



# DRIPLINE



# PNDU

Parenteral Nutrition Down Under

It's been a very eventful three months for the PNDU MC and for members. Happily, we read of two of our 'littlies', Syena and Leo, successfully starting kindergarten this year; and of young Mayana having success with Revestive; we catch up with some members at the Sydney social gathering, and learn how many members had to cancel for the Brisbane social gathering; we hear of the several advocacy groups' conferences that Chris, our president, has attended on our behalf, all with the potential of helping HPNers' (and other rare diseases sufferers') quality of life. PNDU's MC once again requests more volunteers to share the load. And sadly, we farewell Frances (Frankie) Shaw, born in Mt Isa and on HPN for 35 years; 'at peace now' – Norman Shaw.

Gillian

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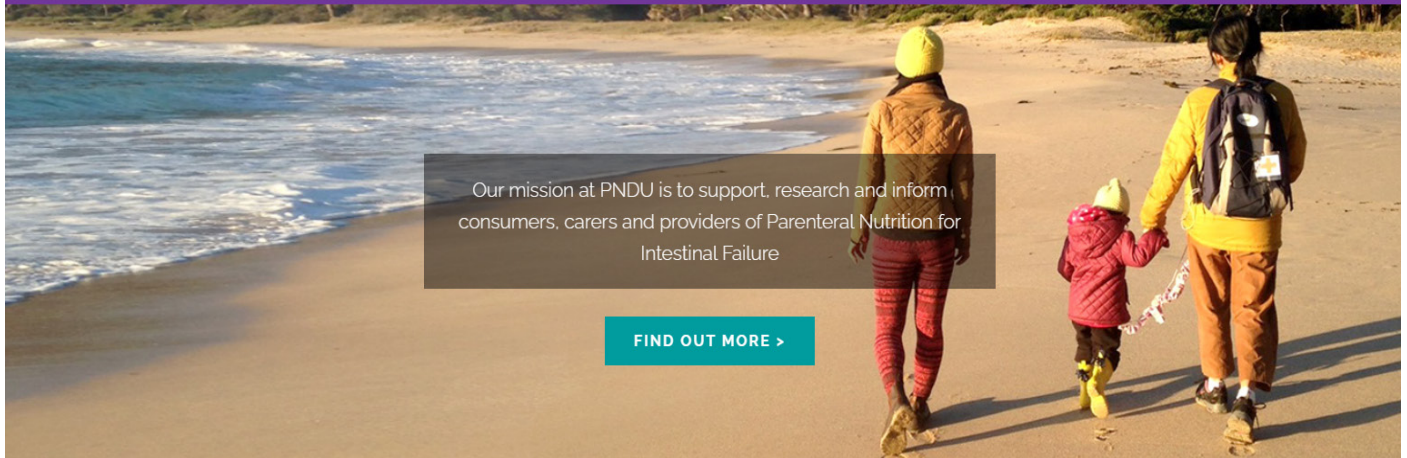
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WHAT IS PN & IF ABOUT US MEMBERSHIP RESOURCES



Our mission at PNDU is to support, research and inform consumers, carers and providers of Parenteral Nutrition for Intestinal Failure

FIND OUT MORE >

## Would you like to be part of a team and help out at PNDU?

*"Alone we can do so little; together we can do so much" – Helen Keller*

Would you like to learn new skills? Or do you have skills you would like to improve?

- Leadership & Teamwork, Mentoring & Training
- Organisation, planning, time management & problem solving.
- Book keeping Treasurer.
- Communication & social media.

## Volunteers enjoy better physical and mental health, make new friendships and enjoy new social experiences.

*"As you grow older, you will discover that you have two hands – one for helping yourself, the other for helping others" – Audrey Hepburn*

PNDU has a mission to support, research and inform consumers, carers and providers of parenteral nutrition for intestinal failure across Australia and New Zealand.

We do this with the help of a small group of dedicated volunteers. The PNDU Management Committee meets online via skype every 6 – 8 weeks and stays in regular contact via email.

As a result of the great work done by the Management Committee - planning PNDU events and social gatherings; organising HPN Workshops; Awareness Week activities; attending conferences and advocating for all HPNers down under; administrating the PNDU Forum, Facebook Page, Instagram and Website - PNDU membership has grown significantly over the past 15 years and now it's time for the PNDU MC to reach out and grow with the help of our wonderful members.

If you would like to help out, please [contactpndu@gmail.com](mailto:contactpndu@gmail.com) for more information.

*"Unless someone like you cares a whole awful lot, nothing is going to get better. It's not" – Dr. Seuss*



# About PNDU



Parenteral Nutrition Down Under Inc. (PNDU) is a self-funded, non-profit support group for consumers and carers in Australia and New Zealand on Home Parenteral Nutrition (HPN). PNDU is a registered charity.

## Follow us on Instagram



**“Unless someone like you cares a whole awful lot, nothing is going to get better. It’s not” – Dr. Seus**

## Syena and Leo Start School



***Editor’s Note: Sending our children out into the wider world of school is an exciting, but also concerning, time for all parents. But when your child has complex medical needs which are not understood by the general population, it adds to parental anxiety. It’s great to read of Syena’s and Leo’s successful transition to school.***

### Syena Starts School

By Julia

There was a time I wondered if our little girl would be strong enough to attend school, or whether we would need to consider home schooling. She was such a sickly baby who had spent more time in hospital than home by her third birthday. But Syena is such a social child, and it was clear that she loved nothing more than being surrounded by other children. We just had to make school work for her!

In the ACT, every four-year-old is guaranteed 15 hours free education a week at their local government preschool, which is attached to the zoned primary school. As our preschool was part of our local Primary School, their administration staff had been involved in supporting Syena’s preschool enrolment. They contacted a Dept of Education

Occupational Therapist, whose recommendations included modifications to the toilet and installation of an air-conditioner.

Syena started preschool in 2023 and had a wonderful year. It was a happy, gentle introduction and Syena had the loveliest teacher and assistants in her classroom. They adored her and she loved them. Her teacher bought a raised sand tray table and a raised water play table so Syena could invite friends to join her at these alternative play areas rather than her just miss out on play in the large sandpit or the mud





kitchen area she had to avoid.

The preschool year was such a success that I tried not to become anxious as I considered the challenges Syena would face transitioning from that protected environment into the much larger, full-time "big school" next door. Would she become "lost" in the crowd? Would she face teasing and bullying that had not been an issue where she had

been surrounded by kids her own age? How would she manage in a much bigger environment while her language development was still so significantly delayed? Would she be able to ask for help when she needed it?

I started meeting with the school executive midway through Term 4 of 2023 to plan Syena's Kindergarten transition. I was sure that one reason Preschool had been a success was that we had put in a lot of preparation and discussion of issues ahead of time, so I wanted to do the same with school. I was a bit concerned that we didn't seem to be having as many meetings, but reassured myself that they knew Syena now, so were less concerned about their ability to meet her needs.

One afternoon, the school Principal called and said he had confidential news to share. I couldn't tell anyone as he hadn't yet told his staff. He wanted to let me know that Syena's beloved preschool teacher had agreed to accept a position as one of the three Kindergarten teachers at the school, and Syena would again be in her class for 2024. I told him that was wonderful, and with that news he had just relieved nearly all my concerns about Syena starting Kinder.

School again contacted HAAS (Healthcare Access At School), ACT Health, who updated Syena's healthcare plan around her enteral feeding needs and visited the campus several times to provide refresher training of several staff members around giving her enteral feeds. Syena doesn't access HPN at school, so that wasn't relevant. I updated her several pages of Emergency Plan regarding all other medical needs (central line/vomiting/dehydration/fever protocol) and that was signed off by her GP.

When Syena started preschool the year before, I had written a social story for other students, along with a letter for their parents, explaining her medical needs, and enteral and parenteral nutrition, in simple terms and asking parents to help us try to keep Syena out of hospital and as healthy as possible by not sending sick children to school.

When Syena started Kindergarten, her Primary School updated this letter and social story from the year before, added new photos and sent it out to all school families and all school staff, so that there would be an awareness and understanding throughout the whole school community of our little HPN warrior from her first day there. This has worked wonderfully. When I walk Syena into school in the morning, she often has big kids from nearby classrooms run up to say hi and to check if she is okay or would like to play with them. They have taken a protective role with her, without becoming bothersome. We knew she would inevitably be exposed to more illness as the trade-off for more socialising with other kids. We are now in Week 8 of school. She has had a couple of days we decided to keep Syena at home when her teachers were off school with a bug, a couple of days in hospital herself when she got RSV and we had to go through our usual fever protocol of IVAB until we had 48 hours of negative blood cultures, but other than that she has been in good health.

And she LOVES SCHOOL! Syena counts off the weekend sleeps until she can go back to school. I haven't yet had the heart to explain school holidays to her.

Syena has some toileting challenges. She often wets herself. Surprisingly, although she has constant diarrhoea, she doesn't often soil herself or her clothes but she does leave the toilet a mess and needs help to clean herself and the toilet after a poo. Syena had a teacher's assistant who moved up from the preschool along with her teacher. Syena uses the nearby toilet block to pee, along with her classmates, but if she needs to do a poo, her assistant accompanies her to a nearby locked disability toilet which allows her privacy and an area where she can be assisted to be washed and cleaned



up afterwards. This also means she doesn't have to worry about embarrassment from the smell or noise her diarrhoea creates.

I am grateful for the school's sensitivity around issues like Syena's toileting. I'm aware of other young HPNers who do not have supportive schools, and that makes me even more grateful that our experience has thus far been only positive. They are aware of protecting Syena from things that are not yet at all a concern for her, being an age where she thinks farts are still the funniest thing in the world and hasn't had anyone say anything nasty to her about body functions she can't control. In our family she happily continues to reign supreme as Princess Farty Bum!

## Leo Starts School

By Anna

Leo started kindergarten in February of this year. Reflecting on his wonderful community preschool we were very fortunate to start his school life so positively. His rooms had higher ratios of teachers to students than other preschools and childcare centres in the area. They were one of the few places that welcomed him with buttons and a central line. All the teachers had extensive experience with preschoolers and their own children with neurodiversity and complex needs, but most had not been hands on with gastrostomy feeds. We are very grateful for amazing preschool Director and NGO management's leadership; that nothing was a problem. A "let's give it a go" attitude made adapting to the changes of his devices, attachments and cares over the two and half years, and as well as multiple abdominal surgeries and admissions, so much easier.

Communication at preschool with all the staff was key to Leo maintaining hydration, minimising pain and providing support to include him with his peers in every activity. The preschool uses an app for all parents, so messages could be left for teachers. This was helpful when gate drop offs occurred, as a teacher would acknowledge the message then write it into his communication care book. Each teacher would then read it, and at the end of the day, a photo of the care sheet was uploaded to the app seen only by me, with information on oral intake if any, boluses, degassing and nappies.

Leo started using words at 22mths before he

used AAC and key word sign and still sometimes does. It was over 12mths attending preschool before Leo talked with peers. And all the teachers celebrated each day to happily tell me "he spoke to so and so today or stood away from the teacher and interacted and played with another student." One group I'm a part of call these 'Smilestones', a small interaction for others is a milestone for us and makes us smile with happiness and pride. Our beautiful preschool teachers celebrated every milestone and visited hospital during each of his long admissions. I provided gastrostomy training and as changes occurred, they were happy to have me in to support them. When he started, all staff were able to join an online training session with our Hospital Intestinal Rehabilitation CNC to provide training on emergency line procedures. Due to his 2023 mid- year, 3mth hospital admission, the director and I placed importance on Leo finishing preschool with his peers, but he was discharged on a significant increase in HPN hours and volume from what he had ever had before at home, and that would require him to be connected at preschool. From 13hrs to 20hrs a day, it was a very stressful time and priority on keeping him and his line safe. Due to developmental and trauma factors he has not been independently safe, unlike reports from many other parents with somewhat similar diagnosis that their child "just knows" but for every child, brain wiring and history is different. Unless he is asleep, he needs to be in arms' reach at all times whilst connected. The preschool director supported us in every way for him to finish the year and graduate with his friends. A beautiful milestone moment. A teacher was always with him with eyes on his fold up small trolley with the micrel backpack and an extension line covered in gaffa tape. I stayed in the office or tea-room doing "Leo admin" till disconnecting him at lunch time. Then I had a short time on my own to get out to shops or breathe before coming back for pickup and then connect at home. He returned to preschool for 6weeks after admission, before finishing for the year. Prior to this, he attended 5hrs a day, 3 days a week. On return he went only two days and gradually increased his hours. There was not time to apply and receive additional funding to support his needs before he finished the year, so as it was for this short period, I stayed at preschool when he was connected.

Thankfully his PN requirements reduced over the Christmas break and started kindergarten on 16hrs. I spoke and messaged with many PNDU parents and carers on their tips for the practical bits of attending



primary school and read through lots of previous Driplines just like I did when we first came home from hospital when he was 9mths old. A very special thank you to Sonya, Mel and Julia who supported me greatly in my near panic of how we were going to manage 20hrs connected, let alone get out of the house or start school.

Our amazing preschool teachers provided me with much information and guidance on the application process, as many had gone through it themselves. Our application was

for a support unit placement in a mainstream school in NSW. I also attended a number of online webinars on parents' experiences of complex kids starting school; rights of children with disabilities; on inclusion and learning with supports. We were very fortunate to have a Community CNC who provided training, a detailed care instructions book and invaluable advocacy with the primary school.

There is so much in our complex medical and NDIS paths that we have minimal control over: the way rules are interpreted; the lack of awareness and

understanding for our rare kids; and the importance of listening to carers and parents. The stress of entering another bureaucratic government system is tiring. We are very thankful that he has an amazing and brave support teacher who writes in a cares communication book each day and so far calls me 3-4 times a week to ask for help and guidance. I disconnect in the school library each morning as school starts and his support teacher meets us there, with a brief verbal handover with detail written in the communication book taken home each day.

After all the meetings, reports and requests he received a spot in a support unit in a mainstream school which was what we felt and still do, is the right place for him at the moment.

At the end of term one of kindergarten, I can say we made it without an ambulance called to school, without a sepsis protocol or obstruction admission and he has made friends and talks and plays with them and received an invite to a classmate's birthday party. Smilestones!

Here is a list of resources which Anna found valuable and put together for your help.

*Transition to School Resources*

*All Means All Kindred*

*People with Disability Australia*

*Plumtree Children's services*

*Berry Street Education Model*

*Lives In the Balance CPS*

*Family Advocacy NSW*

*Association for Children with a Disability Vic*

*Community Resource Unit Qld*

*NCCD.edu.au factsheets*

*Australian Childhood Foundation*

*State Education Department websites*



By Eileen, grandmother

***Editor's note: PNDU doesn't endorse any medical treatments or drugs, but believes that members should be aware of new advances in clinical nutrition, to discuss with their hospital team.***

Mayana was born in Townsville, QLD on the 16/06/2014 with Gastroschisis with malrotation, where most of her intestine died. She was taken into surgery straight after birth and had all except about 20cms removed. At that stage Mayana was only given a limited survival rate. In the days after, she was put on TPN and spent the following 18 months (about 1 and a half years) in hospital between Townsville and Brisbane. Mayana was finally released from hospital to start a life of what has become our normal.

Mayana left hospital requiring seven nights a week on HPN for a total of 12 hours a day. She had iron infusions every two weeks for a long time and eventually they went monthly and now she does not require them.

Mayana went to kindergarten and preschool and then onto school in Townsville and was very stable and developing very well. I decided to re-enter the Defense force and was posted to Sydney. Before we left Queensland, I was told about the new drug Teduglutide, but was told Mayana, because of her extremely short gut, would not be a candidate to try it.

We moved to Sydney in June 2020 and met with our new team at Westmead Children's Hospital. Over the next couple of years, Mayana was progressing well and had reduced her HPN to 10 hours a day, which to me was amazing.

In about January of 2022, we had a conversation with the team at Westmead and they asked if I would be interested in Mayana trying Teduglutide and after being given all the information I decided to let her try it. Mayana started the injections in February 2022 with no guarantee of it working. We went into it with an open mind and were amazed at

the short-term results. Over time the results were better and better. Mayana got to have one night off her HPN which we were both extremely excited about and the results just kept getting better with Mayana continuing to gain weight and growing and developing as per her growth charts.

Now Mayana has been on the injection for two years and has 4 nights a week off her HPN and she continues to amaze me with her strength and



Mayana

resilience for such a young person, as do all our young HPNers.

I am thankful that Mayana was given the opportunity to go onto Teduglutide, it has given us hope for the future.





## Australian Patient Advocacy Alliance (APAA) Summit

27-28th February, 2024

### Transforming Healthcare to Realise Patients' Vision for the Next Decade

As a member of the Australian Patient Advocacy Alliance (APAA), PNDU was invited to attend the APAA24 Summit in Canberra. Our President, Chris, represented PNDU at the summit which was spread across 2 days. The summit was well attended with 80 APAA members, representing Patient Organisations from across Australia. The Summit provided the opportunity to work collaboratively together and identify advocacy priorities that best meet the needs of people living with chronic and complex disease.

Day one was held at the National press club in Canberra with a welcome address from Nettie Burke, Chair, APAA, followed by presentations from industry partners and patient organisations. We learnt about 'The state of play: What it takes to get advocacy cut through with Government.' Three patient organisation presentations highlighted that change doesn't happen overnight and gave talks on "Playing the long game to achieve a National Lung Cancer Screening Program"; "Steering into the Government's agenda, working with Government to deliver pelvic pain clinics" and "Partnering across disease states to pursue NHRA reform and broaden access to CAR-T therapy."

The above three presentations highlighted the need for small patient groups like PNDU to partner with larger advocacy groups to collaborate and utilise the power of a unified voice to help bring about change. I would like to thank the APAA for this wonderful opportunity to attend the 2024 APAA summit.



Pictured – PNDU President Chris – APAA CEO Deidre



### Address from Deidre Mackechnie, Executive Officer, APAA.

She spoke of the power of the APAA in achieving policy change, and the importance of strong industry partnerships. Jamie Nicholson, Corporate Affairs Manager, Roche, spoke. Hearing from industry, he spoke about what does industry look for in a successful Patient Advocacy Group partnership?





Panel discussion: How close do the Health Technology Assessment HTA reforms which are currently underway bring us to an ideal model? What more needs to be done?

- Ann Single, Patient Voice Initiative
- Jo Watson, Deputy Chair, PBAC, Chair, HTA Consumer Consultative Committee
- Patient representative

Workshop session: What does best practice HTA look like from the Patient Advocacy Group and industry perspective? How can we work together to achieve an ideal HTA model?

Day 2 was held at Parliament House, with a member only Summit where the APAA engaged with decision makers, to define its vision for Australia's health system, forming the basis of the APAA's advocacy moving forward.

Welcome address: Minister for Health and Aged Care, the Hon Mark Butler MP & Senator the Hon Anne Ruston, Shadow Minister for Health and Aged Care.

The ministers spoke about Transforming healthcare – a vision for 2034

The summit workshop sessions were about - FINDING EFFICIENCY IN THE SYSTEM – A VISION FOR EARLY DIAGNOSIS AND PREVENTION & A VISION FOR BEST PRACTICE MANAGEMENT OF CHRONIC DISEASE

Stephen Mason, Director of Patient Engagement, Australian Patients Association informed us as to what are patients telling us about the current system? Where to next?

Paul Creech, Chief Program Officer, Australian Digital Health Agency, presented 'Embracing innovations to develop new models of care and improve our management of chronic disease.'

Panel discussion: The system reforms needed to achieve a truly patient centric system. Working session: How do we achieve best practice chronic disease management for all? What role do PAGs play in this?

Working session: bringing it all together and reflections on the day

The APAA vision: - In 10 years we will have achieved our ambition when...

- Health is viewed as an investment not a cost
- Equitable and Timely access to worlds best care
- Australia is a leader in Chronic Disease
- We shift health funding to a focus on prevention
- Patients are at the decision-making table – early in the process
- Patient Organisations are part of the Health Care System & funded appropriately



## Save the Dates for the following free-of-charge-events

### PNDU Social Gatherings 2024

PNDU has organised several social gatherings during 2024 and it would be wonderful if our members are able to come together and be part of something special. With Gatherings already held in Sydney and Brisbane, keep an eye out for other gatherings and events throughout the year.

PNDU Gatherings are great opportunities to meet other HPNers, carers and their families and get to know each other during a relaxed afternoon.

### Adelaide Social Gathering

PNDU will host a Social Gathering in Adelaide During HPN Awareness Week 13 -19 October 2024. The social event will coincide with an awareness week event at Flinders medical centre, to celebrate the contribution to the HPN Community over more than 20 years by Dr Andrew Holt who has recently retired. His dedication and contribution to all our HPNers and HPN field over the years have been invaluable.

Venue Date and Time will be advertised closer to the event.

If you would like to attend this event, please RSVP by email to [contactpndu@gmail.com](mailto:contactpndu@gmail.com)

### PNDU Annual Social Gathering

Sunday 17th November Brisbane

Venue (TBC)

### HPN Consumer Workshop

PNDU is very grateful to be working with AuSPEN to deliver another HPN Consumer workshop alongside the AuSPEN Conference in Brisbane 14th – 18th November 2024

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

More information will be provided in Dripline and on the PNDU forums during 2024

## Expression of Interest (EOI) to attend these events

### PNDU Travel Sponsorship to attend these two events in Brisbane

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

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

To Apply for a PNDU Travel Sponsorship, please forward EOI to attend and EOI for travel sponsorship to [contactpndu@gmail.com](mailto:contactpndu@gmail.com)

Winners will be notified via email and announced on PNDU forums.





By Chris

The Patient Voice Initiative (PVI) has always provided a wonderful source of information for patient organisations, and this year's workshop at the national Press Club was no exception and started a busy week of events leading up to Rare Disease Day in Canberra.

As PNDU is currently working with AuSPEN developing and implementing an HPN registry and HPN Model of Care (MOC), this was a timely workshop to attend, highlighting the importance of consumer/patient & carer input into research to better understand the human experience and enhance patient centred healthcare.

PVI and CaPPRe (Community and Patient Preference Research) co-hosted the research workshop attended by 32 patient organisations. The theme of the workshop was "How patient organisations can generate patient-based evidence". We were welcomed to the workshop by Brittany Keen, Director of Research Operations, CaPPRe & PVI Committee Member Ann Single, ("Learning from patients and their families is essential for good health care...").

Guest Speakers included: -

**Nicole Millis**, Rare Voices Australia (RVA) - Why is patient-based evidence important?

**Jenni Godsell**, CaPPRe - Qualitative insights

Qualitative research aims to understand human experiences Answer the 'how' and 'why' instead of the 'how many' or 'how much'.



**Simon Fifer**, CaPPRe - Patient preferences

Preference research measures what is most important to patients when making treatment decisions.

**Laurie Axford**, CaPPRe & **Sharon Winton**, Lymphoma Australia - Patient reported experience measures (PREMs)

PREMs measure patient perspectives of their experiences while receiving care. Focuses on processes of care (e.g. satisfaction with HCP communication). Can identify gaps in care. and opportunities for quality improvement at service-level. Can inform government policy to support system-wide change. Can enhance patient centred healthcare.

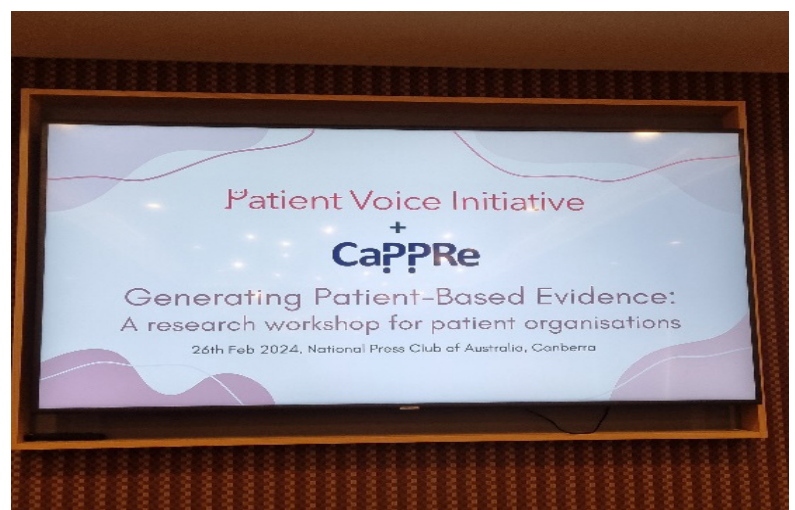
**Simon Fifer**, CaPPRe & **Hayley Beer**, Myeloma Australia - Patient-reported outcome measures (PROMs).

PROMs capture a person's perception of their own health through validated questionnaires. Identify health states and allow comparison of health overtime. Can evaluate impact of condition and treatments beyond clinical endpoints (e.g. quality of life/disability). Can measure and enhance clinical care at individual level.

**Maya Joshi**, CaPPRe & **Hayley Beer**, Myeloma Australia - Other types of research: Service evaluation.

**Cathy Sertori**, thehealthinc. - Top tips for research funding.

Thank you PVI and CaPPRe for delivering a very informative workshop.







By Sal

Our annual gathering for Sydneysiders was a delightful event, despite the sticky and hot weather. Seven HPNers, along with their family and/or carers, braved the weather and enjoyed an afternoon of chatting and catching up at our home. Our little dog 'Pip' got run over for her feet, literally (we ended up hiding the balls, so she wouldn't keep asking for it to be thrown for her!) But Pip enjoyed all the love and attention from anyone who obliged her. Jordan (14yrs HPNer) and Logan (11yrs HPNer) had a blast playing X-Box soccer and are now trying to convince Chris (PNDU president and their 'Pop') and Mum, Brooke, to get them a similar projector set-up for their home. Those interested had a tour of 'Bridget', our 1956 Clipper Coach, that we have fitted out as a motorhome specifically to cater for my HPN care needs. Those who sat in the cool of the house were being entertained by Mayana (9yrs HPNer) playing on the piano. It was great to have newer PNDU member, Anna (HPNer), come along, as well as our Dripline Editor Gillian (HPNer), and it was a good opportunity to chat and get to know each other and share ideas and support each other. Leo (5yrs HPNer) did a fantastic job at keeping us all cool with his little water spray bottle. I loved seeing how much all the kiddies have grown up, especially Emily (now 14, HPNer) and her younger sister Phoebe (excellent ball thrower for Pip). A great afternoon, and big thanks to Chris Walker for organizing it.



Back: Anna, Matt (host), Jordan (HPN), Chris, Logan (HPN), Anna (HPN), Gillian (HPN), Emily (HPN), Eileen, Mel  
Front: Leo (HPN), Brooke, Sal (HPN and hostess), Mayana (HPN), Phoebe (standing)



HPNers: Jordan, Logan, Anna, Gillian and Emily (standing), Sal and Mayana, seated



Having a chat





Light entertainment







## [on Rare Disease Day 29th Feb 2024](#)

By Chris

It was wonderful to be invited to attend Rare Voices Australia's (RVA's) biggest-ever Parliamentary Event on the rarest day of the year, Rare Disease Day February 29th, 2024. The event is co-hosted by the Parliamentary Friends of Rare Diseases and the theme was 'Progress Beyond Policy'.

RVA CEO, Nicole Millis, opened the proceedings and spoke of the progress of the National Strategic Action Plan for Rare Diseases and how this rare disease day we are focusing on two key implementation mechanisms:

- The National Recommendations for Rare Disease Health Care, which have now been endorsed by 9 colleges/institutions and recognised by the Royal Australian College of General Practitioners; and

- The need for Rare Disease Centres of Expertise

Read the speech delivered by RVA's Chief Executive Officer, Nicole Millis.

[https://rarevoices.org.au/wp-content/uploads/2024/03/NicoleMillisSpeech\\_2024RareDiseaseDay.pdf](https://rarevoices.org.au/wp-content/uploads/2024/03/NicoleMillisSpeech_2024RareDiseaseDay.pdf)

Guest speakers also included the federal Health Minister Mark Butler, Shadow Health Minister Senator Rushton, Co-Chairs of the Parliamentary Friends of Rare Diseases Dr Mike Freelander MP, Senator Wendy Askew & Dr Monique Ryan.

It was great to hear about the importance of Rare Disease Centres of Expertise and how they could benefit the estimated two million Australians living with a rare disease.

This year's parliamentary event also saw the launch of Australia's first-ever National Recommendations for Rare Disease Health Care. Dr (Elizabeth) Emma Palmer, senior clinical lecturer at University of NSW, and leading co-author of the Recommendations, spoke of how the recommendations were written to help health professionals provide quality care for people living with rare disease, including people with a diagnosed rare disease and those who have not yet received a diagnosis.



Picture RVA ambassador and PNDU member Ebony, Health Minister Mark Butler speaking





National  
Recommendations for



**RARArEST**

Rare Disease Awareness,  
Education, Support, and Training  
[rarevoices.org.au/rarar-est-project/](http://rarevoices.org.au/rarar-est-project/)

# Rare Disease Health Care



**National Recommendations for Rare Disease Health Care**

<https://rarevoices.us3.list-manage.com/track/click?u=2faa19dd1e6808d16ad363e83&id=8996dc7888&e=d551fee712>

Dr Falak Helwani, Research and Evaluation Manager, RVA, spoke of her personal experience with rare disease.

As an RVA partner organisation, PNDU wishes to thank Rare Voices Australia for the opportunity to attend the Rare Disease Day Parliamentary event.

Read the **National Strategic Action Plan for Rare Diseases**

<https://rarevoices.us3.list-manage.com/track/click?u=2faa19dd1e6808d16ad363e83&id=556221500f&e=d551fee712>



By Chris

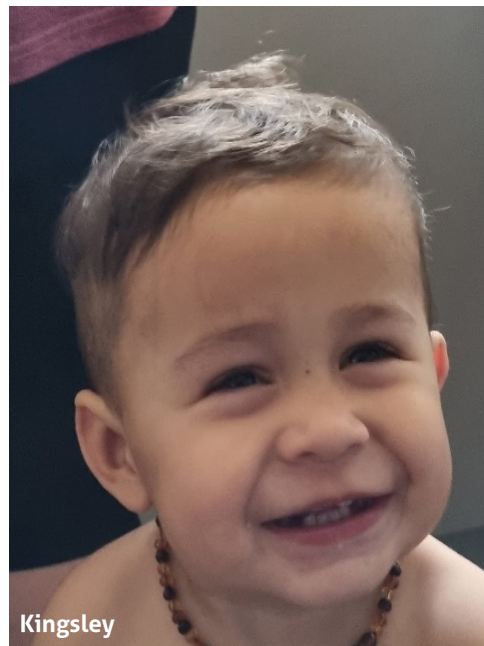
Saturday 16th March, 2024, was the scheduled PNDU social gathering in Brisbane. With 10 RSVP's, I looked forward to an enjoyable afternoon meeting with HPNers, their families and carers. I arrived early at the Roma Street Parklands, setting up under a shade shelter for our gathering, I posted photos and directions on the PNDU forums to make it easy for members to find me. After a few scattered showers the clouds started clearing, revealing a lovely morning in Brisbane. At 27 degrees, partly cloudy with a gentle breeze, I settled back and waited for our members to arrive. Unfortunately, as the day had started with a few showers and clashed with local elections, this may have deterred a few of our members on the day. As I read the incoming emails and messages from our members, I was also reminded how complicated and vulnerable our life on HPN can be. Sadly illness, medical complications and the passing of a PNDU member cut down the expected numbers on the day. I pass on our sincere condolences from the PNDU family and wish everyone who is unwell all the very best for a speedy recovery. Thanking all the members who let me know they couldn't make it.

On a happier note, it was great to catch up and chat over lunch with a wonderful member of the PNDU family, Lindsay. Lindsay, is the husband of our late PNDU management committee member, Fay, who sadly passed away last year.

I also caught up with little Kingsley and his mum Kristie. Kingsley started life on Parenteral Nutrition but has successfully come off PN.



Lindsay



Kingsley

## **The next PNDU Social gathering in Brisbane will be Sunday 17th November**

PNDU will hold our Annual Social Gathering in Brisbane in November alongside the AuSPEN Conference and HPN Consumer Workshop. Sunday 17th November 2024

PNDU will offer travel sponsorships to attend these events.

**For more information, to apply for a travel sponsorship and to RSVP for the Gathering, please [contactpndu@gmail.com](mailto:contactpndu@gmail.com)**





# In Memoriam

## PNDU remembers past HPNers

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

**Frances (Frankie) Shaw** – 28 th January, 2024 aged 69

**Rosie Crosland** - 30th August, 2023, aged 70

**Fay Boyd** - 23rd August 2023, aged 76

**Lily** - 21 June 2023, aged 23 years

**Lynden** – 14 July 2022, aged 68 years

**Tracie** - 5 February 2022, aged 47 years

**Aidan** – 21 May 2020, aged 14 1/2 years

**Lara** – 24 April 2020, aged 37 years

**James** – 9 November 2019, aged 28 years

**Elise** – 19 August 2019, aged 43 years

**Ross** – 23 January 2019, aged 67 years

**Celena** – 27 November 2017, aged 43 years

**Emma** – 9 April 2017, aged 35 years

**Lara** – 16 February 2017, aged 7 years

**Teresa** – 15 February 2017 aged 58 years

**Natalie** – 18 September 2016, aged 27 years

**Sam** – 13 September 2016, aged 14 years

**Carol** – 2 September 2016, aged 67 years

**Jessica** – 24 January 2014, aged 20 years

**Tynasha Rose** – 29 October 2012, aged 5 years

**Aria** – 20 June 2011, aged 5 years

**Pauline** – 29 April 2011, aged 38 years

**Hebe** – 3 January 2008, aged 2½ years



May the cherished memories of these dear ones  
never fade



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, \$5020.

**D. Walker**  
**Takeda**

## 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](#).





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

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

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

## Donating via direct deposit

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



<p><b>Australia (\$AUD)</b>                  Bank: Westpac                  Account Name: <b>PNDU Inc.</b>                  BSB: 032 056                  A/C No.: 482 738</p>	<p><b>NEW ZEALAND: (\$NZD):</b>                  Bank: ANZ                  Account name: IPANEMA                  A/c No: 06 0273 0308799 00                  Please include reference "PNDU"                  IPANEMA (Charities Commission Registration CC21178) is a NZ charity</p>
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## Management Committee Members

**President** - Chris  
**Vice-President** - Gillian  
**Secretary/Public Officer** - Miranda  
**Treasurer** - Naomi  
**Dripline Editor** - Gillian  
**Committee Members** - Julia

## Contact Us

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