

# MDDA Matters

Issue #64 - September 2017



## Building Support, Moving Forward The only limits in your life are those that you set yourself

Welcome to our 64th Edition of the newly named 'MDDA Matters'. You may have noticed the fresh new look logo, enews and website facelift we have been working on over winter. MDDA are continually looking at ways to improve our service to deliver members a better experience and access to information.

In this edition we celebrate IEM Awareness month, we had a tremendous turnout at The Grand Hotel in Warrandyte during the month of May concluding with a showcase extravaganza of delicious low protein menu options served throughout the month.

MDDA member Bianca, gives a wonderful account of her traveling experiences, inspiring us all to pack our bags and go exploring! Articles including Stephanie's wedding, our clinic update from Far North Queensland and news on the PKU global front can be found inside.

Our major event for the year is just about upon us with our MDDA family retreat fast approaching. This year it is being held in October taking place at CountryPlace Conference Centre, Kalorama, Victoria. This will be our 10th family retreat and is shaping up to be our largest yet! The program will feature education sessions, research updates, cooking demonstrations and plenty of time to connect and share with others. There are loads of activities to keep the kids entertained including kids club, laser tag and ropes course. A full run down and photos of the retreat will be in the next newsletter.

It won't be long before we start planning for our end of year celebrations in each state. Keep a look out for dates, if you are able to help or organise an event in your state please contact the office.



Also In this edition, you will still find member favourites with our product and recipe pages. If you come across a new product or a great recipe please share them with us!

We hope you enjoy this edition and the new look!

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# PKU Worldwide

**This July, MDDA president, Monique Cooper, and Vice President, Louise Healy had the opportunity to participate in a history making moment for PKU. Representatives from regional and national PKU support organisations from Europe, North America, South America, Middle East and Australia met to discuss the formation of an international PKU association.**

We are thrilled to say that all 8 participating organisations agreed to found the first ever world PKU organisation. It is a great honour to be involved in founding an organisation that is intended to improve the lives of people with PKU worldwide. Our mission is to try and ensure that every person with PKU, regardless of their origin, has the opportunity to realise their potential.

We achieved a great deal during a pretty short meeting – agreeing on a vision, mission, objectives and the next steps needed to establish the legal and membership structure of such an organisation. This work is proceeding and will include presenting the outcome of the meeting to medical professionals at the International Congress of Inborn Errors of Metabolism conference in Brazil this September.

Both Monique and I left the meeting in Canada feeling excited and very grateful. The meeting gave us the opportunity to understand how people with PKU are supported in terms of access to formula and medication, screening and diagnosis, availability of special medical foods and government support in other countries. We were reminded how fortunate we are that our children were born in a place that provides significant support to people with PKU and other IEM's. It strengthened our resolve to work to help other communities improve access to screening, treatment and support. In terms of opportunities to improve outcomes for our members, there are many opportunities to work collaboratively with the international PKU community on research and best practice that will continue to improve outcomes for everyone.

We are confident that this meeting marks the start of a very important step in improving the lives of people with PKU worldwide. We look forward to providing further updates as the organisation develops.

Further information can be found in the press release.

– Louise Healy

Press release – August 1, 2017

## PKU knows no borders

In July 2017, a regional and several country-based PKU patient organizations from around the world made history by agreeing **to form the first international association for PKU**. This global entity will serve as a supportive umbrella organization to regional and national patient organizations and groups in bridging the gap for PKU worldwide.

The formation of this group is in the early stages. We are pleased to share the following information about the organization at this time.

**Vision** Our vision is that all people living with PKU, despite their origin, will be able to reach their full potential.

**Mission** Our mission is to advance PKU as a global health priority and strengthen PKU associations and groups throughout the world.

**Priorities** As people living with PKU, our priorities are:

- To create a global platform for PKU advocacy that includes ensuring universal access to newborn screening and diagnosis, treatments and comprehensive care;
- To mentor like-minded patient associations and groups and offer best practices and support that are sensitive to their experiences, culture, language(s) and laws;
- To increase collaboration among PKU researchers, scientists, clinicians and patient groups to move basic science and research forward to accelerate new knowledge, treatments, and a cure.

### The Founding Member Organizations are committed to the formation of this new global entity

- Asociación Mexicana de Fenilcetonuria, AC (Mexico)
- Canadian PKU and Allied Disorders
- European Society for PKU
- Corporación PKU Chile
- Grupos de Padres PKU Asociación Civil de Fenilcetonuria de Argentina
- Metabolic Dietary Disorders Association (Australia)
- National PKU Alliance (USA)
- SAFE Associação Amiga dos Fenilcetonúricos do Brasil
- Turkey PKU Family Association

Organizational tasks have been assigned and plans are progressing for meetings over the next year. The founding members would like to thank Abbott Nutrition, BioMarin Pharmaceuticals Inc., Cambrooke Therapeutics, Dr. Schär Medical Nutrition GmbH, Nutricia Advanced Medical Nutrition, and Vitaflo (International) Limited for supporting this initial organizing meeting in Toronto, Canada, to improve the lives of people living with PKU worldwide. During the start-up phase the Canadian PKU and Allied Disorders is acting as financial agent for the global organization.



# Far North Queensland Metabolic Clinic

This year Kim Large and her daughter Jess represented MDDA at the Far North Queensland Clinics that were held in Townsville and Cairns over the 7-11 of May. The MDDA sincerely thank Kim and Jess for taking the time to volunteer and help spread the support of the MDDA and educate those newly diagnosed families about the MDDA.

## Here is Kim's tale of two clinics!

Once again it was my privilege to go on the Far North Qld Clinic run in Townsville & Cairns.

It has become a bit of a tradition to have a pre-clinic dinner and this year was no exception! We had a great catch up in Townsville on 7th May, the Sunday Night, at the Yacht Club before Clinic started on the Tuesday & Wednesday. This year we had Dr McGill and Anita at dinner and on our Clinic run. It is always special and exciting when we get to see Dr McGill a highlight of everyone's clinic visit.

Jess and I drove up to clinic from our home town of Proserpine stopping along the way to check out different sites and attractions. Townsville & Cairns certainly have a lot of beautiful places to visit.

Clinics are a great chance to see your Doctor and catch up with other wonderful people. Another great reason to come to clinic is to sample all the new and improved products that are coming into the market and making our lives a little easier. We were lucky to have some products from Cortex Health for people to take home and sample. There was pasta, wheat starch, baking mix, macaroni and more.

It was also lovely to hear that there has been plenty of romance amongst our Far North Queensland members with 3 lovely couples getting married this year.

- > *Stephanie & Bronson from Brandon Qld in May*
- > *Zane & Alexis from Mackay Qld in May*
- > *Arlie & Tyson from Townsville Qld in July*

Congratulations to these special couples.

In Townsville we saw lots of awesome people. It was lovely to catch up with some familiar faces and meet some new ones. Amongst others we saw; Jamie Leigh, Casey, Zane, Melissa, Angus, Lee, Kurtis, Lucas, Troy & Luke. And Cairns was just as amazing with Xavier, Javan, Shari, Nicholas, Caleb, Lily & new Baby Ella.

Another wonderful May Clinic gone - until next year! Thanks to all the families who make us feel welcome every year and for sharing your stories with us.

*Kim & Jess - May 2017*





# Traveling with an IEM - PKU

Because a low protein diet doesn't have to keep you from eating your way around the world!

by Bianca Albanese

**Whether it's a day at work, a family function or a weekend getaway, every trip requires preparation with a low protein diet. It's even more challenging when you're chasing a flight, eating hotel breakfasts or trying to communicate with a waiter in a foreign language.**

Managing the low protein diet in a new culture and with unusual local foods can make eating quite difficult. But our restricted diet shouldn't necessarily mean restricted travel. With some extra planning and research, people and families dealing with a restricted diet can make the world their oyster (or in our case, low protein alternative).

In this article I'm going to pull from 2 very different experiences, a work/leisure European trip and also a trip to India for a friend's wedding. Both rewarding but also posing their own set of challenges.

## The Planning

**My first thoughts - 'Wow is this really happening?' and the second - 'Will this even work?'** I was coming to terms with the excitement of traveling overseas for 7 weeks. I had just been accepted to present my research findings at an international conference in Spain, and so decided to extend this trip with a work colleague to include a European hockey tour and also some well deserved personal travel.

Once flights were booked, I rang each airline and pre-selected a vegan flight meal with the intention of eating what I could - supplementing with low protein crackers and Vege chips when this fell short (most of the time!). My work conference in Spain was followed by Portugal then London where I joined some fellow Aussies for a European hockey tour. Hockey took me to all over England, Netherlands, Belgium and France. My trip ended with a visit to my parent's homeland, Italy.

A large chunk of this travel was organised through the company heading the hockey tour (including general travel insurance - unlimited emergency medical/hospital expenses, lost luggage etc.). A phone call and an email later, I had confirmed this company would be able to cater to my dietary needs including organising extra airline luggage to help me cart, what was to be the heaviest set of bags on tour. I was granted an extra 20kg of luggage by the airline, which was a godsend as I had chosen to drink my PKU Air formula whilst I was overseas. Because I would be moving every few days, sending formula ahead of time worked out to be a logistical nightmare. This is where luck came in! My dear friend selflessly offered to share some of the formula load. We both carried 15kg of formula with us. Looking back, it was manageable. The best choice? Probably not. Manoeuvring our bags up old, cramped stairwells (no lifts here!) to Airbnb apartments needed some decent muscle power. Sometimes, (okay, okay - all the time!) this was lacking. My struggle must have drawn attention, as at these critical moments a kind European man would suddenly appear to offer a hand. The upside of all this - as the trip went on, there was more and more space for shopping! Score!

During private and work travel in Spain, Portugal and Italy, I made sure that all my Airbnb accommodation included a kitchen. **The amazing fresh produce gave me ample opportunity to cook when I could. However, when this was not possible essential items like low protein pasta, packaged bread, crackers and tortilla chips worked a treat.** I brought 5kg of pasta (carb loving Italian here - consumed mostly in Italy!), 20 packs of tortilla chips, 5 packets of herb crackers and 3 loaves of bread.

Now, how well I could survive India was a bit more of a worry. I knew Indian culture caters for vegetarians quite well, but in saying that it also contains a lot of pulses

and cheese. I would be travelling with a large group of friends many of whom could speak the language, and hosted by my friend's family for a lot of the trip, so that gave me some comfort. Seeing that it was a short trip, about 8 days long, made me think that I would be fine.

What worried me most about India was my unfamiliarity with the food. Sure, I eat Indian here in Australia, but in India I was expecting the food to be more traditional with some ingredients I wouldn't be able to identify. I wasn't too worried about the language barrier. I had talked to my host, and he was adamant he would be accompanying us for every meal apart from breakfast, so would speak on my behalf. A very generous gesture seeing that he had his own wedding to worry about!

My host was able to contact the hotel on my behalf to explain my diet and relay to me the foods they generally served as part of the buffet breakfast. I was able to confirm they would allow me to toast my PKU bread and that they would have a suitable vegetable curry available at breakfast. He was also able to make sure that at every one of the AMAZING 5 wedding events I planned to attend, there would be suitable food for me to eat. I packed 2 loaves of low protein bread and a few packets of crackers and cookies.

## Tips and lessons learned

- > Flight snacks are essential
- > Consider switching to a powdered formula to minimise weight
- > A 4 wheeled (not 2!) travel bag makes moving your huge bags much easier
- > Make yourself familiar with the region's common meals and their ingredients
- > Book accommodation with a kitchen
- > Don't be afraid to bring too many low protein basics (bread & pasta)

## Customs/Boarding Planes/ Travel Time

Prior to leaving Australia on both trips, I asked my PKU specialist to provide me with a letter to outline the food/formula I intended to carry onboard my flights. I kept a copy of this letter available online in case I was ever to lose the hardcopy. This letter was pretty worn by the end of my travel, proving very useful.

My hand luggage was mostly formula (what I needed for the flight plus at least a further 3 days worth) along with low protein tortilla chips, choc chip cookies and crackers. One thing I did forget – a change of clothes! My bags went missing from Lisbon airport, so Barcelona and the start of England saw me wearing the same black skirt over and over. However the one thing (and most important thing) I did have covered was my formula.

I travelled through Indian customs seamlessly. They checked my formula and were satisfied by my specialist's letter. Europe was quite troublefree too, except on one occasion. Following recent events in Paris' airport, security was extremely tight (understandably). In spite of my specialist's letter, customs were requesting I open each cooler to allow a sample to be taken, otherwise they would be confiscated. However if I were to open them all, they would perish in 24 hours, rendering them useless. Customs compromised to allow the amount of PKU Air I needed for my flight. But having lost my bags already once this trip, I was not prepared to risk being without formula if it were to happen again. I was able to talk to an airline representative and explain my situation. They were more than accommodating and after a total of 2 hours, allowed me through.

### Tips and lessons learned

- > Keep a copy of your specialist's letter online for easy access
- > Always carry extra formula onboard to cover a few days
- > Secure liquid formula in waterproof bags in case of spillage
- > Bring a spare change of clothes!
- > Arrive at airports extra early. Expect formula-related delays

## Travel Stories/Food Experiences

For many, a major joy of travelling is trying new food. I am one of those many! I found eating out such a great experience in Europe. There were several dishes I could order straight off the menu with no alterations at all.

My friends/colleagues were more than happy to stroll the stunning streets of Europe until we found a PKU-friendly place to eat. I did do quick searches before we headed out each day to shortlist a few restaurants around areas we'd be visiting. **However, to my surprise I found myself stumbling across produce or meals that were better than anything I could have dreamed up.**



There were a few times I came a bit unstuck. Breakfast seemed to be the most difficult time of day. In Europe, where shops opened at 11am, getting food for breakfast got a bit tricky. Luckily I had the foresight of grabbing bits and pieces from supermarkets as I spotted them. Most countries were quite gluten-free friendly, which made for some low protein finds like panini! When times got really desperate, as they did in Lisbon, I resorted to a good old bowl of Coco Pops.

Europe was my pasta heaven! I carried a packet of pasta everywhere. Every restaurant I asked was more than happy to accommodate, and my gosh was it yummy! On my hockey tour, after every match we would share a meal with our host team in their clubhouse. The tour organisers were fantastic and made sure they cooked my pasta. This made for great conversation as to why I was eating such a different meal including many questions like "So that means you can't eat..." "You can have chocolate right?".

One highlight of my trip was a daylong cooking class in the beautiful Tuscan hills of Florence. I had resigned to the fact

that I would be cooking 'normal' food and bringing along my own meal while everyone chomped down on their day's creations. As we booked, I decided to give it a shot, and asked about catering to my low protein diet. They were more than happy for me to supply my pasta and bread, and a whole vegetable dish was already planned for the day too, so I wouldn't leave hungry.

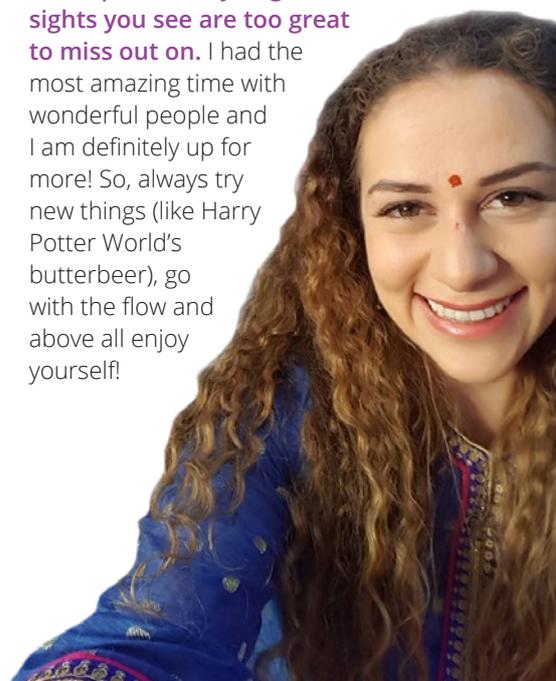
So there began my 100-course meal. I was able to cook a beautiful sugo (pasta sauce), attempt making fresh pasta, construct my low protein bruschetta, prepare mouth-watering roasted vegetables, fail at spinning a pizza base and create a pretty yummy looking gelato. On top of this we were fed antipasti like olives, marinated eggplant and artichoke, not to mention the fresh fruit and coffee for dessert.

So, getting sick in India made for fun times. The dreaded Delhi belly hit towards the end of my trip (is this the travel bug everyone warned me of?). This saw me hotel bound for 2 days, not eating and making somewhat of a recovery to make it on my plane home.

During this time I was able to get all my formula in, keep my fluids up and attempted to eat whatever low protein products I had left. I guess no matter how prepared you think you are, there is always a chance something could throw you off. But don't let that deter you.

**Travelling with an IEM is possible, and very worthwhile. Granted, it takes a lot of preparation and planning, but the experiences you gain and the sights you see are too great to miss out on.**

I had the most amazing time with wonderful people and I am definitely up for more! So, always try new things (like Harry Potter World's butterbeer), go with the flow and above all enjoy yourself!



The month of May saw The Grand Hotel Warrandyte take on the challenge and become the first Australian restaurant to create a unique dining experience for families with inborn errors of metabolism. It was a wonderful way to celebrate PKU/IEM awareness month with our members, family and friends.

Each week in May, a new menu was created and to end the month a grand 3 course family dining event was held. Fifty MDDA members attended, and it was wonderful to have some new members come along. It was a showcase of all the delicious treats from the low protein friendly menu for the month that was suitable for everyone to enjoy.

The food was amazing and no one left hungry. Not a single item outside the low protein menu was needed, everyone was impressed and satisfied. Menu items ranged from 0 - 2.5grams of protein. Some of the favourites included Korean spiced pulled jackfruit bao, Asian Vegetable Rice paper rolls, Sweet potato, pumpkin and zucchini lasagne, while the desserts included Coconut and lemongrass panacotta with poached pear & freeze dried rhubarb and the Grand Vegan Mess – an aquafaba meringue, vanilla coconut cream with raspberry gel and strawberry and kiwi fruit.

Well done to The Grand. The outcome of this month long program has been truly inspirational and we have proved beyond expectation that low protein can be catered for with the right level of creativity, and attitude. The night ended with the Chef announcing that the low protein menu options were to stay!!! We are thrilled to hear that this initiative has continued.



A big thank you to our President Monique Cooper and hotel Manager Peter Appleby, who got this idea off the ground and to the Executive Chef Brad Hawker and Chef Daniel who embraced the concept with such enthusiasm and created such delicious food. It was wonderful to have them take the time to understand the complex low protein dietary needs and adapt their traditional meal preparation techniques.

We hope this is just the beginning of many more establishments around the country taking on this concept. We encourage anyone willing to give it a go to contact us at [office@mdda.org.au](mailto:office@mdda.org.au). Help us make inclusive dining opportunities a real possibility for PKU and other IEM families managing low protein medical diets across the country. The first step is approaching an establishment...from there, look what's possible!!





## Community Education

MDDA president, Monique Cooper took our message to the airwaves on Radio Eastern 98.1 FM with Brian Amos to promote PKU Awareness month and the Grand Warrandyte dining experience.





# The Love Story of Mr. and Mrs. Hutchen



**My name is Stephanie Hutchen, formerly known as Stephanie Butler. The 22 April 2017 was one of the best days of my life as it was the day that I married my best friend who has always looked out for me and always helped me to be the best person I could be.**

This article is a story about how we first met, our life together, how he proposed to me and the day of our wedding. I would also like to say to my new husband; I would not be the person I am today without you; you always take care of me especially when it comes to my PKU diet. You always make sure that I stay on track and I love it when you experiment with low protein food to help me stay on my diet. I will always love you, and I can't wait for the next chapter of our lives together to begin.

## How we met

March 2007 was the first day we met, a shy trolley boy came up to a shy apprentice hairdresser at work and asked for her number. One week went by, and I hadn't received any calls from him, so I just thought that he was no longer interested in me. Until one day nearly two weeks later he came into the salon I worked at and asked me if I would like to have lunch with him on my break, I said yes. We then had lunch together every day from that day on. One day on 22nd April 2007 Bronson asked me to be his girlfriend, I was so happy, so of course, I said yes. Over the following eight wonderful years, we feel deeper and deeper in love with each other, made a life with each other and created a family with our two beautiful dogs Lilly and Marley.

## The proposal

On the morning of 31st October 2015, Bronson went to see my dad Gary to ask for his permission and blessing for my hand in marriage. At midday, I arrived home from what was a very long exhausting shift at work to see Bronson waiting for me on our balcony. As I walked up the stairs he got down on one knee and asked me to marry him, I just dropped all my stuff on the ground and gave him a huge hug and kiss, while saying, yes I will. After proposing to me Bronson told me that he brought the engagement ring a few months prior, but he was waiting for the right moment. That night my parents Gary and Debbie took Bronson and I out for dinner to celebrate.

## Wedding planning

The day of our wedding marked our 10th Anniversary of the start of our life together.

Over the next 18 months Bronson and I planned our wedding, Bronson was happy for me to plan the wedding of my dreams so with my mum we went through everything that I had ever wanted and produced the most wonderful wedding I could ever imagine.

When we went looking to buy the perfect wedding dress I had almost given up, and then we found the Fashion Gallery in Townsville, and the team there made me feel so welcome. I found the dress of my dreams it was so different, something that I have never seen before and the dress just made me feel so beautiful. When I tried it on, I just had that moment I said to my mum, my maid of honour and my best friend that this was the dress, there was no other dress that was

going to look and feel as good as this did on me, so it was decided - that was the one.

Our bridal party contained my maid of honour which was Bronson sister, Tiffany, two bridesmaids which were my older sisters, Kristen and Pamela, the flower girl who was Bronson niece, Minka, the best man, Bronson's brother, Jason, and two groomsmen, brother-in-law Nick and friend, Dean. We also had a ring bearer, Nathan, who was the son of a family friend.

Three days before the wedding my husband Bronson had an accident and broke his two little finger knuckles and unfortunately had to have his hands bandaged and cast on the wedding day. But he told me that there was nothing in this world that was going to stop him from marrying me on that Saturday, although his hands did look worse than they were it did not restrict him from doing anything on our wedding day, and we all got a laugh out of it.

## The wedding day

It was the morning of the 22nd April and the wedding day was finally here! All the girls got ready at my mum's house, and around the corner at our house the boys got ready. I was surprised how well I kept it together as I thought I would be more emotional, nervous and stressed but I wasn't I think I was just so happy. We were running a little behind schedule, but I told Bronson the day before not too worry if I was late because no matter what happened I would get there. When the girls were helping, me put on my dress it hit me, I said "I can't believe I am getting married" I was soon going to be Mrs. Hutchen.

## The Church

When it was time to go to the church we went by horse and carriage, this had always been my dream to have a horse and carriage on my wedding day. They were amazing. In the horse and carriage was my mum, dad and myself. The girls went in the bridal cars.

I remember on the way to the church I started to get nervous and a little emotional and I could see that my parents were so proud of me. When we arrived at the church, I walked in and saw Bronson at the end of the aisle he looked at me with the biggest smile. I remember thinking to myself, God was here and were about to do this. I had my mum and dad walk me down the aisle it was one of the best moments of my life, and I was so happy to have them both to give me away.

While the ceremony was happening, I remember Bronson holding my hands and telling me everything is okay. I was so happy and emotional and so much in love with him and I could tell he felt the same. At the end of the ceremony, we had a balloon release to recognise the family members that had passed away and were unable to be there for our wedding day, but who were definitely there in spirit. The ceremony was at The Sacred Heart Catholic Church in Ayr followed by our reception at Populins Hall

in Ayr. Next, we had photos done with our guests at the church and then with the bridal party and immediate families at Plantation Park.

## Reception

When we went to the reception, I just remember looking and thinking how the final product of our decorations were the most amazing thing I had ever seen. My mum and I both put so much effort into making this day the most beautiful day it could be. I will never forget the work that my dad put into making my candy cart; this was one thing that I wanted. I had seen one I liked at a wedding expo in Townsville, and my dad decided to create one. With the help of my mum and a couple of Bronson's brothers they built us a beautiful candy cart from scratch. It was a hit at the wedding.

## Catering

Mum and I found Fusion Cafe and Coffee Shop caterers, who do catering for a variety of functions. They were so fantastic in creating my menu for my PKU, and they also worked in with some of my guest's allergies as well.

We also had to source out a cake baker and decorator. I was always planning for my mum to make our wedding cake as we did not think that anybody would be able to cater for my PKU, but about

a month before the wedding, we found a lady who just happens to be local that was willing to make the wedding cake of my dreams. I had always imagined my cake design to be an old-fashioned wedding cake that had a fountain and bridges on it. We ended up finding Deborah from Deborah's Cake Creations I told her my plan, and she made the most wonderful cake. It came out better than I could ever have imagined, it was just perfect and beautiful. Deborah also made an extra cake that was gluten-free, dairy-free and PKU friendly. This one was not part of the actual wedding cake, but she made it so that I could eat some cake myself.

## The honeymoon

After our wedding, we enjoyed a lovely honeymoon on a P&O cruise to New Caledonia and Vanuatu and even though we did not get to go to Port Vila due to a cyclone we still had the best honeymoon we could have ever dreamed. Our highlight was visiting the Islands, The Great Gatsby Night and the Titanic experience at P&O Edge.

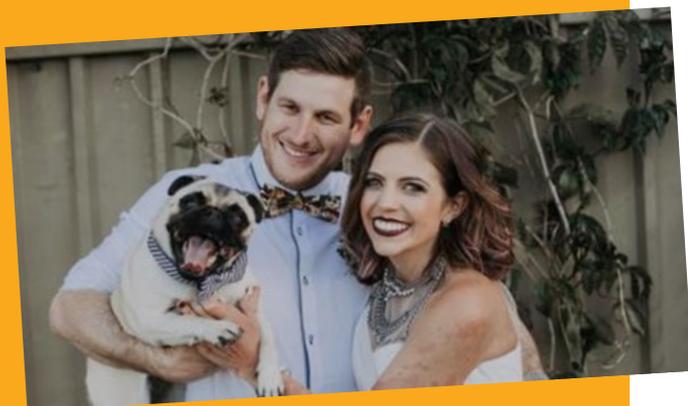
**I had the most wonderful time at my wedding it was the best day of my life. I would not change a thing, it was a perfect day. I have found my Prince Charming, and I am going to spend the rest of my life with him.**

# Congratulations!

## Congratulations

Congratulations to **Alexis and Zane Large** married 20 May 2017 in Mackay

Wishing you love and happiness as you begin your life together!



## New Arrival – Baby Boy

**Oliver Andrew Wright**

born on 24/7/17 at 1:47pm. 8 pounds 14 ounces

Congratulations to Rebecca, Jamie and Emily.

Glad to hear Emily is loving being a big sister!



# Medical Alert Jewellery and Emergency ID products

A topic of discussion recently in one of our Facebook groups has been the need for Medical Alert/ Emergency ID products for an IEM person.

There are now many choices available. It is just a matter of choosing one that fits in with your or your child's lifestyle.

Some of the options available now are;

- > Velcro wrist bands  
*(for kids seem to be a popular as they are less likely to fall off)*
- > Medical Alert pendants
- > Bracelets
- > Wallet cards
- > Silicon Sports bands



## What to list:

There is no right or wrong answers – remember you want to make it as easy as possible for a paramedic or Dr in an emergency situation to identify the condition especially in the event that the person is unable to communicate for themselves.

Some website recommend the following things to list:

- > Medical condition,
- > Medications you are taking,
- > Foods/medicines you can't have
- > In case of Emergency a contact phone number

Perhaps the best advice is to ask your Dr what they recommend.

Please see below a couple of sites that provide emergency ID/ Alerts. You need to carefully decide what you are looking for as some companies offer a membership and will store your information in a secure database. These details can then be accessed by emergency services and healthcare professionals via there 24/7 Emergency Response Service, which is operated by professionally trained staff should it be needed.

### Emergency ID Australia

<https://www.emergencyid.com.au/faq/mens-range#n8040>

### Medical Alert Foundation

<https://www.medicalert.org.au/>

## Notice of 2017 Annual General Meeting

The Annual General meeting of the Metabolic Dietary Disorders Association (ABN 99 021 391 381) will be held on

**Saturday 7th October  
6pm**

**The CountryPlace Conference Centre  
180 Olinda Creek Rd  
Kalorama Victoria**

Any financial members wishing to nominate for the Board of Management positions may contact the office for a position description and nomination form. These to be returned by

**Monday 2nd October**

Nominations for the General members are called for in all States and Territories.

## In memory of Alex Shaw

Alex Shaw, part of our Victorian IEM family, passed away on the 27th May 2017.

Many wearing Yellow and Black in support of his beloved Tigers, joined together to celebrate Alex's life. Alex had written his own eulogy, which was full of both humour and the love he had for his family. Family and friends spoke of such a kind, funny, generous, humble, sometimes (or quite often it seemed!) mischievous man. For those of us who were fortunate to have met Alex, he will always be remembered fondly.

Our sincere condolences and support will always remain with his lovely wife Sam and their 4 beautiful children, 3 of whom have PKU.



# Fundraising Updates

## Fundraising Market Night

Recently grade 6 students at Laurimar Primary School in Doreen Victoria, were required to organise a market stall to learn about budgeting and running a small business.

Three students, Charli, Charlotte and Lucia kindly nominated the MDDA as the charity of their choice to receive any profits made on the day. Charli's younger brother Jesse has PKU so the girls were aware of the MDDA and IEM's. The girls market stall raised an amazing \$122.50.

A big thank you to Charli, Charlotte and Lucia for choosing us as their charity and for raising awareness about PKU & IEM's in their school community. Looking good in your MDDA caps girls!



## Entertainment Books

Thank you to Tracey Scott for organising the sale of the Entertainment Book and to all those who purchased one.

It's not too late, you still have time to make use of all the wonderful deals. -

<https://www.entertainmentbook.com.au/orderbooks/91531w0>



## SAVE THE DATE

### Queensland Christmas/ End of Year get together

Sunday 5th November  
Taylor Range Country Club  
Ashgrove, Brisbane

More information closer to the date.  
Please contact Louise Healy -  
louise@mdda.org.au if you can help.

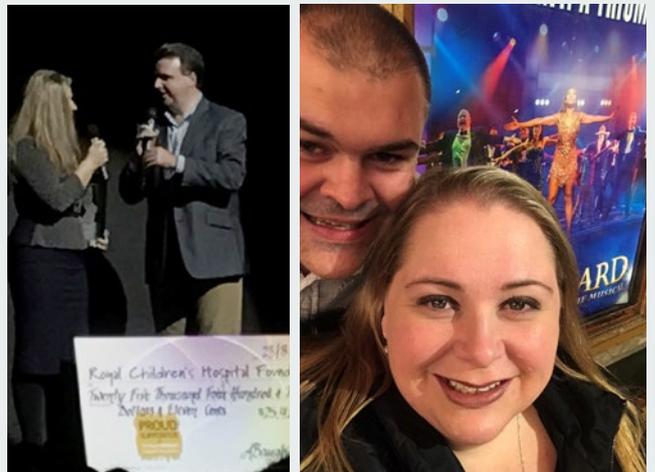
## The Body Guard Charity Dress Rehearsal Performance

Thanks to those MDDA members who made their way along to the Body Guard Charity Dress rehearsal on the 23rd of August at the Regent theatre, Melbourne.

This was in support of the Department of Metabolic Medicine at the Royal Children's Hospital Melbourne (RCH). The cast and crew held a charity dress rehearsal specifically for the RCH staff, families and supporters.

Over \$20,000 was raised.

Thanks to Katy and Richard for the photos! Looks like a great night was had by all.



## SAVE THE DATE

### Victoria Christmas/ End of Year get together

26th November 2017  
The Grand Hotel, Warrandyte

# PKUNSW Updates

## City2Surf – August 13th 2017

Among the 80,732 entrance in this year's City2Surf were three "Phen" the Platypus mascots joining PKUNSW families and supporters.



Our group walked and skipped their way around the course and whilst doing so brought plenty of attention to themselves - creating awareness of PKU and managing to get in the newspaper and news. Well done!

It was a great public event to raise awareness of PKU and also to raise funds for the research currently underway at the Children's Hospital at Westmead. A wonderful, yet tiring day was had by all!



## Running for PKU

Well done to Kate Kline who ran 12km through the Ku-ring-gai National Park, NSW in April in support of her two nephews with PKU and to raise awareness. Her fundraising effort raised \$2796.95 for PKUNSW.

## IEM GRANT

Just a reminder that to remain eligible for this grant you have individual responsibilities such as maintaining your diet as evidenced by regular blood tests and keeping clinic appointments. Failure to comply may mean your access to the grant could be removed.

### Payment Schedule for 2017

The IEM food grant payment for 2017 is due by the Friday of the first full week of each month. Payments due to arrive by:

6 October, 10 November, 8 December

For questions please contact the Department directly on (02) 6289 8980 or

[iemprogramofficer@health.gov.au](mailto:iemprogramofficer@health.gov.au)

## Why your membership matters

Membership ensures MDDA can continue to support all individuals living with an IEM and help them achieve positive health outcomes

- > provide more informed choices, resources and support
- > provide support by way of website, newsletters, recipe resources, Peer support, conferences, family retreats, social activities and many other programs.
- > enables MDDA to provide a voice to government and decision makers on all levels, to promote research into inborn errors of metabolism
- > to raise awareness to the greater community and to advocate for all individuals and families living with an IEM.

Please contact us [office@mdda.org.au](mailto:office@mdda.org.au) if you would like to check on the status of your annual subscription or would like to become a member of the MDDA.

To further involve yourself with any of our initiatives listed above please contact us.

We rely on the passion and generosity of all our volunteers to continue to work for the benefit of all members and the IEM community.





These burgers can be served with a low protein roll or a delicious salad.



### Corn Burger

**Ingredients:**

150g low protein flour  
 1 teaspoon baking powder  
 6 teaspoons fajita spice mixture or similar  
 Salt and pepper  
 2 teaspoons dried oregano  
 120ml water  
 2 teaspoons tomato puree  
 50g spring onions - chopped  
 100g capsicums (mixture of green and red) finely chopped  
 1 cob of fresh corn (lightly steam/microwave for 4 minutes then cut kennels off) or 175 g tinned corn  
 Oil

**Method:**

Mix together the flour, baking powder, spice, salt & pepper and oregano. Mix together the tomato paste/puree and water then add to dry mixture mixing until creamy  
 Add in the spring onions, capsicums and corn. Mix well.  
 Form mixture into a ball of your choice and then gently flatten.  
 Heat a little oil in a frying pan or BBQ. Cook burgers over medium heat until golden brown.



### Mushroom Burger

**Ingredients:**

3 cups finely chopped mushrooms  
 3/4 cup finely chopped onion  
 Egg replacer  
 2 tablespoons tomato sauce  
 3 tablespoons low protein flour  
 1 cup low protein breadcrumbs

**Method**

Using a food processor chop mushrooms and onion. Crumb low protein bread to make breadcrumbs. Mix all ingredients together by hand (not in food processor). Refrigerate 30 minutes prior to cooking.  
 Heat a little oil in a frying pan or BBQ. Cook burgers over medium heat until golden brown.

Some quick sweet fixes (adapted from "Apples to Zucchini" cook book)



### Toasted Cinnamon-Honey Sticks

**Ingredients:**

1 ½ tablespoons melted butter  
 2 tablespoons honey  
 ¼ teaspoons ground cinnamon or to taste  
 4 ½ inch thick slices low protein bread (160gm)

**Method:**

Preheat oven to 200° C. Stir honey and cinnamon into melted butter  
 Brush both sides of the bread with the butter mixture. Cut each bread slice into 4 sticks  
 Place the bread sticks on baking paper, and bake for 10 -15 minutes or until crisp and golden brown.  
 Delicious hot or cold. These can be kept in an airtight container for several days.



### Cinnamon – Sugar Sautéed Bananas

The bananas can easily be substituted for the fruit of your choice.

**Ingredients:**

3 medium ripe bananas – peeled and cut into ½ inch thick slices  
 2 tablespoons of butter  
 2 tablespoons brown sugar  
 ½ teaspoon ground cinnamon  
 Squeeze of fresh lemon juice.

**Method:**

Melt butter in a large fry pan. Add sugar and heat until the sugar dissolves. Add banana slices and sautéed for a few minutes, turning once, until they are lightly brown and heated through but don't overcook or they will go mushy!  
 Add a squeeze of lemon juice and serve immediately.  
**Serves 4**

Spring will soon be upon us and these recipes are perfect to enjoy eating outdoors enjoying the beautiful spring days.

*\*calculate all recipes as per guided by your dietitian*

## Special Medical Foods Suppliers



### Nutricia / PKU Connect / Loprofin

[www.pkuconnect.com.au/product-category/low-protein-foods/](http://www.pkuconnect.com.au/product-category/low-protein-foods/)

[www.nutrition4me.com.au/homeward-pharmacy](http://www.nutrition4me.com.au/homeward-pharmacy)

Ph: 1800 889 480



### Vitaflo / V2U / Fate

[www.vitaflo.com.au/products/metabolic-disorders/apps/vitaflo-choices/fate/](http://www.vitaflo.com.au/products/metabolic-disorders/apps/vitaflo-choices/fate/)

[www.vitaflo.com.au/home-delivery](http://www.vitaflo.com.au/home-delivery)

Ph: (03) 5229 8222



### Cortex Health / Cambrooke

[www.cortexhealth.com.au/products/low-protein-foods](http://www.cortexhealth.com.au/products/low-protein-foods)

Ph: 1800 367 758

### PKU Direct Oceania

[www.pkudirect-oceania.com](http://www.pkudirect-oceania.com)

### Platypus Foods

[www.platypusfoods.com.au](http://www.platypusfoods.com.au)

## Nutrition Information Panel

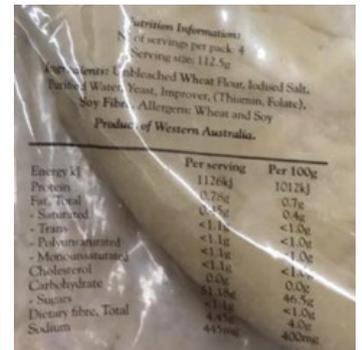
### Product Alert

### Turkish Bakeries Stone Baked Pizza base

Incorrect panel states 0.7g per 100g

The company has been contacted and are in the process of changing the packaging to reflect the correct protein amount.

Be aware that there may be stock packaged before this correction on the shelves.



## Artificial Sweeteners

Some artificial sweeteners used in foods contain Phe and should be avoided. To find out whether a product contains these artificial sweeteners check the ingredient list on the food label.

Additives 950, 951, 961 and 962 (also called Nutrasweet, Equal, Canderl, Neotame or aspartame-acesulphame) contain aspartame, which is a source of Phe. Another way to find out whether a product contains these artificial sweeteners is to check for a warning statement saying that the product contains phenylalanine. These sweeteners are used mainly in diet drinks, sugar free lollies and chewing gum and some medications.

NOT OK		OK
950 Acesulphame		952 Cyclamate
951 Aspartame		953 Isomalt
961 Neotame		954 Saccharin
962 Acesulphame-Aspartame		955 Sucralose
Nutrasweet		956 Alitame
Equal		957 Thaumatin
Canderl		965 Maltitol
		966 Lactitol
		967 Xylitol
		968 Erythritol
		Mannitol
		Sorbitol

\*reference ASIEM - Phenylketonuria-PKU - Handbook page 50

# Product update



## Cocofrio: coconut ice cream

Protein per 100g: 1.3  
 Protein per serve: 1.1  
 Serving size: 80g  
 Available from: IGA and Jefferies



## Orgran: Gluten free tomato soup mix

Protein per 100g:  
 Protein per serve: 1  
 Serving size: 200ml  
 Available from: Coles & Woolworths



## Kettle: Salted caramel popcorn

Protein per 100g: 6.3g  
 Protein per serve: 0.7g  
 Serving size: 11g pkts  
 Available: IGA and Health food stores



## Cocofrio: mango ice cream

Protein per 100g: 1.2  
 Protein per serve: 1  
 Serving size: 80g  
 Available from: IGA and Jefferies



## Monster Health Foods co: Free & Lo Muesli

Protein per 100g: 4.8g  
 Protein per serve: 2.2g  
 Serving size: 45g  
 Available from: Woolworths



## Vege Deli Crisps: original blend

Protein per 100g: 3.1g  
 Protein per serve: 0.6g  
 Serving size: 20g  
 Available: Woolworths and Coles



## Smooze Fruit Ice

Protein per 100ml: 0.5g  
 Protein per serve: 0.3g  
 Serving size: 65ml  
 Available from: Coles



## Biona Organic: pear & apple spread

Protein per 100g: 1.5g  
 Available: IGA and Health food stores



## Oliana Dairy free: feta

Protein per 100g: 0g  
 Protein per serve: 0g  
 Serving size: 40g  
 Available from: Woolworths



## Genius: gluten free white bread

Protein per 100g: 2.4g  
 Protein per serve: 1.7g  
 Serving size: 2 slices  
 Available from: Coles/ IGA



## Biona Organic: red pesto with sun dried tomatoes

Protein per 100g: 1.3g  
 Available: IGA and Health food stores



## Free from: Gluten apricot bites

Protein per 100g: 1g  
 Protein per serve: 0.3g  
 Serving size: 32g  
 Available from: Woolworths

# MDDA Family Weekend Retreat

Friday 6th - Sunday 8th October • CountryPlace, Kalorama Victoria

MDDA retreats are designed to be relaxed weekends away to get to know and enjoy the company of other families and members of the MDDA. With plenty of activities to join including;

Cooking Demonstrations and Workshops

Discussion Forums

Doctor and Dietician Presentations

Team Building Exercises

Kids & Teens Club

and much more

## COSTS

### MDDA Members

Adults (Twin Share):	\$225 pp
Adults (Single):	\$285 pp <i>(subject to availability)</i>
Teens (13-17):	\$95 pp
Kids (3-12):	\$75 pp <i>(incl. Sat kids club)</i>
Kids (2yrs or under):	Free

Costs are ALL INCLUSIVE and include 2 night's accommodation, all meals and activities.

Includes low protein and special dietary meal requirements, some snacks included (alcoholic beverages at own cost).

### DAY RATE - SATURDAY ONLY

*These rates are arriving after breakfast and leaving before dinner (8:45am -6pm)*

Adults:	\$55
Teens:	\$45
Kids:	\$35

### DAY RATE - INCLUDING SATURDAY DINNER

*Should you wish to stay for Saturday dinner, prices would be:*

Adults:	\$75
Teens:	\$65
Kids:	\$50



Limited spaces available  
Day rates available

BOOKINGS  
ESSENTIAL

Register online today!  
[www.mdda.org.au](http://www.mdda.org.au)



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Kerry Tulloch

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This newsletter will only grow and get better with your input.

Please share your stories, ideas and tips, birthday celebrations and functions with us via [office@mdda.org.au](mailto:office@mdda.org.au)

**Disclaimer:** Information presented in this newsletter is intended for general purposes only and should not be construed as advising on diagnosis or treatment of any medical condition, if you have interest in any of the foods or treatments contained in this newsletter check first with a qualified health professional.

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