DRIPLINE

PNDU
Parenteral Nutrition Down Under

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In this issue read about Intestinal Failure (IF) Day; the final 2 winners of the 2025 PNDU Awards receive their certificates; read about Sydney's Social Gathering 2025; learn about MLAK keys, the National Public Toilet Map and APP; the National Companion Card Program; AuSPEN Conference '25 and Consumer Workshop; and learn why it pays to be organised.

Gillian

Dripline editor

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Intestinal Failure Awareness Day

The Leading Intestinal Failure Equality initiative, (LIFE) launches the second 1F Day - international awareness day for Intestinal Failure (IF) on February 1st 2026. LIFE is dedicated to raising awareness of IF, the challenges faced by individuals living with the condition, and calls to address the significant disparities in care that currently exist.

Intestinal Failure (IF) is a life-threatening condition that impairs the body's ability to absorb vital nutrients and fluids due to significant loss of gut function. It often results in prolonged hospitalisations and numerous distressing medical procedures, that can have a destructive impact on quality of life. Patients rely on life-saving home parenteral nutrition (HPN), which is considered the gold-standard of care. However, its availability varies significantly between, and within, countries and IF continues to be under-recognised and underfunded.

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.

Sarah, 51, Australia Autoimmune Autonomic Ganglionpathy

What is the biggest challenge in living with IF?

My biggest challenge has been being a Mum and trying to make life normal, despite living with IF, for my family. Trying to put on the brave face and carry on despite the pain or exhaustion.

How has IF changed your daily life?

Living with IF has meant dreams for the future have been brought forward and made into reality, if possible, as each day being alive and well, has been a gift. Nothing and no one is taken for granted, for tomorrow is never assured.

Romeo - 8 months old with Australia Microvillus Inclusion Disease (MVID)

What is the biggest challenge in living with IF?

The biggest challenge is not enough research into his diagnosis/condition. With presently only 2 in Australia and just over 200 in the world, it's very rare and there is not enough research on it and we truly hope for much more in the future.

What is your most important learning or reflection about life with IF?

Our most important reflection on learning is that he is healthy, happy and here with us. Life looks a little different now. We carry a PN bag with us daily which is different, but we have learnt just how much we can do in life with big limitations. As long as Romeo is happy and here with us, that's what matters most to us and our family.

Brothers Jordan age 16, Logan age 13, country AUS

X-Linked chronic Intestinal Pseudo Obstruction XCIPO

What is the biggest challenge in living with IF?

Jordan & Logan: We would like to be able to do the same things our friends can do.

We can't go swimming, play contact sports like rugby football, we can't even sleep over at our friend's house.

Jordan - I would like to be able to self-care and engage in the community without the need for a support worker.

What would you like others to know about intestinal failure?

It takes a lot of support from our family to keep us healthy; our life is restricted by being connected to Parenteral Nutrition for 15 hours every day and we always have hospital and doctors' appointments.

What gives you strength in difficult moments?

We love spending time with our pop.

How has IF changed your daily life?

We were born with IF, as we have grown older, we have realised how different we are to our friends.

Felicia, 40 New Zealand - Intestinal failure GI dysmotility

What is the biggest challenge in living with IF?

All it takes is one thing to derail your plans, second guessing every little symptom as to whether it could be serious or okay to ignore, and then having to convince your team that you do know your own body.

And also having to explain to people why "no I can't just eat a little of that..."

What is your most important learning or reflection about life with IF?

No matter how hard, how traumatising, how complex, how different or how crazy life is with IF, you need to first acknowledge how you're feeling and why and then refocus on the important things, family, friends, life - no matter how restricted or different, fight for what matters to you.

What gives you strength in difficult moments?

My family, especially my nephews and nieces and my friends, my work, my faith, finding ways to feel like I can contribute

Gillian, age 71, Australia, Short Bowel Syndrome.

What is your most important learning or reflection about life with IF?

I've been on HPN now for just on 20 years, so it's my normal. Being organised with set routines has made life easier e.g. getting my week's supply of consumables together; keeping track of my consumables for my monthly order; setting up in the same place at the same time, to name a few.

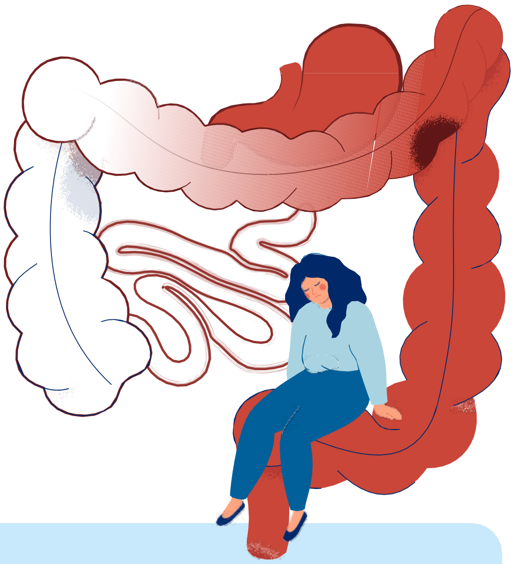
What gives you strength in difficult moments?

My faith; my husband and children; knowing others through PNDU who have similar issues and are a great moral support because they understand what life on HPN is like.

Intestinal Failure
Awareness Day

LIFE
Leading Intestinal Failure Equality

What is Intestinal Failure (IF)?



Intestinal Failure (IF) is a life-threatening condition in which the gut cannot absorb enough nutrients, fluids, and electrolytes.

IF can affect people of all ages, often following major surgery, chronic intestinal disease, cancer, or congenital conditions.

Although rare, IF has a profound impact on daily life.

IF is treatable

Home Parenteral Nutrition (HPN) provides life-sustaining energy for many people with IF, but access varies widely across countries.

Innovative therapies, such as **GLP-2** analogues, support bowel adaptation and may reduce long-term dependence on parenteral nutrition.

Challenges

- Disparities in access to care
- Low awareness
- Insufficient research
- Shortage of specialist centres

How We Can Make a Difference

- Speeding up diagnosis
- Delivering comprehensive care
- Working together to share best practice and data
- Providing access to appropriate treatments

Vision

LIFE's vision is that all patients with IF should receive a high, standardised level of care by 2030.

IF is treatable.

Share this infographic to raise awareness.

Join us

for 1F - Intestinal Failure Awareness Day.

Scan the QR code or visit **intestinalfailure.org** to learn more

Editor's note: for the full write up about all the winners, read 'PNDU Awards 2025 in the last issue of Dripline, #53. These 2 recipients hadn't received their awards at that stage.

PNDU Outstanding Achievement Award

This is a prestigious award to an individual/group/body who has made an outstanding contribution to IF/HPN throughout their time working within the field. This could include someone who has published key HPN-related research papers, developed a new product or educational service to help improve the health and quality of life for HPN consumers.

PNDU Outstanding Achievement Award
Associate Professor Sharon Carey
Nominated by Chris Walker

Associate Professor Sharon Carey is the President of the Australasian Society for Parenteral and Enteral Nutrition (AuSPEN) and the manager of Nutrition and Dietetics & Intestinal Failure Service at RPAH. As an Intestinal Failure Specialist Dietitian, Sharon has been a dedicated advocate for the patient voice, believing that the lived experiences of HPNers should guide the development of a National Model of Care (MOC) for all HPNers. Sharon has played a pivotal role in the development of the Australian HPN Registry and MOC.

With many years dedicated to research in Chronic Intestinal Failure, Rare Diseases, and Parenteral Nutrition, Sharon's life's work has been directed towards improving the lives of all HPNers. Sharon has numerous publications in rare diseases and advanced gastrointestinal nutrition. Sharon is a deserving recipient of the PNDU Outstanding Achievement Award.

Chris presenting Asst Prof Carey with her award

Paediatric Parenteral Nutrition Professional of the Year

Nominated by Mariann

Claudia Borg has been the Clinical Nurse Consultant for
Intestinal Rehabilitation at The Children's Hospital at Westmead for 6 years. She is deeply committed to improving the lives of children on HPN and their families.

Claudia consistently goes above and beyond. She brings HPN families together, actively participates in HPN Awareness Week, encourages families to attend pharmacy tours and become a member of PNDU. Her commitment, advocacy, and leadership are widely recognised and highly valued by HPN families.

For our family, Claudia has been exceptionally kind, thoughtful, and supportive. She is always prompt in responding to emails, ensuring we have what is needed for appointments and helping to coordinate care with Baxter, CHW Pharmacy and other suppliers. Her communication with multidisciplinary teams and specialists within the hospital has been a significant support and she willingly provides education and training whenever needed.

Claudia celebrates milestones and the positive progress of children on HPN. She is encouraging and compassionate during the most challenging times of long admissions, surgeries and complications. Claudia is one of the most important advocates for children and families navigating HPN care, and her dedication has made an enormous difference to many family's experience and confidence in managing long-term parenteral nutrition.

Mariann and Samuela presenting Claudia with her award(s)

MLAK Keys

Have you ever found a public toilet locked? Or a queue for the 2 or 3 toilets within the female/male toilet section, but see that there is one door outside the toilet block that is locked? MLAK keys is an Australia-wide program that gives people with a disability secure, 24/7 access to public facilities.
From the website:
The Master Locksmiths Access Key (MLAK) system is a Master Locksmiths initiative that allows people with disability access to dedicated public facilities. This includes facilities in National Parks and many Council municipalities, elevators at railway stations, the new Changing Places facilities throughout Australia, disabled toilets that are locked, and even the Liberty Swing.

Different states have different ways of obtaining a key, as well as varying costs. Just 'google' (or use a different search engine of your choice), for example, 'MLAK keys NSW' to find the appropriate details, or your local council website.
Having an MLAK key provides an extra level of confidence when out and about, especially when driving in country areas that might have fewer toilets.

By Gillian

Sunday 9th November was a lovely day, perfect temperature and sunshine, a great day for a picnic/get together with our PNDU members. All together there were 22 people meeting – 10 HPNers - chatting, discussing, eating and playing over a few hours at the Joseph Sargeant Community Centre in Erskinville. Members travelled from as far away as Canberra and Raymond Terrace, as well as all over Sydney, to catch up with others whose lives revolve around life on HPN. It's a chance to talk in depth about things that affect us, in a way that isn't possible on a chat group. We discover that we aren't the only one who has certain issues to deal with, as well as having suggestions made by someone with similar issues that might help us. It's also a chance to find out what else, non-HPN related, is happening in people's lives, such as trips, or work, or school, or leisure time events, etc.

The centre was an excellent venue for this, size-wise as well as the outdoor space. The kids made good use of the plastic climbing cubes, as well as the basketball court. These events are terrific for the children to make friends with others with similar lives on HPN, and to discuss their problems and frustrations with others who 'get it'. It's wonderful, too, for us adults to see these children growing up.

Attending these events is always worthwhile. As one member said, 'it's so much easier and quicker to talk in person about all things HPN, rather than posting or messaging. It's encouraging and lovely to see how various young HPNers have grown (from tiny tots) and are managing new and different stages of life on HPN.'

HPNers: Logan and Jordan (on top of cubes)
Gillian, Raquel, Sal, Emily, Ariel and Karen (standing)
Samuela and Syena (seated in front)

AuSPEN Conference and Consumer Workshop 2025

By Gillian

In November, AuSPEN held its annual conference at the Hilton Hotel in Sydney. PNDU was kindly allowed to have a stand again, which was in a prominent position, allowing our MC members to have many clinicians to talk to as they passed by. This year had the greatest number of MC members taking turns to work with president, Chris, on the stand (only 2 members allowed entry at a time), so it was wonderful that Chris was able to work with Miranda, Sal, Mariann and Gillian. One welcome visitor, who came to attend the consumer workshop, was PNDU's past president, Karen, who 'helped' us at the stand for a few minutes.

This conference is a fantastic way of introducing clinicians, who may be new to working with HPNers, to some of our support materials, as well as the fact that there is a support group available for their patients. It was also a time to catch up with PNDU's industry supporters, Baxter and Fresenius Kabi, and chat about relevant events.

On Saturday afternoon, the much-anticipated HPN Consumer Workshop was held and well-attended, both in-person, with 17 HPNers and carers, as well as on-line, with 14 streaming. AuSPEN has been hosting these for many years and their work in selecting relevant topics and finding someone willing and able to give a talk is much appreciated. This year the topics included an update on the HPN Model of Care project, HPN and Dental Health, Micronutrients and HPN, and long-term health on HPN. Our sincere thanks to Associate Professor Dr Sharon Carey, AuSPEN president and dietitian at RPA as well as Suzie Daniells, dietitian at St George public hospital for organising this event; and to Emma Osland, dietitian at Royal Brisbane and Women's Hospital; and to Liz Beyer, CNC, and Dr Belinda Errington, both at RPA, for presenting talks.

Below, PNDU President, Chris, with MC members helping at the stand...

...with Miranda.

...with Gillian, and past president, Karen.

...with Mariann.

...with Sal.

...with Baxter.

...with Takeda.

...with Fresenius Kabi.

National Companion Card Program

The Companion Card is for people with significant and permanent disability who have a lifelong need for attendant care support when accessing the community. The Companion Card allows a cardholder's support person free entry into participating venues, events and transport (although this may vary by state).

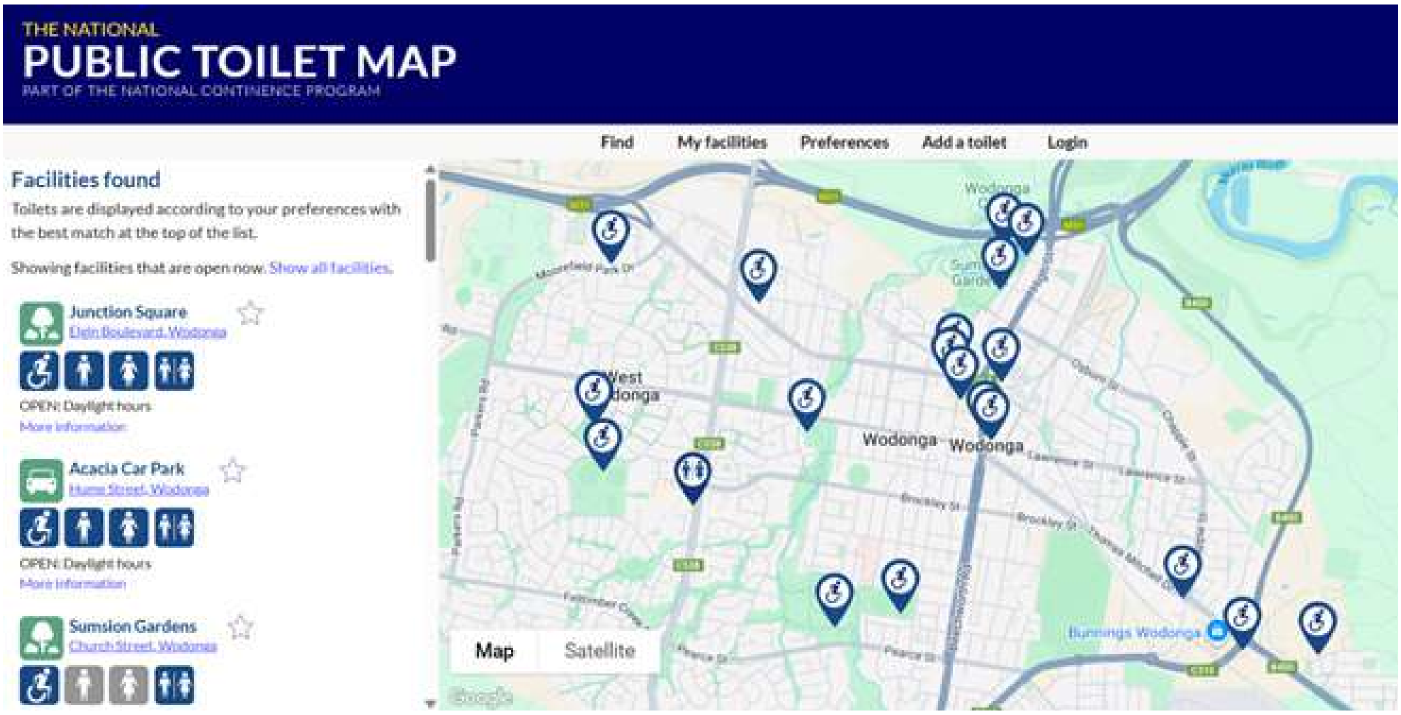
Access for the Companion Card varies by state. It is not a given that if you are accessing NDIS that you are eligible for a Companion Card. A doctor's assessment that the disability is permanent and that carer's support is required for accessing events. You generally need to contact an event venue via telephone or email if you are wanting to use the Companion Card, although some might indicate how to make a booking with it on their booking page.

Doing an internet search for 'companion card [insert your state]' will take you to the appropriate webpage.

The National Public Toilet Map and APP

By Rachelle

This map app is a must for PNDU members to have on our phones! It allows for searching from wherever you are located to find all toilets including disabled, MLAK and Changing Places. You are also able to add toilets to the map which might not already be captured. Here's an example for Wodonga where I live:Below, PNDU President, Chris, with MC members helping at the stand...



Facilities found

Toilets are displayed according to your preferences with the best match at the top of the list.

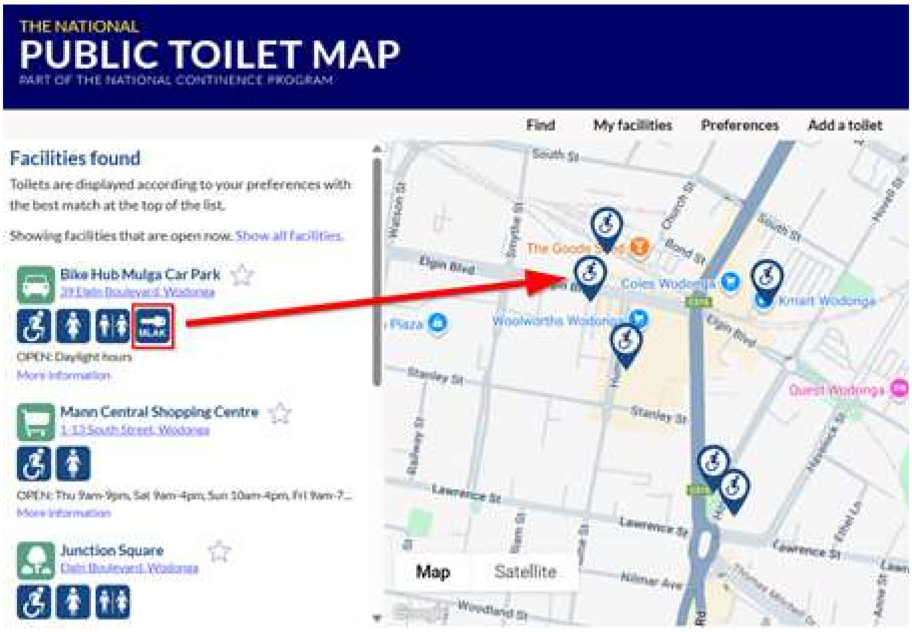
Showing facilities that are open now. Show all facilities.

Junction Square
Elgin Boulevard, Wodonga
OPEN: Daylight hours
More information

Acacia Car Park
Hume Street, Wodonga
OPEN: Daylight hours
More information

Sumsion Gardens
Church Street, Wodonga

You can set your own preferences for the types of toilets you want to locate, for example the MLAK toilets:



Facilities found

Toilets are displayed according to your preferences with the best match at the top of the list.

Showing facilities that are open now. Show all facilities.

Bike Hub Mulga Car Park
39 Elgin Boulevard, Wodonga
OPEN: Daylight hours
More information

Mann Central Shopping Centre
1-13 South Street, Wodonga
OPEN: Thu 9am-9pm, Sat 9am-4pm, Sun 10am-4pm, Fri 9am-7...
More information

Junction Square
Elgin Boulevard, Wodonga

It Pays to be Organised

By Gillan

I've been on Home Parenteral Nutrition (HPN) for 20 years come June, and I've found that being organised and developing a routine for HPN related activities really helps life go smoothly (as smoothly as it's possible). Different activities require different routines and varying amounts of time spent on them, but each go more smoothly and faster if done in an organised fashion, I've found. Here is my list of things to do.

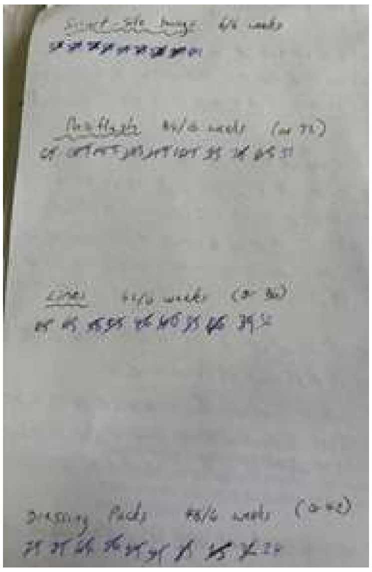
Every 2 years I have a bone density scan to keep an eye on any deterioration. My GP refers me, so I need to remember so that I can remind her in case she forgets.

Every year I have an annual blood test that includes a raft of tests of micronutrients, as well as many others in addition to my usual blood tests. Again, I keep track of when I'm due for it, so it doesn't get forgotten.

Every 2-3 months, depending on what my hospital team decides, I have a 'regular' blood test.

Every month, as for all HPNers I imagine, I have a delivery of my consumables from my pharmaceutical company, so I need to be aware of the delivery date so that someone is home to accept delivery, or to arrange for an alternative.

Also every month, in the 2 weeks before and after consumable delivery, I (and you too, I assume) have to order the replacement items that I need. This requires accurate record-taking so that I don't forget something and potentially run out of it; or alternatively, order things I don't really need yet and have even more boxes to store. You can be very organised and have a spreadsheet on your computer which you update each week, or just have a pen and paper record, as I have.



Weekly, I stock a box with the consumables that I need for setting up for the following week. This saves going to several boxed every night to gather what I need. As I get what I need of each supply, I adjust the numbers on my 'spreadsheet' to keep it current.

Also weekly, I change my dressing on my CVAD site. This might be something that varies from team to team.

Also weekly, and most importantly, my PN is delivered weekly and someone needs to be home to receive it and put the bags away in the fridge. This means that either my husband or myself have to be careful that we remember this and don't both make plans for that day.

Daily, I set up and flush when I disconnect. I find setting up at the same time is helpful as I don't need to change the infusion time on my pump, and I use the end of infusion alarm as my wake-up alarm. It also means that I don't lose track of time and forget to set up until later than I like.

One other important thing related to being organised is the old adage 'a place for everything and everything in its place'. Store your supplies in an accessible place and make sure you keep them there so that you aren't looking all over the place for some essential item that has been misplaced.

All these things provide a framework for my life on HPN. With that in place, all runs smoothly and life on HPN is just a bit easier.

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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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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