DRIPLINE

PNDU

Parenteral Nutrition Down Under

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2026

Welcome to another issue of PNDU's Dripline. Advocacy and talking to clinicians and industry workers at conferences are the main ways that PNDU has progressed from a small number of HPNers in Australia and New Zealand who lived with this extremely rare form of nutrition and who relished the idea of support from others who understood their issues, to a well-known and respected support group which receives invitations from various allied groups to attend and/or speak at conferences, which provides the opportunity to advocate for positive change. Our president, Chris, has a very full diary, meeting regularly with industry representatives and working with hospitals and AuSPEN as well as attending conferences. Chris has written up three of these activities to give us an idea of events centred around Intestinal Failure, the cause of our life on HPN. As well as these articles, there is an opportunity to be involved in research looking into healthcare acquired infections, to be part of the steering committee. Learn of 3 members' experience with transitioning from paediatric to adult HPN, and finally, be encouraged to take a holiday with your family.

Gillian Anderson

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Upcoming Events

Chris will represent PNDU at:

- Gastroenterologist Nurses College of Aust conference (GENCA) 15th-17th May, 2026
- Oley Conference 10th-13th July in USA

Opportunity to be Involved in the James Lind Alliance Priority Setting Partnership Protocol

Calling All HPNers and/or Carers!

Do you want to have your say and be part of preventing healthcare acquired infections? PNDU members have been invited to join this very exciting new opportunity to partner in research. Check out the information below:

Expressions of Interest to be part of the steering committee for James Lind Alliance Priority Setting Partnership

We are inviting one or two representatives from PNDU who have experience with hospital infections to take part in a project.

The project will help identify the most important research questions for patients and clinicians, so future research focuses on what matters most.

If you take part, you would:

- Join a short online meeting about once a month (steering committee)
- Complete a survey about your priorities (around 30–60 minutes); this will be open to all PNDU members later in the year
- Attend one online workshop (approx. 6-8hours) to help agree on the top 10 priorities

You will be paid for your time ($50 per hour). We will work with you in a flexible way, based on what suits you.

If you are interested or would like more information, please feel free to get in touch. Expressions of Interest or enquiries can be emailed to Assoc Prof Jessica Schults j.schults@uq.edu.au by the end of May, 2026.

All PNDU members will also be offered to participate in the round 1 survey.

Transitioning from a Paediatric to an Adult HPN Team

Editor's note: Transitioning from being a paediatric to an adult HPNer is something that all families with young HPNers will go through. The process that each hospital team follows will vary, but it pays to discuss what that process is and when it begins with your team, and how it might affect you or your child, as they approach the nominated age. Here are some comments from three of our PNDU members.

Freya

'Transitioning' at the end of high school was the perfect point in time to simultaneously become an 'adult' in my personal and healthcare related life. I formally transitioned from paediatric to adult care when I was 17, however, the process started much earlier. I remember my team at the children's hospital highly encouraging me in starting the first half of my appointments by myself from the age of 13. I think this played a big role in building my confidence in speaking to health professionals and forming my own voice and opinions. This is also a point in time where teenagers may become uncomfortable talking about things to their parents and health professionals can bring it up in a judgement-free zone. I think one of the most important things about the transition process is empowering the patient before the actual transition occurs. As a parent, carefully releasing the reigns and handing over responsibilities to their child and involving them in their own care for as early as is appropriate is extremely beneficial. And as a health professional, giving plenty of preparation time, but also agency to the young person to decide what timing is best for them. I myself am now a paediatric nurse and I see situations and interactions every day that I can tell will make a positive or negative transition experience. I worry that sometimes the 'adult world' is sensationalised to be a scary place where you are fending for yourself with no backup and patients and families can then become fearful of the unknown. Now, from my experience, care in adults is not as sugar-coated as paeds, but like the real world, you are the leader and advocate of your success and there is always a team in your corner. I was personally very excited to move into this role of responsibility, however I understand there are many factors at play for individuals and that's why I think the gradual preparation and transition is important. When my transition got closer, I had a few appointments back and forth between hospitals until everything was moved over. Something that I didn't get a chance to do, which I think would have been even better, is meeting with both teams together, even if it was just one of the team members, such as my nurse. Overall, my experience was very smooth and I can't fault it. If you take anything from my experience it would be, start preparation early, empower the young person to embrace this exciting right-of-passage in their life!

Mel (carer)

Emily is with the trapeze program via our hospital. The process began when she was 16 and will take a few years with so many teams to coordinate. Although we haven't met many adult teams yet, we have successfully lobbied for her to stay with the children's teams until she finishes school, when she will actually be almost 19. Her current teams have been quite proactive in finding suitable adult services and we are looking forward to meeting them over the next year. One of the best pieces of advice was to source an excellent GP who is happy to oversee overall care, write referrals and can deal with basic every-day things like flu shots, medical clearance for driving etc. It took time and lots of failed attempts, but we now have an excellent GP as Emily had never had one before.

It would be great to hear from anyone who is further along in the process than us and has any useful tips!

Chris (carer)

For the past 17 years since Jordan was born, we have worked closely with our hospital to develop a supportive multidisciplinary team who provide coordinated care for both Jordan, who will turn 17 this month, and Logan [brother, also on HPN] who is now 14. We might have been off to a rough start with fragmented care with no coordination at all, but as the years progressed our team is now like an extended family. Monthly hospital appointments are coordinated between treatment teams and the clinical HPN MDT appointment; this ensures we only have one hospital appointment per month, which is much better than the once-a-week appointments we had in the past.

18 months ago, we started discussing what lay ahead for the boys and how the transition to adult care would work, but sadly 18 months of talk and no action as yet. Our hospital has a transition worker, so at our recent appointment I passed on information and contact details to our team for the NSW Children's Hospital Transition Program, called Trapeze (see details below).

Trapeze Sydney Children's Hospitals Network's health transition service

Trapeze, Sydney Children's Hospitals Network's health transition service

We provide transition support to young people who meet the following criteria:

* 16-25 years old
* Living with a complex chronic illness currently treated at SCHN, and
* Have an unclear health transition pathway.

Queensland I asked the QLD HPN Steering Committee how their program worked, with the following answer:

"Queensland Children's Hospital has a close relationship with Royal Brisbane, Princess Alexandra and Gold Coast Hospital and are very supportive of their patients during the transition."

Victoria The Royal Children's Hospital Melbourne

Transition Support Service : Transition to adult care

The Agency for Clinical Innovation provide information on transition services.

Transition Care Network | Agency for Clinical Innovation

It would be wonderful to hear from our members on how well the Transition to Adult services has worked for you.

Intestinal Failure Day #1FDay 1st February 2026

1F Intestinal Failure
Awareness Day

On 1st February 2026, PNDU, AuSPEN, Baxter Healthcare and New Zealand Intestinal Failure and Rehabilitation Service (NIFRS) joined together in support of the second world 1F Day to raise awareness and call for equal access to care for people living with Intestinal Failure (IF) requiring Home Parenteral Nutrition.

This was organised by Leading Intestinal Failure Equality – LIFE

Marek Lichota, patient and co-chair of the LIFE initiative, says:

"Living with IF can be extremely challenging, from accessing treatment to managing daily life.

Intestines are equally as important as other parts of the body, and they fail like the heart, kidney. Or any other organ."

Intestinal failure is a rare, life-threatening condition that still needs greater recognition. Awareness is essential, not only among patients, but also among healthcare professionals and decision-makers. #1fDay brings together patients, clinicians, and experts worldwide to make Intestinal Failure visible and better understood.

PNDU extends our thanks to the team at Children's Hospital Queensland for organising and participating in "A Day in the Life" Challenge.

1FDay - A Day in the Life Challenge

Words by Julia – Children's Hospital Queensland

Shining a Light on an Invisible Condition: Inside the 'Day in the Life' Challenge at Queensland Children's Hospital

Intestinal failure is one of the least recognised and most misunderstood organ failures — despite the profound impact it has on the children and adults who live with it every day. Marking World Intestinal Failure Day, Queensland Children's Hospital (QCH) set out to change that by inviting leaders to step into the shoes of families navigating this complex condition.

World Intestinal Failure Day is supported by organisations including AuSPEN, PNDU, and industry partners such as Baxter, whose involvement helps raise awareness of a condition that remains largely invisible to the broader community.

As is all too familiar for those living with intestinal failure, daily life is shaped by medical routines that rarely pause. Many of you spend hours each day connected to intravenous nutrition, rely on specialised equipment, and plan every outing around pumps, lines, supplies, and safety. Yet to most people, intestinal failure is something they have never heard of.

This year, three senior leaders from QCH — Leanne Johnston (Executive Director, Allied Health), Kristie Bell (Director, Dietetics & Food Services), and Dan Pocock (A/Divisional Director, Surgical & Perioperative Care) — volunteered to take part in a "Day in the Life Of" challenge designed to build empathy and awareness across the health system.

Walking a Mile in a Backpack

Each leader wore a simulated home parenteral nutrition (HPN) backpack for a full 24 hours, receiving timed text prompts that mimicked the interruptions, decisions, and problem solving tasks families face. The exercise was not intended to replicate the full reality of living with intestinal failure — because only those living it can truly understand that — but it offered a powerful window into the constant cognitive and emotional load families carry.

What emerged from the challenge was a deeper appreciation of how even the simplest activities become complex negotiations. One participant described how taking the dog for a walk required planning around pump timing, line safety, energy levels, and contingencies. Nothing was spontaneous. Everything had to be thought through.

The Hidden Psychosocial Load

Alongside the clinical demands of intestinal failure, the psychosocial burden is significant and often overlooked. The Day in the Life challenge highlighted just how much mental and emotional energy goes into planning, anticipating, and managing daily tasks.

Hypervigilance, reduced spontaneity, social isolation, and the identity shift that comes with becoming a full time medical coordinator are common experiences for many living with intestinal failure.

These pressures are not peripheral — they shape daily life just as much as the medical care itself.

At the same time, the challenge also reinforced the extraordinary resilience within the intestinal failure community. Families find ways to cope through routines, humour, peer support, and strong partnerships with their clinical teams. Their strength is remarkable, but as one organiser reflected, "the load shouldn't have to be."

Why Awareness Matters

The Day in the Life challenge reinforced a critical message: intestinal failure care must extend beyond medical management. Quality of life, participation, and psychosocial support are essential components of effective care — not optional extras.

By shining a light on the lived experience of intestinal failure, QCH and its partners — including AuSPEN, PNDU, and Baxter — hope to drive greater understanding, better system design, and stronger advocacy for the families who navigate this condition every day.

Looking Ahead

We hope to expand the challenge next year, inviting more hospitals and clinical teams to participate. The more voices involved, the clearer the picture becomes — and the better equipped the health system will be to support those living with intestinal failure.

World Intestinal Failure Day is about awareness, but it is also about action. By listening to families and learning from their experiences, health services can build systems that recognise not just the medical complexity of intestinal failure, but the human complexity as well.

Thank you very much to the team at Children's Hospital Queensland
Katie, Kristie, Daniel, Leanne & Julia
#1fDay #IntestinalFailure #ClinicalNutrition #LIFE #ShortBowelSyndrome #HPN #HPNLife

A Day in the Life of an HPNer – Family Holidays

By Gillian

Organising holidays is a lot of extra work when a family member is on HPN. For the past 19 years I have been on HPN, so this has become fairly routine for me. The PN delivery needs to be planned and approved by your pharmaceutical company in advance (up to a few months if the holiday is overseas); consumables need to be checked so that you have adequate numbers on hand until the next delivery after your return; consumable numbers have to be calculated for the duration of the holiday, adding some spares to allow for accidents or faulty equipment, and then packed. Plus, soap-on-tap, paper towels, alcohol for bench, dressing pack and hands. Don't forget your backpack and pump! (I once left the electrical cord for my pump charger at home! Unbelievable!

However, the benefits are certainly worth it, in my opinion. Getting away to somewhere different (or somewhere familiar), breaking your usual daily routine, participating in different activities for a change and sharing this with family or friends – or even just by yourself – is a different type of medicine.

I have been going to our timeshare at Sawtell for a week most years for the last 39 years, firstly with my husband and two children, then as they grew up and left home, usually just my husband, and more recently, my 2 children again and 2 grandaughters. There are so many activities to do that Ray and I used to joke that we needed to return home for a holiday, we were so worn out – the swimming pool, of course, canoeing on the creek nearby, tennis, half-court tennis, miniature golf, squash, and walks, wanting to do several things a day. This year, as my granddaughters are about the same age as my children were when we bought in, it was interesting to see them running from activity to activity, wearing their parents out, with Ray and I joining them, or not, as we chose. Being a grandparent is much more relaxing!

It was lovely to have this time to share with them, especially since my son and his family live in Canberra, so time together is limited. One outcome of holidays is making memories, and it's lovely to know that we have all gone home with the memory of happy times together.

If you haven't yet taken the step to stay away from home, I'd urge you to give it a go; start with just one or two nights not too far from home, if you're nervous about it, then build on that. Happy holidays and happy memories are worth it!

Family time in the pool.

Trying paddle-boarding
NB My team allows me to swim in clean water. In 19 years swimming hasn't caused an infection.

Making Dumplings

Family time at the table

Rare Disease Day February 28th 2026

Held annually on the last day of February, Rare Disease Day provides the opportunity for everyone around the world to join in raising awareness and generating change for the 300 million people worldwide living with a rare disease, their families and carers.

PNDU has the privilege of representing our patient community at various events in support of Rare Disease Day.

Rare Diseases NSW Rare Disease Day Summit 27th – 28th February 2026:

This year's theme - Care Connect Cure - 670 voices. One shared goal: better outcomes for people living with rare diseases.

Words by Chris

It was the first time I have had the chance to attend an event hosted by Rare Diseases NSW (UNSW, Sydney Children's Hospitals Network) held at the UNSW Health Translation Hub in Randwick. An amazing gathering of the Rare Diseases NSW community. A mix of families, carers, patients, researchers and clinicians coming together to connect and advocate for change.
Prof Adam Jaffe delivered some of the key messages: - which can be found on the Rare Diseases NSW website Rare Disease Day 2026 - Rare Diseases NSW

Chris speaking with Prof Adam Jaffe about centres of expertise - Photo credit: Abbie Lygate, ASL Photography

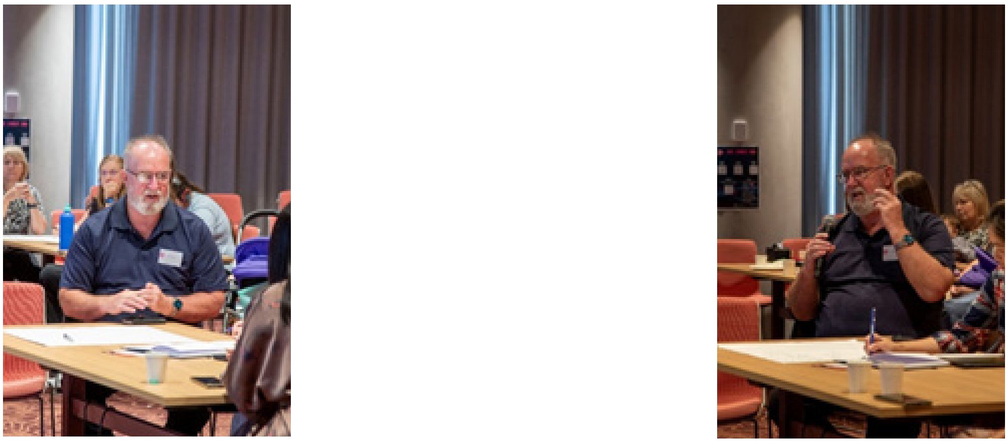
1. A NSW Rare Disease Strategy is within reach

The NSW Government has committed to developing a state-based Rare Disease Strategy and Action Plan. This event demonstrated that the community is organised, evidence-informed, and ready to partner with government to shape it We learnt of the launch of The McKell Institute's new report 'A Rare Kind of Care', officially launched by Ryan Park MP, NSW Minister for Health — a milestone for the rare-disease community and a significant signal of the NSW Government 's recognition of the urgent need for change.

2. Rare diseases require coordinated, system-level change

People with rare diseases continue to face fragmented care, delayed diagnosis and limited access to treatments. There was strong alignment around the need for:

- Integrated, multidisciplinary models of care
- Clear navigation pathways
- Centres of expertise
- Better coordination across primary, tertiary and community systems

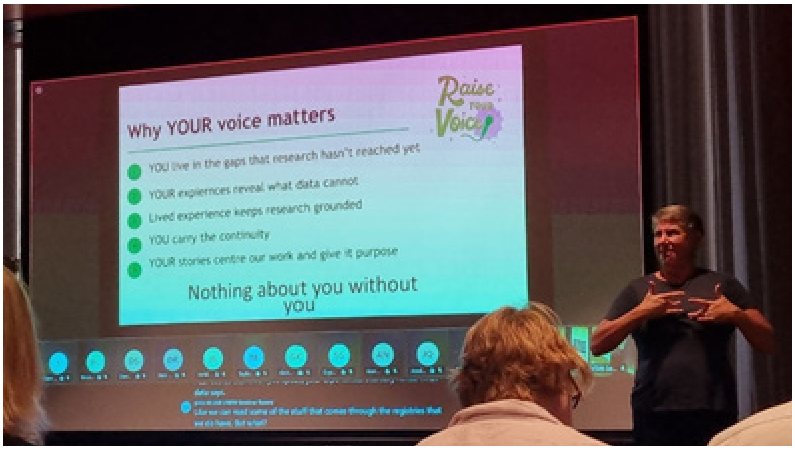


Chris participating in the Rare Disease Day Workshops- Photo credit: Abbie Lygate, ASL Photography

3. Research must be done with the community, not to the community

4. Science is advancing – but access must keep pace

5. Communication in healthcare is a system issue



Why YOUR voice matters

- YOU live in the gaps that research hasn't reached yet
- YOUR experiences reveal what data cannot
- Lived experience keeps research grounded
- YOU carry the continuity
- YOUR stories centre our work and give it purpose

Nothing about you without you

Event Highlights

Keynote and masterclass by Rachel Callander on healthcare communication.
Launch of Rare Power — Rare Diseases NSW's consumer engagement, involvement, & participation program.
Presentation of the Sydney Children's Hospital's Network Kids Advanced Therapeutics Program (21 gene therapy trials at SCHN).
International perspectives from Professor Krister Westlye Fjermestad, University of Oslo, Norway, on sibling support and mental health.
Launch of the world-first Easy Read booklet on intellectual disability — co-designed by people with intellectual disability as part of the GeneEQUAL team.
A resource from the Rare Diseases NSW Rare Disease Day Summit that might be helpful for families.

Belongside Families

Welcome to Belongside Families, an independent, family-led not-for-profit by families, for families raising children with disability, developmental delay, Autism, rare and genetic conditions. We provide free programs, so you can feel more confident and supported raising your child.

Belongside Families - For Families Raising Children With Disability

Rare Voices Australia Rare Disease Day Parliamentary Event 1 March 2026

It's always a privilege to represent PNDU at the annual Rare Voices Australia (RVA) Rare Disease Day Parliamentary Event in Canberra. This year the event was held on Monday 2nd March 2026. It was hosted by the Parliamentary Friends of Australians Living with a Rare Disease.

The event followed the Rare Disease Day theme of Equity for People Living with a Rare Disease, an opportunity to raise awareness among politicians and policymakers.

Key Speakers at the event included CEO of RVA Nicole Millis, RVA Chair, Dr Tarun Weeramanthri AM, RVA Scientific and Medical Advisory Committee member, Clin/Prof Gareth Baynam.

Hon Mark Butler MP, Minister for Health and Ageing and Minister for Disability and the National Disability Insurance Scheme

Senator the Hon Anne Ruston, Shadow Minister for Health and Aged Care
Senator Wendy Askew, Co-Chair, Parliamentary Friends of Australians Living with a Rare Disease
Dr Mike Freelander MP, Co-Chair, Parliamentary Friends of Australians Living with a Rare Disease
Dr Monique Ryan MP, Co-Chair, Parliamentary Friends of Australians Living with a Rare Disease
Over 100 guests attended, making the event one of RVA's largest-ever Parliamentary Events. Guests included RVA partner organisations, including people living with a rare disease, RVA Ambassadors, politicians, researchers, clinicians and industry.

RVA commented "The Importance of Federal Parliamentary Events'
"Parliamentary Events enable stakeholders to meet and speak with parliamentarians to further highlight rare diseases. - having such a diverse range of stakeholders in attendance is testament to the momentum gained by the rare disease sector. This strong diversity is especially important as the collaborative implementation of the Australian Government's National Strategic Action Plan for Rare Diseases (the Action Plan) continues."

The National Strategic Action Plan for Rare Diseases - Rare Voices Australia

Chris & Dr Mike Freelander

Chris & RVA CEO Nicole Millis

The event provided the perfect opportunity to launch the first round of resources for the nationally codesigned Rare Disease Disability Toolkit, which is available on RVA's website.

Rare Disease Disability Toolkit

Rare Disease Disability Toolkit (the Toolkit) development was codesigned with people living with rare disease disability and facilitated by Rare Voices Australia (RVA). RVA is the national peak body for Australians living with a rare disease.
The Toolkit was funded by the Australian Government through the Peer Support and Capacity Building grant for the National Disability Insurance Scheme (NDIS).
Rare Disease Disability Toolkit - Rare Voices Australia

The Toolkit:
1. Includes new peer-to-peer supports.
2. Builds capacity in disability rights and self-advocacy.
3. Supports people to better access and navigate disability and other systems (such as health, education and employment).

How to Use the Toolkit
Each resource includes a main guide and extra tools to help you speak up for yourself and use together with your support team.

Following on from the Rare Disease Day Events, I had the pleasure of representing PNDU at the APAA Summit in Canberra. Day 1 was a full day of presentations inside the Theatre at Parliament House Canberra. Day 2 was combination of presentations & workshops in the conference rooms at Rydge's Canberra.

The APAA Summit provides the opportunity to hear from both sides of government on how they are improving disease management for complex and chronic diseases.

The government and Chronic Disease - Hon Mark Butler MP, Minister for Health and Ageing and Minister for Disability and the National Disability Insurance Scheme

The Opposition and Chronic Disease Senator the Hon Anne Ruston, Shadow Minister for Health and Aged Care

Improving Disease management – A fireside chat with Dr Mike Freelander MP, and Dr Monique Ryan MP. Improving the lives of Australians with chronic conditions

The Australian Government is investing $110 million over three years to support new projects that help prevent chronic conditions and improve care for people living with them. The funding will be delivered through a new Chronic Conditions Prevention and Integrated Care Grants Program. The funding coincides with the launch of a refreshed National Strategic Framework for Chronic Conditions 2026–35, which sets out a clear and co-ordinated approach to supporting Australians with long term health issues.

"The new framework, supported by the new grants program, will improve the lives and health outcomes for Australians living with, or at risk of, chronic conditions."

Mark Butler MP
It was wonderful to catch up during the workshops and plan future advocacy for chronic disease with Deidre Macknie APAA EO, Leanne Raven Crohn's and Collitis APAA Board Chair and Sarah Gray OAM CEO ausEE

Chris & Deidre APAA

Chris & Sarah Gray OAM ausEE

Thank You

PNDU is very grateful for the support given by the donor listed below. We wish to thank the following for their generous gift.

S Thong

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.)

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