sites across both countries! Each event was a fantastic experience for our visitors and our Baxter colleagues to share stories from both sides, those who make HPN products and those who use them.

Marketing Manager of Nutrition, Katie Barovs, organised this year's HPN Awareness Week activities to show our teams how we support patients on Home PN.

"We're incredibly proud to show our support for HPN Awareness Week and connect with our patients in Australia and New Zealand to better understand their experiences and how we can best support them," said Katie.

On Friday, employees from across the whole company also tuned in to a special live event featuring our Baxter Compounding teams and PNDU patients and carers to learn more about their experiences with Home PN.

The General Manager, Brendan, Belinda (Compounding and Nutrition Director), and Martel (Senior Director of Compounding APAC & EMEA), took on The Challenge for the week and were given a small glimpse into the life of a Home Parenteral Nutrition Patient from Tuesday to Thursday. The trio were tasked with wearing a backpack filled with 2L Baxter PN solution and infusion pump similar to that of a Home PN patient. Wearing the backpack for three days, and monitoring the pump for alerts and system checks (simulated by text message alerts throughout their challenge time), Brendan, Martel and Belinda saw a glimpse of firsthand life on Home PN.

We asked them a few questions about their experience and how they used the week to raise awareness:

How would you explain to others why you are wearing the backpack?

"In a very small way, I'm putting myself in the patient's shoes, to experience a part of what it means to be on this life sustaining Baxter therapy," said Brendan.

"Every day, we got a text message instructing us to wash our kitchen bench and hands for an extended period of time during what would be our "hook on" time and then buy a coffee for someone and tell them about the challenge. We got into some really deep discussions with a lot of colleagues who hadn't heard about what being on HPN really means," commented Belinda.

What did you think of the processes of unboxing and setting up when you were beginning the challenge?

"It was really interesting to see the different versions and set-ups required by each patient. You can see why multiple options of products and services are needed to make the experience the best for each individual or family." - Brendan

How did wearing/carrying the backpack make travelling to and from work different?

"I tried to put it in the boot twice and caught myself on an elevator door! It was the set-up that really took extra planning and extra time for me, getting my full "infusion" in before a night flight had me awake at 5am to start" – Brendan.

"I didn't think ahead for my flight and had my backpack confiscated from hand luggage!! It also took a lot of extra planning for bathroom trips with a backpack" – Belinda.

"I found it harder to manage the backpack at home; I kept walking away from it when I was trying to do things around the house." – Martel.

Do you think that being an HPNer for the day has helped you to empathise with Baxter HPN users?

"Undeniably, it was a very humbling experience. It really helped to connect with being a patient and appreciate their experience. It also humanised the therapy for me," mentioned Martel.

"Yes, absolutely. Living with the need for TPN would be hard enough, however the issues with equipment/ deliveries etc is an unnecessary challenge. I have come away with a lot of insights as to how we can help service HPNers and their families" – Brendan.

"Completely, I didn't really know what HPN was before this week and the experience has been eye opening. I am also incredibly proud to be part of a team that provides products that make it possible for HPNers to have their treatment at home" – Belinda.

Imagine you were told you would have to do HPN every night/day for the rest of your life…how would you react?

"I would be shocked initially, eating and cooking food is a significant and important part of my life. However, [having completed] The Challenge and hearing the HPNers who shared their stories at Toongabbie on Friday, I would feel grateful that HPN could help me to continue to live my life," said Martel.

"Honestly, probably not well. However, it has been great to hear from HPNers who are thriving and making the most of life." - Brendan

What would have to change in your life if you were on HPN twelve hours per day plus time to hook up/ off:

"I would have to organise myself to ensure I could still do my personal training and running. My health would have to be prioritised and I would need to get a better balance between my work and home life. I would need to rely more on my friends in times when I was unwell as I am quite independent. I would value being part of a support group like PNDU where I could be in touch with others in a similar situation. Travelling for work would need more planning, especially overseas trips!!" – Martel.

Thank you PNDU for hosting such a fabulous Awareness Week – we are honoured to have celebrated with you.

Western Australia

Victoria

Queensland

South Australia

Auckland

Christchurch

Sydney HPNer talks and tour

Katie Barovs, Marketing Manager of Nutrition, left, Chris Walker, PNDU president 3rd left

Personal stories

The focus of HPN Awareness Week is to bring about a better understanding of HPN Our Life. A very big thank you goes to PNDU members Julia and Stephanie for presenting their HPN Journey in front of a packed house during the Baxter tour in Sydney.

Had a great tour of Baxter on Friday and saw the clean room where they make the life-saving parental nutrition each week for Sissy. She looked through the big glass windows at the specialists, all gowned up on their head-to-toe PPE gear making up individually compounded HPN scripts and squealed "That's my PN!"

Lovely moments through the day, watching her and Steph show each other their gastric buttons, sharing conversations with Baxter employees and other HPN families, then watching Sissy playing with her gorgeous little friend, who is her age and the only other person I know of in Australia born with her rare medical condition, Vanishing Gastroschisis.

Happy HPN Awareness Week!

Fresenius Kabi Tour

Gillian and I caught up with Michele and Leah from Fresenius Kabi for a tour of their HPN compounding facility, Slade Health Mt Kuring-Gai. Absolutely amazing to learn how they compound HPN, the dedication of the staff and attention to detail, to ensure our HPN is produced and delivered safely. It is something that must be seen to truly be appreciated. Following the tour, we all enjoyed playing the interactive PNDU HPN quiz, FK set up a link for mobile phones, fastest finger first; well-done Gillian. Networking over morning tea you soon learn how very much appreciated the work of PNDU is with the FK and Slade staff. HPN Awareness Week brings about a better understanding of HPN Our Life.

Thank you, Fresenius Kabi, for your support of HPN Awareness Week.

Baxter Pharmaceutical Tour

By Emily, a 13 yr old HPNer PNDU member.

The tour of Baxter pharmaceutical was an amazing day, filled with many wonderful and exciting things. It was a day for HPN (Home Parenteral Nutrition) Awareness Week. There were HPN consumers, people who care for others on HPN, and even some of the pharmacists who support others with some sort of parental nutrition.

During the day we got the wonderful opportunity to get dressed up in the PPE outfit that each worker needs to put on before entering the different labs. It was amazing to see the incredible effort employees go to ensuring the most sterile workspace for our PN to be made. Every part of their body is covered in several layers of “clean” clothing which must be hot and awkward to work in.

We also got the opportunity to go on a tour into the office areas and around the labs. We got to see the amazing workers doing what they do best. Each bag of PN has each component measured meticulously and added to individual bags in a controlled environment. The two little HPN kids (aged 4) were so excited to see where their PN was made and waved frantically to employees dressed head to toe in PPE. It was evident to see the employees take equal joy in seeing some of the people behind the names on the PN bags they make up each and every week. After we did the tour, we went to a gathering room and got to chat with everyone. This was really nice because everyone got to know each other better, because everyone had been on similar and yet individual journeys.

Two brave people got to share their stories and they were really inspiring and interesting to listen to. We then had the opportunity to get to know each other more over a cuppa and a snack in the nearby cafe. I was lucky enough to exchange numbers with an older HPN receiver, because she was really inspirational. I have been a member of this amazing PNDU community for many years and have fond memories of meeting others who have similar bits and pieces like me! It was just wonderful to see some of those people again and meet many new people who all came together in the spirit of HPN awareness week.

Emily; our two 4yr old HPNers playing; 2 PNDU members facing the gowning up challenge

Melbourne HPN Consumer Workshop and Social Gathering 2 Events not to be Missed!

PNDU invites all our HPN members, family and carers who are able to join us in Melbourne, to join us at these 2 awesome events.

AuSPEN HPN Consumer Workshop 17th November 2022.

PNDU is very grateful AuSPEN has organised another HPN Consumer Workshop, specifically for HPNers and their carers.

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

Date: Thursday 17th November.

Time: 9:30am – 12:30pm

Venue: CROWN PROMENADE, 8 WHITEMAN ST, SOUTHBANK, VIC 3006

For PNDU members who are unable to attend in person the event will also be live streamed.

To register please click the link: https://cvent.me/2g8ZaG

AuSPEN HPN Consumer Workshop

9.30 AM - 12.30 PM, 17 NOVEMBER 2022
CROWN PROMENADE, 8 WHITEMAN ST,
SOUTHBANK, VIC 3006

Consumers and carers only.
Not for clinicians.

PNDU Annual Social Gathering Melbourne 20th November 2022

It is wonderful to be able to host our first face to face get together after 3 long years of isolation and lockdowns.

The PNDU annual social gathering is held alongside the AuSPEN conference and HPN Consumer Workshop. This year we are visiting Melbourne and would like to meet as many HPNers, family and carers as possible. The annual gathering is a great opportunity to meet other HPNers who share a similar journey of HPN Our Life, share stories, make new friendships, and learn more about PNDU and what we do.

Date: Sunday 20th November

Time: 12:00 – 4:00 PM

Venue: The Hub @ Docklands – The Atrium Long Room

80 Harbour Esplanade, Docklands 3008

the hub at docklands - Search (bing.com)

PNDU gatherings are open to all HPNers, Family and Carers.

To register for the gathering.

Please contactpndu@gmail.com

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

Celebrating 10 Years of Rare Disease Advocacy

PNDU President Chris was invited by Rare Voices Australia (RVA) to attend Parliament House in Canberra for the celebration of 10 Years of Rare Disease Advocacy and to welcome the new members of the 47th Parliament of Australia. Chris, has been associated with RVA since they formed in 2012. During this time Chris has had the privilege to represent PNDU on the "Fair for Rare" campaign, where he invited PNDU members to share their personal stories of living with a drip (HPN). The culmination of this work was the development of the National Strategic Action Plan for Rare Diseases, which was released by former minister for health the Hon. Greg Hunt MP in March 2020, with bipartisan support. Part of this process was the formation of RVA Partners, PNDU has been an RVA partner organisation since 2017.

Chris was invited to share centre stage for a photo opportunity with his local member the Hon. Meryl Swanson MP. (Left) Chris, The assistant Health Minister, the Hon. Ged Kearney (Centre), RVA CEO Nicole Millis and the chair of the standing committee on health and aged care, the Hon Dr Mike Freelander. (Right)

Today also marked the recognition of the RVA Ambassador Program, how wonderful to have our new PNDU management committee member Ebony named as an RVA ambassador. I wish Ebony all the very best as she represents everyone living with Intestinal Failure requiring Parenteral Nutrition.

Welcoming the new ministers was also the perfect opportunity to highlight the inequality that exists within our healthcare system in the delivery of care to HPNers across Australia. During the one-on-one talks with the assistant minister for health (a former PN Nurse) I was also able to discuss the lack of access to infusion nurses for HPNers, a service available to home dialysis and Hospital in the home (IV antibiotics etc.). This is now something the minister wishes to follow up on.

Engaging with your local MP helps bring about change.

Learn more about The National Strategic Action Plan for Rare Diseases - Rare Voices Australia

Donations Using Book Depository – Christmas is coming!

If you are a person who buys books on-line for Christmas presents, then here is a very simple way to support PNDU. When people buy through the PNDU website, we receive 5% of the total amount of your purchase. The quickest way to do this is to control click on the link below, which takes you directly to the Book Depository site – and that's it! Just browse, purchase what you want and PNDU automatically receives 5%! How easy is that??

https://www.awin1.com/creadphp?awinmid=10921&awinaffid=782771&ued=https%3A%2F%2Fwww.bookdepository.com%2F

If, at a later stage, you can't find this link, simple go to our website, pndu.org and scroll down the home page towards the bottom, where you'll see a turquoise box saying 'support PNDU: buy at Book Depository' and click on that to be directed to Book Depository.

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

PNDU is proud to be a founding member of the international support group PACIFHAN

PACIFHAN is marking World HAN Day 2022, with "Getting out and about with HAN"

"Do what you can, with what you've got, where you are."

Theodore Roosevelt

Please find the links to content related to World HAN Day 2022:

YouTube: https://youtu.be/NmyyNgW2jws

Twitter: @pacifhan

www.pacifhan.org

If you have any questions, please don't hesitate to contact us: info@pacifhan.org

Upcoming Events

- Rare Voices Australia Rare Disease Summit, Sydney 11-12th November, 2022
- AuSPEN Annual Scientific Conference, Melbourne 17-19th November, 2022
- AuSPEN Annual HPN Consumer Workshop, Thursday 17th November, 9:30-12:30
- PNDU Social Gathering, at The Hub@Docklands, Sunday 20th November, 12:00-4:00pm
- IVNNZ, 17th-19th November, 2022, Christchurch, New Zealand

Thank You

PNDU is very grateful for the support given by the donors listed below. We wish to thank the following for their generous gift. Total donations $5205.

Alison
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Planning Overseas Travel

As a founding member of PACIFHAN (International Alliance of Patient Organisations for Chronic Intestinal Failure & Home Artificial Nutrition), PNDU can put you in contact with sister organisations in various countries overseas (UK, USA, Czech Republic, Denmark, Italy, France, Poland and Sweden) which may be able to assist with any HPN travel questions in those countries. Just ask us at contactpndu@gmail.com

Membership for Aussie and Kiwi HPNers and carers

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

Benefits:

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

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

Donations

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

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

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

Donating via direct deposit

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

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