

# MDDA Matters

Issue #69- June 2019



## “Planning for a better future”

**MDDA is always looking to the future to see how we as an IEM community can improve things.**

A better future may mean different things to different people... more food choices, greater awareness, an understanding of IEM's or perhaps its our vision for all individuals living with an IEM - to ensure that they are leading a life at full potential, not limited by choice or resource, that captures the meaning best.

‘Planning for a better future’ was the theme at the retreat held recently in Western Australia. Many areas were discussed in determining what role we can all play in achieving this. A huge thank you to all those that helped make it such a successful event.

Also in this edition you can read about The Great Protein Challenge and Rare Disease Day. While these events are behind us we still have plenty more to come for 2019! Our National Retreat is coming up fast in Tasmania the 4-6th October. Registrations are now open so make sure to check out the back page to see how you can register.

We would also like to welcome 2 new staff members to our MDDA National office team.

With thanks to a recent successful grant

application, we are very excited by the appointment of our Tele-Health nurse, Joanne, who will be working 3 days a week out of our MDDA office in Croydon, delivering MDDA's new Patient Pathways program, supporting IEM individuals and families in a national capacity.

We also welcome Isabella Hendricks, who joins the team to help drive our digital communications priorities delivering programs and services to our members, as well as expanding upon our many awareness campaigns and activities.

Behind the scenes our team has been working hard with our app designers on our soon to be launched “My Low Pro PAL”. Our new mobile app has been designed by MDDA to specifically help Australians living with PKU (or other Protein based IEM's), to better manage and track daily protein intake and achieve other health and wellbeing goals. Compliant with the ASIEM protein counting guidelines, this app will also feature creative and easy to follow low protein meal plans (tailored to suit your allowance), recipes and a comprehensive low protein product catalogue, along with many other features soon to be announced. The app will be launched later this year at our National Retreat.

We are also finalising our newborn starter PeeKabU bags. These bags are

filled with information and resources to help our newly diagnosed families begin their IEM journey. These fashionable looking backpacks along with many of the goodies inside, will also be available soon for purchase on our MDDA online store - launching later this year.

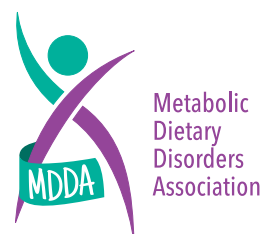
It is time for our membership drive. As a MDDA member you are part of building a stronger future and stronger community. To stay up-to-date and connected with support, resources and services please renew your membership and consider adding a donation to strengthen your impact.

Keep reading to find out more about what our wonderful MDDA community has been doing.

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are tax deductible





# How Low can you Go?

the great protein challenge.com.au

THE GREAT  
PROTEIN  
CHALLENGE

FEB  
2019



**The Great Protein Challenge kicked off for the second year on the 1st February and concluded on the 28th February, Rare Disease day. Through this challenge we together raised over \$18,000.**

We encouraged all Australians to eat under 10 grams of protein for one day in the aim of raising awareness and funds in support of people living with a protein Inborn Error of Metabolism.

This year we initiated a school lunch box challenge, and the dietitians challenge. Well done to the Queensland Metabolic Clinic for winning the Dietitians Challenge and raising \$1645. Also a "shout out" to our top 3 Individual players, Kim Cooper and Melinda Turco raising over \$2000 and Louise Conlisk over \$1000. Our top teams "Team Evie" and "Charlie's Angels" also raised over \$1000. We are so grateful for your amazing efforts. We have been touched by inspirational and heart warming stories by those that did the challenge as the understanding of rare Inborn Errors of Metabolism continues to grow. We have shown that we are not alone. While we may be small in numbers (we are rare after all), we all have a huge heart and an enormously welcoming community. We are definitely better together.

Our agenda for the last day of the Challenge and Rare Disease Day was jammed packed! We wrapped it all up with a number of significant and fun events!

The day began with MDDA and members being represented, by Monique (President) and Jenny (Executive Officer), at the Genetic Support Network of Victoria (GSNV) event – Bridging Health and Social Care. There were around 40 other leaders from rare disease support groups, government representatives, the Murdoch Children's Research Institute and The Royal



Some of  
our top  
Players



Children's Hospital, Melbourne clinicians.

Next on our Rare Disease day agenda was a special tour of the Newborn Screening Laboratory at the Royal Children's Hospital in Melbourne. This was followed by a special low pro afternoon tea (complete with low pro treats from the team at VitaFlo) with the Victorian clinicians and dietitians that were taking on this year's Great Protein Challenge.

In Queensland there was a visit by Louise (Vice President) and Evie, to the Queensland Lifespan Metabolic Service – who had been doing the Great Protein Challenge for THREE days!

We finished the day and The Great Protein Challenge came to an end with a Low Pro feast at the Grand Hotel Warrandyte. What an experience! A complete menu of low protein delights that pleased everyone.

The menu choices certainly made it easier for those doing the





challenge. Thanks again to our friends at the Grand Hotel for their continued support.

The Great Protein Challenge, coinciding with Rare Disease Day, literally lifted the roof in terms of our expectations and experiences! A HUGE thank you to everyone who got involved in the Great Protein Challenge for 2019! You have all shown that those with an Inborn Error of Metabolism can absolutely THRIVE in a supportive environment where we share a greater understanding and appreciation of this rare disease.





# Raising Awareness at Parliament House

**MDDA were pleased to attend Rare Voices Australia Rare Disease Parliamentary Luncheon.**

On the 22 February Metabolic Dietary Disorders Association headed to Australia's Parliament House in the lead up to Rare Diseases Day on 28 February. Together with Rare Voices Australia, and other representative groups of rare diseases from across Australia, we were there to raise awareness about the challenges and inequities people with rare diseases, such as Inborn Errors of Metabolism.

Over the past few years, we've seen some great advancements in the treatment and funding for those with IEMs - but there is more work to do! The MDDA will continue to advocate for the 1600 Australians who live with a protein IEM and their families. This event provided an opportunity to raise important issues for our community such as access to sapropterin for all responsive patients, consistent and reliable access to PBS products, Newborn Screening additions for IEMs not diagnosed by the current tests, and actions required by the MDDA in preparation for the review of treatments on the Life Saving Drugs Program.

This year, the theme for Rare Disease Day was 'Bridging Health and Social Care'. Together, we want to help create greater coordination between medical, social and support services to help those living with a rare disease.

Thanks to Louise Healy, MDDA's Vice President and Rare Voices Australia Director, Nicole Millis for representing us all so well.



*Sean Murray, CEO, Mito Foundation; Louise Healy, Vice President, MDDA, Nicole Millis, CEO, Rare Voices Australia; Megan Donnell, Founder, Sanfilippo Children's Foundation*



## PKU in the News

**Our small group was once again in the news this month when Health Minister Greg Hunt announced that sapropterin (Kuvan) would be listed on the Pharmaceutical Benefits Scheme for children and adolescents.**

The listing is the result of several years of advocacy by the MDDA and our community. We are continuing to advocate for a listing for adults too. This treatment, which approximately 30% of patients with PKU will respond to, may assist in the management of PKU. Please contact your metabolic clinic or our office for more information.

## 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.





# Life Saving Drugs Program Announcement for Tyrosinaemia Type 1 Patients

MDDA is pleased to see ongoing support for Tyrosinaemia Type 1 patients with new formulations of nitisinone on the Life Saving Drugs Program (LSDP) announced as part of the recent federal budget.

Your treating physician can provide advice on the most appropriate formulation.

In addition the LSDP expert panel will be seeking input from MDDA and Tyrosinaemia Type 1 patients and their families as part of ongoing processes to ensure the LSDP responds to patients needs.

There is a FAQ sheet from the government that provides more information about the role of patients in the review processes (please see link below). MDDA have provided input to the program and will continue to do so.

**More information is available at these web addresses;**

The Budget announcement - <https://bit.ly/314FjrB>

Government FAQ sheet - <https://bit.ly/2MqjeR1>

If you have any questions please contact our office.

## Far North Queensland Clinic

**On Sunday the 28th April 2019 Kim and Roy Large set off on their annual Townsville and Cairns clinic road trip for the MDDA.**

A dinner was held in Townsville on Monday night which has become a regular event on the social calendar at clinic time. *For those able to attend it's a great way for our small community to socialise and connect with others who share similar experiences and challenges.*

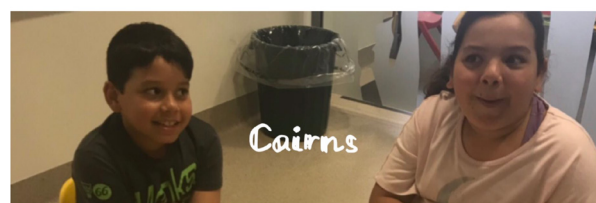
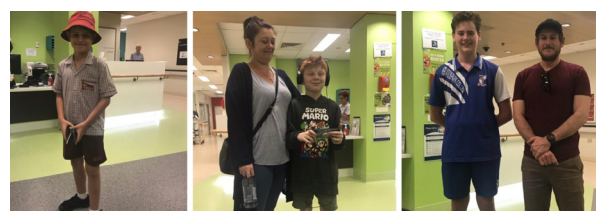
Thank you to Rachael and Ella making the enormous effort and 4.5 hour journey from Cairns to Townsville to attend the dinner.

It's always a very special clinic visit when Dr McGill and Anita make the trip North. We are very fortunate to have such caring, reassuring and supportive healthcare team looking after us.

Much discussion and excitement was held around the Tassie retreat and those who may attend. Other topics of interest were the listing of sapropterin for children on the PBS, the low protein dietary app and new low protein products.

After the Townsville clinic and catching up with many familiar faces, Kim and Roy travelled to Cairns for two nights, where they attended the clinic taking time to connect and catch up with families, and help educate about the support and new initiatives MDDA have to support all members. These outreach clinics are an important medical and social date in the calendar for our IEM community in outer regional, rural and remote areas.

A big thank you to Kim and Roy who take time out of their busy schedules and volunteer to help the MDDA at these clinics. Their attendance and faces have become an important part of the FNQ clinics and the experience for many would not be the same without you. Thank You!







## “Planning for a better future”

The Vines Resort and Country Club, Swan Valley WA 30-31 March 2019

**Western Australia was the destination for our first Family Retreat for 2019.** We had over 100 attendees, a record attendance for a WA MDDA event! Members, health professionals and key stakeholders enjoyed one and a half days in a welcoming inclusive environment.

MDDA Family Retreats are wonderful experiences, a chance for us to feel a sense of belonging in a positive environment where we can feel accepted fully for who we are, share our unique challenges and offer support to one another as we all share a similar journey.

This retreat offered a valuable networking opportunity, many attendees had never met anyone else with their condition, some finding out they lived in neighbouring suburbs. We had members attend with PKU, HCU and MMA. Unsure of what to expect it was wonderful to see at the conclusion of the retreat, the apprehension and uncertainty being left behind, replaced with new found knowledge, friendships and connections to a wider supportive community.

**Retreat Summary** - MDDA President, Monique Cooper and Vice President, Louise Healy opened the retreat and gave an overview of MDDA current programs and initiatives.

One of the most popular presentations at our retreats is given by our own Louise Healy. Louise spoke about how we can create a healthy mindset & build resilience for ourselves and our families. How we can learn from our experiences and see them as opportunities to make better choices next time.

Throughout the retreat, attendees had the opportunity to attend various presentations and given opportunity to discuss topics, ideas and concerns.

A/Prof Damon Bell spoke about a variety of issues impacting older persons, presenting - Health considerations for an ageing population.

Kath Harrigan (Dietitian, Perth Children's Hospital) presented - What's in my formula & Transitional milestone considerations for parents of IEM children.

Catherine Manolikos (Dietitian, Royal Perth Hospital) presented - Weight Control & What's in my formula & What's on your plate?

Damon, Kath & Catherine made themselves available to us for the day and we are grateful to them for their time, sharing their knowledge and supporting our program.

Further topics and presentation were held regarding; Updates on Advocacy for sapropterin, other clinical trials, research & development, Q&A panel open forum, formula tasting for both adults and children, facilitated discussion forums on 'Transitioning for a better future', IEM Tweens/Teens- transitional considerations, tips & tricks, Goal setting for adults, teens & kids. MDDA presented on the soon to be released dietary management app and wellbeing program "My Low Pro PAL". We heard from Bianca Albanese on her - Personal Empowerment & clinical trial journey. An interactive low protein cooking activity was facilitated by local members Taylah Shier & Julie Nolan showcasing their culinary skills and favourite recipes. We think the sales of Jack Fruit has skyrocketed in Perth!

**Kids Club Program** - We had over 30 kids joining in our kids program and they had a blast! They enjoyed many activities including mini golf, tennis, life size games, cupcake decorating, pizza making, low pro cooking, movie watching and hours of fun out in the sunshine enjoying the resort playground and pool. Our IEM tweens also got to spend some valuable one on one time with our teens mentor Bianca Albanese sharing some great advice and stories about growing up with PKU.

**Weekend Menu Options** - It was only with the support of many hands from the MDDA team and local members that saw our low protein menu options be such a hit. There was a great variety and new food options for people to try. The build your own pizza night on Saturday proved to be a favourite with all ages.

In closing, on Sunday afternoon there was an opportunity for attendees to reflect on the weekend with many expressing their heartfelt appreciation and gratitude to the MDDA and retreat organisers. We thank all those who participated and opened themselves to make the most of their retreat experience.



# My MDDA Retreat Experience



Hi, my name is Taylah Shier and I'm an eighteen-year-old PKUer from Western Australia.

I was fortunate enough to be able to attend this year's WA MDDA retreat which proved to be yet another amazing retreat full of opportunities, experiences and new connections with other people living with a protein IEM.

One of the stand out things for me at all retreats has been the cooking inspiration and motivation I get from attending these events, but for me this year has been a stand out. From learning how to cook and incorporate jackfruit into meals to including low protein products that I had never tried before it was truly special. I believe everyone took home something new from the demonstrations and food available over the weekend.

Listening to the guest speakers was a fantastic way to get updated on the progress being made for PKUers and other IEMS. Being able to have that opportunity to ask all the questions you may have and getting instant, informative answers will always be one of the most attractive aspects of attending these events. One of the stand out speakers for me was Louise Healy and the idea that perspective and mindset play an important role for people living with an IEM and the people supporting them.

I left the retreat feeling refreshed, motivated and reconnected. Not only are the retreats a great family getaway but they allow you to meet other people who can relate to your situation and you can create lifelong friends.

For anyone who is yet to attend a retreat I highly recommend doing so whether you have an IEM, are a parent/caregiver of someone with an IEM or a family member looking to learn more, there simply is something that everyone can gain from these events. They play an important role for many in refocusing them on working towards compliance with their diet and other personal goals surrounding their IEM. You truly never forget the memories, tips, advice and opportunities that you get from going to these retreats!

## Thank You - Julie & Taylah

With a passion and enthusiasm for low protein cooking and making a difference for local WA members, Julie Nolan and Taylah Shier enthusiastically offered to take on the enormous role of catering for the WA Retreat low protein menu.

Julie, grandmother to Frankie (PKU) and Taylah (PKU Adult) spent many hours creating, organising and preparing a delicious low protein menu enjoyed by retreat attendees.

Their energy, enthusiasm and willingness to share their knowledge and skills made such a huge contribution to the weekend.

Julie's Not Dogs, Frankies Mac n Cheese, Ultimate Chilli, Jack Fruit, burgers and Taylah's Fried Rice, Mexican Rice, Stir Fry and Pudding were delicious, varied, new and inspiring meals that can easily be added to your cook at home menu. These delicious recipes have been added to our recipe tab on our website.

Thank you to Shelly, Brian & Nicky who assisted throughout the weekend, we are grateful to you all for pitching in and your willingness to help us to provide an educational and inclusive weekend.

We couldn't have done it without you!

The MDDA thank the Western Australian metabolic clinics at the Perth Children's and the Royal Perth Hospitals for their support of this year's retreat, and also our many sponsors, in kind partners, speakers and volunteers that all played a key role over the weekend.





# WA Retreat Feedback

Thinking about coming to our next retreat?  
Here are some reasons from our WA members as to why you should consider it.....

It is so important for my PKUer to be part of this community to experience being part of something where she is not only not alone but a majority. Thank you MDDA for your tireless efforts and all you do for our community.

*Nicky*

A marvelous opportunity for connection, learning and rebuilding of resilience.

*Scott*

This was the very first retreat that I attended and I loved everything about it. My kids enjoyed and had a great time. It was a great opportunity to meet new people and was happy to find out they were living very close by. I would like to thank everyone who made this retreat possible.

*Fatima*

This retreat was amazing. To meet so many new friends & eat so much fantastic food was so good.

*Ellen*

It was awesome to network with families and adults at all stages of the journey.

*Brad*

Loved it. Wonderful for our grandchild to feel part of a community of people with the same daily issues

*Julie*

This is exactly what i needed to get me on the straight and narrow. It has been so beneficial to me to meet everybody and share our stories and struggles and I feel as if i have found a second family. xx

*Megan*



I always love the retreats. So much amazing food. So many people to meet and relate to who are going through the same issues. It is invaluable.

*Anna*

The retreat was a great way to connect with friends and make new ones I am excited to see what WA has to hold in the future.

*Andrew*







*Build your own pizza night and cupcake decorating were activities loved by all!*





# PKU Adult Member stories ....

**Name: Olivia Sanginiti**

**Age: 29**

**Occupation: Assistant Store Manager**

I am a PKU adult. I'm on 10g of protein I am currently trying to lower my levels as I want to be in better health and better mind. I'm currently working as an assistant store manager but I'm looking into going back to school to become a teacher's aide in special needs. I want to make sure that I am giving myself the best opportunities to do well and get through without problems. I've been on diet my whole life. I say on diet very loosely as my teens I was not eating things that were good for my body.

## **Describe growing up**

Growing up with PKU wasn't the greatest, but it wasn't really the worst.

I did unfortunately get bullied a lot through my school years from year 1 all the way to year 11. Fear of not understanding my condition was mostly why I was being bullied.

I was challenged by the some of the silly people in school around me, the over cautious family members who constantly try to tell me what's right for me when they really don't know. I rebelled very hard to my PKU because I just longed so much to be normal and not judged or teased or told what to do any more. But the things that I did love about growing up with PKU was when we had family events, my grandmothers would always make me special PKU food that all my cousins would be jealous about because mine would look and taste so good. For parties with my friends, my mum would always make me lots of yummy treats that I could have so I didn't feel left out. My mum always made me the best PKU birthday cakes and always made my lunches yum and special, and even now as an adult I could eat a loaf a day of PKU bread. My food was never boring and I loved going to restaurants and getting my chips and salad as a special treat.

## **Explaining PKU**

I usually explain to people that I have a metabolic condition that prevents me from digesting high amounts of protein and if I do eat it, it can turn toxic in my blood and give me brain damage.

## **Favourite thing to do**

I am super into dancing I dance once a week for a dance studio a hip-hop class. I also have started getting into cooking and baking more low protein foods and posting new recipes and things I have tried in restaurants on Instagram.

## **Describe a usual meal time.**

I am very bad at eating 3 times a day I never eat breakfast. I find it so much easier to pack my lunch for work as working in a shopping centre is hard to get any PKU friendly food as there is only a few food vendors and all are really not that good for me as its really only hot chips (my weakness). Dinner is usually small and mostly vegetables. I eat out a lot with my family and friends. I always check ahead to see what the menu has on it so I can either plan my food intake for the day or even know if this is a restaurant I can eat at. It is a lot easier than it was 10 years ago to request changes on food, so now I don't feel uncomfortable asking for things to be taken out or things to be added. A lot of places now have vegetarian and vegan options and that makes

me so happy!

## **What do you generally have for lunch/Dinner**

I usually have a bigger lunch then dinner. Lunch is usually some sort of fruit, carrot and celery, crackers and usually one packaged treat like a fruit bar or small pack of crisps.

Dinner is usually vegetables and some sort of carbs like PKU pasta or a PKU slice of bread.

## **What is your favourite food?**

Hot chips are my absolute favourite they are also my weakness! But now that I am finding new recipes, like how to make Pulled Jack fruit, I'm trying all sorts of fun new foods. I don't want to keep having the same foods over and over there are bigger and better options for me to have now.

## **Life Experience**

As per any normal person I have normal people problems. I was in a 7 year long relationship and it ended, in the same month I lost my job due to liquidation which caused me to spiral uncontrollably for a long time. I was on 3 month clinics with the hospitals my levels were about 1000 – 2000 because I would not eat at all or I would eat anything in site PKU or not . The feeling of numbness was addictive and I just didn't care about myself or my health. But with help from social workers and seeing my clinic a lot, it gave me the strength to get back on track and feel better. Still now am I slowly working on it, but with the help of my other PKU friend it's getting easier.

## **Favourite moments**

The one thing that I love about PKU and other IEMs is the people who have them and the parents of someone with them, they are always so lovely and friendly. PKU camp is where I met some of the best friends in my life and the MDDA retreats are so rewarding I always learn so much from going. I now enjoy that I keep meeting new people every time that I go. It's an escape from my problem with people who have the same problem, who really truly understand what I too am going through. One thing I wish that didn't happen is that I didn't lose touch with people in my state with PKU it would have helped when I was a teen. I now keep in touch with quite a few PKU pals and I go to them when I feel low and we try make each other feel better.

I now every day think that my PKU isn't and wasn't a bad thing because I like the feeling of being special. The advancements I've seen in the last 10 years of all the foods and formulas has me very excited that its only looking up from here.

PKU isn't something we need to fear it's a challenge yes but I am not letting it be an unwinnable battle. So I can't eat a lot meat, so I can't eat dairy, so I can't eat a lot of things but *this doesn't define me and this doesn't hold me back from my dreams.*  
*You can follow Olivia on Instagram - "Missollie14"*





**Name: Anna Hoar**

**Age: 36**

**Occupation: Visiting Teacher of the Deaf**

**Growing up with PKU:** I am the youngest of three children. My sister is 6 years older and my brother is 4 years older. Neither of them have PKU. My Mum was a midwife and had a basic knowledge of PKU, so when I was diagnosed, she wasn't hugely distressed. My Dad, however, had no idea, so he was quite worried.

When I was a child, everything was very strictly managed. My Mum was the main go-to for food and measuring/weighing, baking bread, cakes, making meals etc. I don't remember Dad being involved with food production much. Any time there was a school excursion or a camp, my Mum would come along as a parent helper, complete with a storage cube full of my food. She came with me on Year 7 camp. She seemed to have enough faith in me that by the time I went on a ski trip to New Zealand in Year 10, she didn't need to go. I took an extra suitcase for my food and Maxamum XP.

I remember one time in Year 7, Mum had been baking my bread with Metamucil as one of the ingredients to hold it all together. Bread fell apart quite often and was useless for sandwiches. The Metamucil helped bind it all together. This particular time, she couldn't get any regular Metamucil and ended up getting the orange flavour. Well guess who ended up with orange sandwiches in her lunch box that week!

In primary school I would always have a packet of crisps in my lunch box. My Mum baked heaps of yummy low protein cakes and things and my brother would get really jealous and want to eat my food. He also loved to remind me what I couldn't eat. My sister wasn't bothered by it.

I went to many of the activities run by the clinics... picnics, Christmas parties etc. I remember very clearly going to Princess Margaret Hospital for all my clinic appointments with the late Dr Desmond Gurry. One time I remember seeing a boy there with PKU who had just had his appointment and he was getting Burger Rings from the vending machine. I couldn't understand why he got to eat them but I didn't. This was in the days before nutrition labels.

When I got to 12 years old, Dr Gurry let me have 3 "diet free days" (DFDs) a year, as long as they were 3-4 months apart. Naturally, I chose Easter, my birthday and Christmas. I had a ball. The very first one was my end of Year 7 river cruise and I tasted so many things I had never eaten before. It was a whole new world. As I went through high school, I continued these DFDs and have probably tried 90-95% of foods available in a typical Australian diet.

When I became an adult, I recognised that my "day" was stretching out to 3 days. The day before I would say to myself "Oh it won't hurt to have this since I'm having a DFD tomorrow". The day after, I would say "Oh it won't hurt to have this since I had a DFD yesterday". I made the decision to only have a DFD for Christmas and have stuck to it ever since.

I want to be clear about this.... If you are a child/teen with PKU reading this. I do not recommend DFDs! I honestly think my life would be so much easier if I had never had them in the first place. Once you go there, it is incredibly hard to go back. Once you have tasted things, you miss them. Ignorance is bliss, please don't do it!

**What are the challenges you/family have faced?** When I think of my life now and how things were back then, I am amazed at how well my Mum did. They had no nutrition labels for food. They had a fraction of the low protein foods that are available to us these days. They had one or two recipe books with weird combinations of things to make equivalents e.g. I always had cream mixed with water to make "milk"

for things like cereal (of which I could only eat a tiny amount of the very sugary varieties). We lived in Karratha for half my childhood, 1200km away from our nearest capital (Perth) and would have to fly down for clinics every 6 months. I was the only person there with PKU. The formula had to be delivered there. The other half of my childhood we moved around a lot, including 18 months in Victoria. They had slightly different policies on how long to do the diet. Thankfully we moved back to Perth before I got to that age.

One thing I struggle with now as an adult is weight gain. I have really stacked it on since having kids and I can't seem to be able to lose it since my formula is so full of calories. As a Mum I don't have time to exercise or even cook proper meals for myself. It's so hard to stick to such a strict diet when you are feeding everyone else in your household. I often end up eating a potato and salad for dinner about half an hour after everyone else has finished. I often end up eating chips for lunch on my work days because I haven't had time to cook myself anything the night before. I'm getting better at that one, but it's hard, hard work.

**How do you go about educating friends and family? Work place?**

I just work it into the conversation casually, usually when eating lunch or discussing food. I'll say something like, "Oh I can't eat that". Then they say "why not?" and I launch into my explanation. Or they have seen me eating something "weird" and ask about it.

**How do you explain your PKU? Me:** I have a Metabolic Dietary Disorder called PKU. I can't eat anything high in protein. There's an amino acid called phenylalanine, which is toxic to the brain if you have too much. Your body can process it properly but mine can't, so it builds up. It's in pretty much everything. If I eat a low protein diet, I can avoid eating too much of it. **Them:** Oh, so how long have you known about that? **Me:** Since birth. They test babies for it when they're born. **Them:** Wow! I don't know how I could live without meat. What happens if you eat lots of protein? **Me:** If I had eaten whatever I wanted from birth, I would have severe brain damage by now and be institutionalised.

**Them:** (Various exclamations and declarations of how they couldn't manage etc.... then it dawns on them) But everyone needs protein! **Me:** (Launches into explanation of formula)

**What is your favourite thing to do?** I love reading books. I have a stack about 12 books high on my bedside table because unfortunately I don't get much time to do so these days. I'm also getting into 500-1000 piece jigsaw puzzles these days.

**Describe a usual meal time:** I try to cook something for the family that I can adapt for me. E.g. I make tacos and just put salad in mine, or stir fries with chicken for everyone else but not me. If it's a meat and 3 veg type meal I just leave the meat out. There's OFTEN potato involved. It's my staple (and probably my weight loss downfall). Sometimes I can't adapt though and that's the potato and salad nights.

When I go out to eat, I always look up the menu beforehand and make my choice about what to have. If it's a spur of the moment thing, I usually end up with chips and salad. I often eat more protein than I should e.g. bruschetta uses regular bread but try to make up for it during the rest of the day.



.....continued page 12



## ... member story continued

**How was your school and now how is your workplace in accommodating any special requests/requirements?** School pretty much left it up to Mum and allowed her to come along to everything. I went to 5 different primary schools and they were all similar. When I was in Year 1, my teacher made me sit in the corner and eat my lunch until it was finished because Mum had told her she had counted all the food. I ended up missing playtime and half of the next class activity. Mum talked to the teacher again and they worked out how to count what I had managed to eat instead of the whole lot. The poor teacher was doing her best to make sure I was alright.

**What do you generally have for lunch/Dinner?** I'm really into Bruschetta for lunch at the moment because it's quick, easy and very yummy. Otherwise crackers with butter and vegemite and fruit, soup or other leftovers if I have them. Chips if I'm out or if I'm wanting to be healthy I'll have salad too or maybe vegetarian sushi or rice paper rolls if they're available. Dinner varies a lot but most of the time it's something I've adapted (see above) or something from one of my low protein recipe books if I am feeling creative. **My favourite food?** I have PKU. Do you need to ask? POTATOES!!

**Advise for travel /holidays etc?** Get a letter from your doctor regarding your formula. And even then, still expect to be asked to drink a bit of it at the airport boarding gate (past experience) to prove it's

nothing suss. Maybe if you have contact with PKU friends in the place you are going, they could pre-order you some formula so you don't have to drag it around with you? Raid the local grocery stores for products that are low in protein e.g. konjac noodles, certain brands of gluten free bread, jackfruit etc. ALWAYS stay somewhere self-catered/with a kitchen/ette.

**What would you like everyone to know about growing up with PKU?** Growing up, although hard sometimes, is only the beginning. It's the easy part. You have your parents mostly in charge and what they say goes. You don't have to plan, cook and prepare your own food. You are taken care of. When you become an adult, that's when the challenge begins. I am so so so thankful to my parents for being so strict at keeping me on diet and Mum for teaching me how to manage my diet myself from my tween years.

But being an adult is not all doom and gloom. It's just more responsibility. I don't want to scare any kids off growing up. Being an adult is also great fun and it's fantastic to have the freedom to meet up with many other adults with PKU. It's vital. Get connected and supported. Teenage me didn't feel she needed a "support group". Adult me loves it.

**Any tips in incorporating living with an IEM into their everyday life and ensuring it is as easy as possible?** Ha! Wish I knew.

# FUNDRAISING



QLD

Thank you to Stef Hutchen who set herself a 6 week weight loss challenge - raising money and awareness for MDDA.

Thanks to Nicholla Kinscher for organising a Tupperware fundraiser with family and friends with proceeds being donated to the MDDA.

NSW

SA

A recently joined member - Carmela - had the wonderful idea of a Celebration Donation for her daughters Christening. Thanks to this idea

templates will soon be available on our website for others to use for different events in lieu of gifts. Thank you for your generous donation which will be used towards our new PeekabU bags.



SAVE THE DATE

**WA Quiz night**  
26 October 2019

Manning Community Hall, WA

Join us for a night of competitive fun & games!  
Book a table with your family & friends. Details coming soon!

WA

Fun run

VIC

**Congratulations and thank you to Ben Van Tiggelen**, Head Chef from the Grand Hotel Warrandyte for running for PKU. Earlier this year Ben competed in a half marathon at Warburton in the Yarra Valley and raised \$480. Recently on the 19th of May he took off again running The Great Ocean Road marathon finishing in an amazing 3 hours & 42 minutes! Thank you to everyone, who has supported Ben.



Tracey Scott is once again selling Entertainment Books to raise money for the MDDA to go towards research. Books are still only \$70 and can be

bought for ANY state in Australia. If you buy these each year, please consider purchasing one for a cause close to all of us.

Its as simple as when you order your book membership go to; [entertainmentbook.com.au/member/confirm-fundriaser](http://entertainmentbook.com.au/member/confirm-fundriaser) and type in **Tracey Scott**.



# PKUNSW Updates



## PKUNSW Association Research Symposium

On Friday 3rd May the PKUNSW Association and PKU Research Group at Children's Hospital Westmead held our first PKU Research Symposium at the Novotel Darling Harbour. 100 people gathered to hear the latest research happening in Australia, which is largely funded by the PKU Association of NSW. Attendees included metabolic specialists, dietitians, nurses, people with PKU and their families.

We were honoured to have Professor Maria Gizewska, Vice Chair of the Scientific Committee of the ESPKU, give the plenary address about her maternal PKU research.

Prof Gizewska is a paediatrician who has been treating patients with PKU in Poland for many years. The audience were fortunate to hear her commentary on the way PKU is managed in Europe, and we reflected on the good fortune of

PKU having been discovered and treated by the three 'PKU Pioneers' – Ivor Asbjorn Folling, who discovered PKU; Horst Bickel, who developed the low protein diet; and Robert Guthrie who introduced newborn screening.

The day highlighted the amazing research happening in Australia covering a wide range of topics from quality of life, psychiatric aspects of PKU, MRI brain scan research and new treatments via probiotic and personalised therapy for PKU.

Conn Nicomede gave an excellent insight into his experience as a young person growing up with PKU.

The PKU Association of NSW and PKU Research Group Children's Hospital Westmead are thankful to Biomarin for supporting this important event.



## Cortex Health - Helping you find your balance

How often do we find ourselves juggling between our day to day commitments, whether it's kids, family, work, school, sport, illness and anything else that decides to creep into our day?

Thinking of what low protein meals to eat, how to prepare it can often pose a challenge. Adding variety and keeping everything else in our life balanced, requires us to be in the right frame of mind.

At Cortex Health we acknowledge the demands and commitments of life and are always here to help.

Cortex Health have developed (and are constantly developing) low protein recipes that are easy to prepare, mouth-watering and are suitable for the whole family to enjoy. Our recent roadshow around Australia was a true testament of this.

- Thank you to all who attended.

At the end of the day, supporting you holistically to manage your IEM on a day to day basis, ensures that we are helping you to "find your balance".



## Recipes

PREP/COOK 5 MINS/25 MINS  
SERVINGS 6  
SERVING SIZE 63 G  
CALORIES 71 KCAL  
PROTEIN 1.3 G  
CARBS 8 G  
SUGAR 4 G  
SODIUM 203 MG

### PAN-ASIAN STICKY MUSHROOMS

1 ½ Tbsp (21 g) olive oil  
297 g shiitake mushrooms, sliced  
2 small (6 g) garlic cloves, minced  
½ Tbsp (8 g) fresh ginger, minced  
½ Tbsp (8 g) lemon grass, minced  
½ tsp (3 g) salt  
1 ½ Tbsp (19 g) brown sugar  
½ tsp (5 g) toasted sesame oil  
2 scallions (28 g), sliced very thin on the bias

Heat 1 tablespoon of the olive oil in a 12" skillet over medium high heat and add the mushrooms. Cook, stirring occasionally, until the mushrooms release their liquid, about 5 minutes. Increase heat to high and cook, stirring occasionally, until the liquid has evaporated, about 8 minutes longer. Add the remaining olive oil, reduce heat to medium and cook until mushrooms are dark brown, about 8 more minutes. Add garlic and cook, stirring constantly, until it is fragrant. Add the ginger, lemon grass, salt, brown sugar and sesame oil. Cook another two minutes or so until brown sugar has caramelized. Remove from heat and stir in the scallions. Serve over rice, see our Perfect Sushi Rice recipe.



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

1800 367 758



Cortex Health Pty Ltd



CortexHealth\_Aus

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Please enjoy this recent mouth-watering recipe created for our IEM community at the recent roadshow cooking workshop





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



## Tasty Vegetable Soup

### Ingredients:

1 tablespoon olive oil  
1 tablespoon butter  
1 onion chopped  
1 clove garlic crushed  
1 carrot, peeled and diced  
1 sweet potato, peeled and diced  
1 zucchini diced  
2/3 cup frozen beans  
4 cups vegetable stock  
Salt and pepper

### Method:

In a large saucepan heat oil and butter, add onion and garlic and cook until

soft.

Add carrot and sweet potato, cook 3 to 4 minutes.

Add zucchini and beans, cook for 3 to 4 minutes

Add stock and simmer for 40 minutes or until vegetables are tender.

Season with salt and pepper to taste.



## Potato Rosti

### Ingredients:

2 large Desiree potatoes  
3 tablespoons low protein flour  
1/4 teaspoon baking powder  
1 small onion diced  
1 medium capsicum  
Dill sprigs (optional)

### Method:

Grate potato and squeeze out excess water and discard. Set potato aside.

Fry the onion in a small amount of oil until soft.

Remove from pan.

Dice capsicum. Then mix all ingredients together.

Fry dessert spoonfuls of the mixture in oil until cooked through.

Drain on kitchen paper towel and serve immediately.

Top with your favourite condiment or low protein dip.

## Pumpkin Scones

### Ingredients:

60g Nuttelex  
1/4 cup caster sugar  
1/2 cup cooked pumpkin, mashed  
1 teaspoon egg replacer mixed with 2 tablespoons water  
2 1/2 cups low protein flour  
3 teaspoons baking powder  
1/2 teaspoon salt  
3 tablespoons rice milk

### Method:

Preheat oven to 210°C.

Cream Nuttelex and sugar until light and fluffy.

Stir in pumpkin and egg replacer mixture, mixing well.

Add the dry ingredients, mixing thoroughly.

Add in the rice milk and mix to form a soft dough.

Turn out onto a floured board and knead lightly.

Roll out 2cm thick and cut into round shapes using a 5cm scone cutter.

Brush with a little extra rice milk and bake for 15 minutes.

Enjoy!





# Product update



**Eco Organics:  
Purple sweet  
potato noodle**  
Protein per 100g: 0.4g  
Serving size: 100g  
Available from:  
Asian Grocers



**Green Vie:  
Haloumi-style block**  
Protein per 100g: 1.2g  
Protein per serve: 0.3g  
Serving size: 25g  
Available from:  
Vegan Perfection



**Well & Good:  
Slider buns**  
Protein per 100g: 0.7g  
Protein per serve: 0.2g  
Serving size: 35g  
Available from: Coles, IGA &  
Health food store



**Streets:  
Vegan Cornetto**  
Protein per 100g: 0.4g  
Protein per serve: 1.0g  
Serving size: 250ml  
Available from:  
Coles & Woolworths



**Hanabi:  
Seaweed Spring  
Roll**  
Protein per 100g: 1.9g  
Protein per serve: 0.5g  
Serving size: 25g  
Available from:  
Coles & Woolworths



**Coles:  
Gluten free  
lamington fingers**  
Protein per 100g: 4g  
Protein per serve: <1g  
Serving size: 22.5g  
Available from:  
Coles



**Solar fruit:  
Fruit pieces apricot**  
Protein per 100g: 2.9g  
Protein per serve: 0.3g  
Serving size: 10g  
Available online &  
selected IGA



**Keep it cleaner:  
Konjac rice**  
Protein per 100g: 0g  
Protein per serve: 0g  
Serving size: 125g  
Available from: Coles



**Coles:  
Coconut Mango  
Pops**  
Protein per 100g: <1g  
Protein per serve: <1g  
Serving size: 54g  
Available from: Coles

## Special Medical Foods Suppliers



**Cortex Health / Cambrooke**  
[www.cortexhealth.com.au/products/low-protein-foods](http://www.cortexhealth.com.au/products/low-protein-foods)  
Ph: 1800 367 758



**Nutricia / PKU Connect /  
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**Platypus Foods**  
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Ph: (03) 5229 8222

*Always check the nutritional panel on products*



# 2019 national family retreat

TASMANIA ■ 4-6 OCTOBER 2019 ■ TAMAR VALLEY RESORT, GRINDELWALD



Set on over 150 magnificent acres amid numerous spectacular lakes with breathtaking views. Tamar Valley Resort is located 30 minutes drive north of Launceston airport.

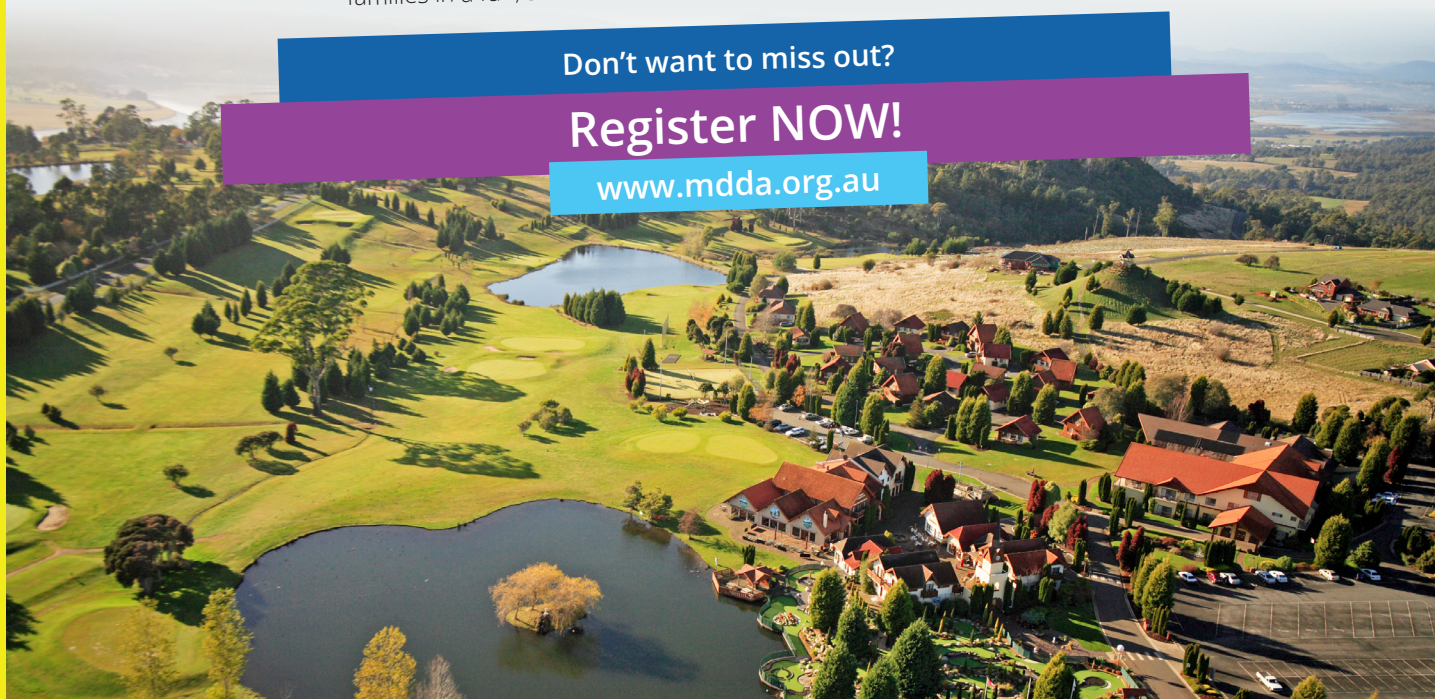
Meet other members of the MDDA community and their families in a fun, social environment.

**Educational sessions and workshops**  
**Health Professional presentations**  
**Team building exercises**  
**Kids, Teen club & more!**

Don't want to miss out?

**Register NOW!**

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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)

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