

DRIPLINE PARENTE PARENTE DU Parenteral Nutrition Down Under

Welcome to our latest issue of Dripline. I give thanks to our several members who took the time to contribute their articles and share their thoughts and comments with the rest of us. There are several 'save the dates' in this issue, so please take note of them and consider if you are able to attend any, or all, of the events. Also, it's time for our biennial PNDU Awards, so start thinking of which clinician or employee you might nominate, who does exceptional work in caring for you. Have you heard of green banana powder? It might be something that could help you. Read about how some of our members manage life on HPN while working – and sadly some who can't. We also learn of one member's soap-making hobby. We are reminded of the importance of regularly maintaining our pumps so that they continue to function well. I hope you enjoy the read,



Gillian Editor

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Amylose Resistant Starch and Green Banana Powder



By Julia

Editor's Note: PNDU doesn't recommend or support particular products, or types of products. However, we feel that members should be made aware of products that may be of benefit to them. The most important thing is to discuss this with your medical team before trying.

Resistant Starch may help some people with Intestinal Failure and chronic diarrhoea.

I hadn't heard of resistant starch before it was mentioned by Syena's surgeon at Children's Hospital Westmead during a medical review, when I said that one of my biggest challenges was managing her copious diarrhoea. Our doctor said that amylose resistant starch may be a help as the hospital had found it helpful for other children with Short Gut Syndrome.

"Resistant starch is starch that 'resists' digestion in the small intestine." https://www.csiro.au/en/research/health-medical/nutrition/Resistant-starch

There are a range of starchy foods that are high in amylose, one of the two components that makes up starch. I was recommended to give her potato, particularly twice-cooked (initially cooked, then refrigerated and cooked again before serving) as this increases the amount of resistant starch. I said that it would be challenging to get enough into Syena as the amount of food she eats varies so much from day to day. That's when I was told about HiMaize, a high amylose resistant flour made from corn. HiMaize is used in food manufacturing, particularly by bakeries, to enhance the nutritional value of their products. Some hospitals in NSW have supplied HiMaize to patients with Short Gut Syndrome and have found it helpful.

My interest was piqued when I found an interesting study online which added HiMaize to Oral Rehydration Solution and gave it to patients infected with Cholera, with positive results. "...those who received resistant starch supplemented oral rehydration solution not only significantly reduced the duration of diarrhoea but also significantly decreased total stool weight."

https://www.nejm.org/doi/full/10.1056/ NEJM200002033420502

As we don't live in NSW, I asked our hospital nutritionist if they could provide some to us so we could see if it helped reduce Syena's diarrhoea. Of course, the process of obtaining it through hospital has been a long one, so while we waited, I looked for any other sources of resistant starch that I could obtain and use regularly.

That's when I came across Green Banana Powder, a nutritional supplement available through health food stores and suppliers. Our hospital nutritionist and paediatric gastroenterologist gave us the go ahead to try, so I started adding Green Banana Powder to Syena's enteral formula, which she gets through her Mic-Key button. I don't think I would have succeeded getting her to consume food or drinks made with the powder, which smells of banana but does not taste at all pleasant.

I started with a small amount and slowly increased it until we started seeing some benefit. For the first time in her four years of life, our little girl produced a poo that actually looked like a poo!

Green Banana Powder is not the easiest product to use. I found it quickly settles in the bottle of formula and sits at the bottom as a thick slurry. To get it into her, I've found I need to use a thick extension tube on her 60ml Enfit syringe I use for bolus feeds.

I need to keep the bottle in motion as I fill her syringe, and then do the same as I gravity feed it into her. So long as I keep the formula with green banana powder in motion, it doesn't have an opportunity to settle and block the tube. This does happen, though, and blockages are inevitable, but not too difficult to clear.

While I eagerly await our hospital providing HiMaize powder, I've found Green Banana Powder a significant help — along with all the regular medication Syena was already taking to try to address her diarrhoea. It isn't a magical solution and we still battle with the problems I'm sure others are familiar with, including Small Intestinal Bacterial Overgrowth (SIBO), but Green Banana Powder is another useful weapon in our arsenal.

If you think it might be helpful to you, please make sure your first step is to have a discussion with your nutritionist.





As HPNers and carers, we know that it takes many hands to manage HPN care. Is there a professional or healthcare worker who does a marvellous job when it comes to HPN care? Here's your opportunity to give thanks and show you appreciate them!

This is PNDU's 6th year of bestowing awards on the dedicated people nominated by our members. PNDU Awards recognise the great work being done by our healthcare workers or company employees to help with delivery of compounded PN and ancillary products for those of us living in Australia and New Zealand with HPN.

There are a few different categories and you can nominate as many people as you like. For the HPN Professional Awards categories, you can even nominate winners from previous years (see PNDU Annual Awards page on our website for a Roll of Honour listing all winners):

- **HPN Professional Awards** recognise positive efforts by health professionals and industry to provide high quality service to HPN consumers (your favourite HPN clinician and/or a dedicated professional at your homecare company). There are 3 categories of HPN Professional Awards you can nominate for:
 - Adult Parenteral Nutrition Professional of the Year
 - Paediatric Parenteral Nutrition Professional of the Year
 - Commitment to Patient Care Company Employee of the Year
- **Lifetime Membership Award** is a special award for any member who, as an HPN consumer, parent or carer, has given their time "over and above" for PNDU.

Nomination forms are available only online- look out for an email about the PNDU Awards in the coming weeks, or look up the PNDU Awards page on our website, pndu.org

Simply complete the online form(s) by Friday 1st September. All winners will be announced at PNDU's AGM.

A Day in the Life of an HPNer – Employment



<u>Editors' Note:</u> Employment is something that is very difficult for many adult HPNers. Many are unable to work at all, or to work as much as they would like, or financially need. The reasons for this are varied: they might feel too ill or too weak; their commute might wear them out before they begin; they might be connected to their PN bag during working hours, which would make some jobs difficult or impossible to do; they might have an employer who is unwilling or unable to be flexible to accommodate doctor's appointments etc. Thank you to these 4 members who have shared a bit about their employment experience with us.

Naomi

I have not been able to work for over 10 years due to multiple health issues and hospital admissions/ daily doctors' appointments. It makes me feel extremely guilty and depressed that I am not able to contribute in a meaningful way. I always endeavoured to help others, but feel so stuck and helpless that I am not able to do that. It has been hard for me to watch friends and family achieve their goals and work so hard to get there, yet I feel so useless and unable some days to manage the most basic tasks. Being

connected to PN/ IV fluids for 18hrs a day is further limitation and makes it just that much harder to believe I will be able to get where I want to go... yet I am hopeful that one day things will improve and I will be more able to participate in daily life and work activities.

Susan

I work in Administration. I have a very good relationship with my employer and supervisors.

I have been working at the same place for nearly 39 years.

I work 7.5hrs a day on a 9-day fortnight. When I'm feeling sick and awful sometimes, I think it helps to get me up and moving.

There are days where I have to stay in bed in the morning and am now set up and able to work from home in the afternoon if I need to, which is great.

The issue I have at the moment is my Iron and Hb are always low and I seem to be having bad side effects with Iron Infusions, so I'm having blood transfusions every few months.

Being dog tired and trying to work is a battle that I sometimes do not win, but my colleagues are very understanding and help in any way they can.

I think being open with my employer helps. I have an hour off every week for a dressing change and bloods etc.

The weekends are all about recharging and it is very hard to keep up with housework and other chores around the house but I get there eventually.

Sal

I am fortunate that I am stable and well enough to work 2 days a week in an admin and reception role. It's light work, but gets me out of the house and gives me a sense of self-esteem that I am able to contribute towards our household expenses. I have a very supportive and understanding boss, who knows my health situation and has been flexible if I've needed to swap days or leave early.

Jacqueline

I commenced TPN in 1999 after unsuccessfully battling with enteral feeding for over a year and have continued it almost nonstop since then. Other than having time on sick leave, I've continued to work part time as a nurse throughout the years.

There are several reasons I've continued to work... they being my desire to not be defined by illness and to have an outlet that I enjoy and can contribute to society; financial reasons, because although we're entitled to Medicare, we're not entitled to any pensions, or other government support; a need to connect with others who have become long term friends who, if I hadn't worked, I would never have met and since we came to Tasmania later in life we have no childhood or other long term contacts. I've studied long at university doing 2 degrees and a masters, and post grad diploma and don't want to "chuck in work" if I don't have to, so I guess it's a

sense of pride. I also connect with my medical team through work (now we've moved to the north of the island I work with them) and I feel somehow more involved in my care. As an example, for the fourth year running, I've spoken to fourth and fifth- year medical students on the impact of chronic health and this year was guest speaker in the physicians' final exams. I honestly feel that invite was due to the fact that I bump into relevant people in the corridor and am on various committees with them.

So, a day in my working life is basically as follows.

I moved from A&E and Critical Care 5 years ago to a day Oncology / Haematology out-patient department, which meant I transitioned from shift work to day work. I find this harder as mornings aren't good for me and our opening hours are 0800 – 1630.

As I only work one day per week where I start at 8a.m. and the other (max) two days per week are 6-hour shifts, it's easier for me now to cope. I must say my manager is very supportive and accommodating and has become very flexible, which has been a huge benefit for other staff as well as myself. The other two days per week are at my discretion depending on how well I am. As we're always short staffed, I can literally work any hours or days extra I want.

I have dropped to 6 nights per week PN, although at present this isn't enough nutrition. So, on Monday nights I only have normal saline, which means I can just disconnect and go to work. I have major adrenal problems causing blood sugar issues when I titrate off PN, so it's a work in progress at present and it's easier not to have PN than run the risk of being unwell at work.

Due to ongoing Covid issues and the need for us to continue wearing full PPE, we're not allowed morning tea, which is causing many problems for all of us...not least me. We, as a unit have decided our own health and safety is more important and have started taking an unofficial break when possible. This helps me maintain a reasonable blood sugar. My colleagues let me know if I start to get numbers around the wrong way, as that's an indication I'm hypoglycaemic.

Due to the highly specialised staff requirements in our unit and the stressful nature of our work, it's a very tiring day, not only for myself, but all staff find the same. I was seconded to the Launceston General Hospital from Royal Hobart Hospital 3 years ago and it was the best thing I've done as I honestly couldn't have continued working otherwise. Even

down to the parking, which is now easy and at \$3 day instead of \$18, who wouldn't be happier?

When I first started working in my current position, I didn't disclose any illness issues and wanted to be perceived as a healthy person, although my manager was aware of some of my health issues. I struggled for about a year with anxiety and a feeling of incompetence and felt like I was being judged. As some staff have moved on and new, younger staff are now part of my team, this isn't really an issue. So many of us are struggling at present, especially since Covid, and we all support and nurture each other. This has allowed me to be more open about my illness and I feel more comfortable talking about it and not feeling guilty if I can't work. The other thing that has really changed is that now we're allowed to gather socially for meals, I have attended and just sat with a small drink and felt comfortable. No one ever asks why I'm not eating and I'm not sure if they know or not, but it feels so much less threatening and I feel more connected to my peers.

When I get home from work, I'm absolutely exhausted and so having a shower, connecting up and early to bed (about 7pm) is the usual routine. The shorter days are usually not as exhausting, firstly because I've had PN the night before, and secondly 6 hours instead of 8 makes a difference.

The other benefit I have at present is that my infusaport requires needling weekly and that is done by staff in my unit instead of having to go to

Day Procedure Unit and being admitted, which takes about 2 hours. This of course is a waste of my time and government resources.

On the subject of finances...when we moved here, we were required to take out income protection insurance, which we have had to continue. As I've not been able to work much for many years it pays a small amount fortnightly to boost my income. Without this I would be forced to work more. So, at least for the next 2 years, I have some stability in income.

I find it very easy to become depressed and this increases if I'm at home for a few days, even if I'm in my studio working. [Editor – Jacqueline does many arts and crafts] But going to work takes that away and I seem to have a brighter outlook. After working in the very stressful and really unrewarding area of A&E where I was frequently abused by patients, I now work with patients who are grateful and generous. Because our patients are often with us indefinitely, we form good connections and friendships with them. This in itself is rewarding. Definitely this is the place to work if you like chocolates! We're constantly supplied with cakes, chocolates, honey and other gifts and so many thank you cards.

I find working very tiring and difficult, my job is stressful and very demanding, and I often am just not well enough to go (either mentally or physically), but my current position makes things easier.

Caring for our HPN Pumps



We all know how important our HPN infusion pumps are, and how vital it is that they work properly.

All HPN Pumps are considered as Life Support Equipment; to ensure our safety and the correct functioning of our HPN Pumps, our HPN Pumps require regular servicing and preventative maintenance.

Is your pump overdue for a service? PN infusion pump servicing is an important matter. We can all play our part. All HPN pumps should have a service/calibration sticker on them, stating a service/calibration date. (Annual servicing is calculated from the date you receive your pump). Please record this date in your calendar or diary. In the unlikely event your pump providers have not contacted you by the service date, please call their Home Care Services team to arrange for regular servicing and preventative maintenance.

If there is a problem with your HPN pump, please report it to your hospital team or PUMP provider and organise to have it replaced. **Don't hang on to your old pumps.**

HPN Pump Tips and Tricks

"Pumps at home - tips from Baxter Healthcare"

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HPN Pump Tips and Tricks

"Pumps at home – tips from Baxter Healthcare"

We know that using medical devices isn't always smooth sailing! Below are some tips to ensure that the device you have on hand is working for you.

1. Keep your device clean.

Dust or fluid in the pumping chambers can cause blocked sensors or damage to the internal mechanisms. Do not submerge your pump in water, but keep it clean by using a damp clean, lint free cloth. Report any significant spills immediately to your provider.

If your pump is dropped by accident – report it to your provider immediately. Even if it seems to function normally, there is a real risk that the internal mechanism is impacted and requires calibration.

2. Have your device serviced on time.

Pumps used at home usually require routine servicing every 1-2 years depending on the model. Keep an eye on the service due date and if unsure, contact your provider to book the pump in for maintenance.

3. Be familiar with basic troubleshooting.

Machines are simple – always go back to the basics if you are having a problem.

Try turning the pump on and off, reset your giving set/tubing, check for any occlusions and make sure it is properly plugged into power. If the issue persists call your provider and provide all the relevant details to report a product complaint.

Important details include: the device serial number, your regimen, how long and when the issue occurs.

4. Know what to do in case of a pump failure or emergency.

From time to time, device failures can happen, PN bags can burst, power can be cut off, fridges can freeze over, natural disasters can hit and pets can eat through packaging!

Discuss all the situations with your HPN Co-Ordinator and have a plan in place so you can avoid panic and hopefully avoid presenting to hospital unnecessarily. Especially if things happen out of hours.

This may include checking what you should do if you cannot access PN, determining if you need spare products or devices on hand in case of emergency and knowing at what point you need to call for help.

5. Report any issues as soon as possible

Being a HPNer, you are the expert in your own processes. If something isn't right or your device is not performing as it should, contact your provider as soon as possible to report it.

Again, be ready to report all the important details so that a product complaint can be raised and investigated with the manufacturer and you can access a replacement device to ensure you can continue infusion.



By Jacqueline

I've dabbled in soap making for many years with varied success, so when I recently met an experienced soap maker willing to take a class for four of us, I jumped at the chance. It has helped refine my skills and so far, every further attempt has been successful and so I thought I'd share a brief story about the art of soap making.

There are many books with recipes and techniques available, along with the online articles but it's often the little-known hints that are missing which can be the difference between failure and success.

Everyone knows that the idea of soap is to clean but it's also the result of a chemical reaction known as saponification. Primitive soap making was probably developed by ancient Mesopotamians who discovered a greasy and smelly goop that lifted dirt away, this dates back to approximately 2800BC. It was produced when a combination of the fat rendered from cooked animals landed onto ash in the fires and was mixed with water.

The idea of making pure soap with natural ingredients without adding parabens, toxins and sulphates is what lured me into the subject, but actually soap contains the toxic ingredient of caustic soda. There're three forms of soap making ...cold process, hot process and melt and pour, but it's the cold process soap making technique that I'm familiar with. If soap fails, there is a procedure called 'rebatching'** and I've become quite familiar with this technique.

The alkaline substance which we use caustic soda for replaces the ash ingredient. (caustic soda is added to water to produce lye) The animal fats are still used today, however as I'm a vegetarian, I choose to use vegetable oils and butters. As fat values of different oils varies, some calculation of lye is required when replacing certain oils. Calculators are available online for such adjustments. Colours and fragrances can be added if desired along with an exfoliate agent such as sesame seeds.

Safety is essential when soap making and work space should only contain relevant equipment and all children and pets should be kept well away. Again, for safety reasons, all the soap making equipment is used only for this purpose and never used for cooking. PPE, especially mask, gloves and goggles are used, especially while mixing the lye, and I use a number 5 plastic container, which means the heat generated from the lye doesn't affect the container.

Once the ingredients are gently mixed together, a stick blender is used to thoroughly mix the ingredients aiming to get the oils and lye to emulsify and then on to 'trace'. (Trace means that the mixture becomes thickened). Once this has occurred, the mixture is poured into moulds and left for 48hrs. It can be cut if needed at this time as it's still soft, but is still slightly caustic. I store it for 6 weeks in a cool and dry place until it has completely reached saponification.

Since doing the recent workshop, I now have contacts with interstate suppliers where the purchase of colours, fragrances and oils are more readily available and at a more reasonable price.

I don't think soap making will ever be a real source of income for me but certainly it's a fun hobby and great to experiment and develop my skill to produce



Jacqueline's soaps



A soap that Jacqueline aspires to make one day



PNDU's AGM

Please save the date 13th September 2023, 12pm (AEST) - online

All members are warmly invited to attend PNDU's Annual General Meeting.

If you would like to hear a snapshot of what activities PNDU has been involved in throughout the year, meet the Management Committee members, or would like to have a sneak peek at what we have in store for the following year, we highly encourage you to (virtually) come along!

The agenda for the AGM and details of how to join us will follow, so please look out for a further notice in your in-boxes.

HPN AWARENESS WEEK

Please save the date 15th - 21st October, 2023

Look out for details of any activities that you could join in closer to the date.

PNDU Annual Social Auckland NZ

Sunday 12th Nov 2023

Kia ora to all PNDU members - PNDU will be hosting our annual social gathering in the city of sails.

We hope to welcome as many HPNers and their Carers as possible in Auckland on Sunday 12th November 2023 to this 'Free of Charge' event.

PNDU invites all our HPN members, family and carers who are able to join us in Auckland NZ, to come along to a social gathering, meet with other HPNers and carers in a relaxed friendly atmosphere, exchange stories of life on HPN with other HPNers who really understand your journey. Learn more about PNDU and what we do for you.

Venue and time to be confirmed.

For more information and to register email contactpndu@gmail.com

PNDU Travel Sponsorship to attend the PNDU Social Gathering in Auckland



PNDU is offering Two Travel Sponsorships, to the value of \$600 each, to assist HPNers and Carers attend the PNDU Social Gathering. Priority will be given to PNDU members who haven't before attended the PNDU Annual Social Gathering. If you have attended PNDU events in the past, you can still apply again. If you're not yet a PNDU member, complete the membership form on our website today. (Pndu.org)

PNDU would love to hear from you, it's simple to apply.

Those of us who have attended PNDU gatherings in the past know how wonderful it is to meet other HPNers who share similar HPN journeys and who really understand what life is like living with a drip.

Simply write a few words to us describing why you would like to attend the social gathering and what benefit attending will have for you. Send your email to contactpndu@gmail.com

(One sponsorship per family, travel must be completed and receipts forwarded to PNDU before reimbursement can be made). Winners announced at the PNDU AGM 11th September 2023.

AuSPEN HPN Consumer Workshop



The AuSPEN HPN Consumer Workshop is a unique opportunity to learn more about your HPN from expert clinicians working in the field. We are very grateful that AuSPEN has provided this opportunity specifically for HPNers and their carers since 2014.

Following on from the wonderful feedback provided by our PNDU members, the format for this year's HPN consumer workshop has changed and AUSPEN will offer 2 x 1-hour webinars (1 x Adult and 1 x Paediatric). These webinars would be streamed separately and at a different time of year than the AuSPEN Conference.

To ensure AuSPEN and PNDU deliver webinars that are as informative and interactive as possible, we would love to hear from our members.

A live streamed webinar 12.00 – 1.00pm on a weekday would allow PNDU members to interact and ask questions during the event.

Would you be willing to log in and join a live streamed webinar?

Or would you prefer a prerecorded webinar?

What HPN related topics would you be interested in learning about?

To provide input and suggestions please contactpndu@gmail.com



Sadly, a PNDU member, Lily Thai, 23, passed away peacefully, on Wednesday 21 June 2023. Lily was diagnosed with Ehlers Danlos Syndrome and Autoimmune autonomic ganglionopathy and was terminally ill. Lily spent her final moments at the Laurel Hospice in the Flinders Medical Centre, SA. Lily's name has been added to our In Memoriam roll.

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.

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

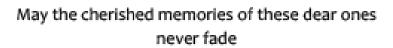
Jessica - 24 January 2014, aged 20 years

Tynesha 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 21/2 years





Upcoming Events



- PNDU AGM Wednesday, September 13th 2023 12pm EST
- HPN Awareness Week, 15th 21st October, 2023

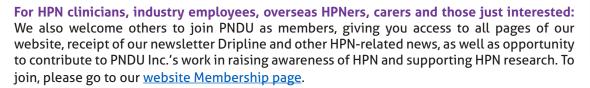
Membership for Aussie and Kiwi HPNers and carers



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 <u>website</u> <u>Membership page</u>.

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.







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 <u>Donate page</u> on our website for <u>PayPal</u> and <u>Direct Deposit</u> 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.

Australia (\$AUD)

Bank: Westpac

Account Name: PNDU Inc.

BSB: 032 056 A/C No.: 482 738

NEW ZEALAND: (\$NZD):

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

Management Committee Members

President - Chris

Vice-President - Gillian

Secretary/Public Officer - Miranda

Treasurer - Naomi
Dripline Editor - Gillian
Committee Member - Julia

Contact Us

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PNDU Inc.'s privacy policy is available on our website