

Metabolic Dietary Disorders Association

# MDDA Matters

Issue #65 - December 2017



## "Choose your own adventure"

**Everything in life is a choice...the key is making sure your choices count and are right for you.**

You can choose to be healthy, choose to be diligent with your IEM management, choose to think positive and foster independence and resilience (in your kids and in yourselves as an adult and/or parent) or you can choose to let negative thoughts get in your way.

Choose your own adventure was the theme at this year's retreat. It is about encouraging us to accept and face challenges with positivity and gratitude and not be distracted with unhelpful and limiting thoughts.

Choosing to accept challenge and striving to reach our full potential was the essence of this year's program and can be applied to our day to day life. Discovering that failure can be empowering when given meaning and purpose. Read more from the retreat and meet our retreat speakers who helped make it such a successful event.

Also in this edition we hear about the ESPKU conference. Our member stories are from a MSUD and PKU member, mother and grandmother, and of course you will find recipes and a product guide.

Take into the festive season this...life is an adventure that doesn't have to be perfected, just explored!

We wish you a safe and happy holiday season – Merry Christmas and Happy New Year! We look forward to sharing 2018 with you all.

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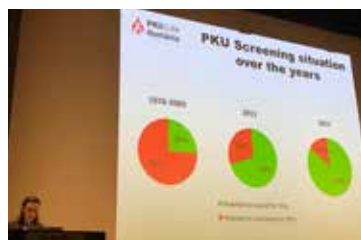
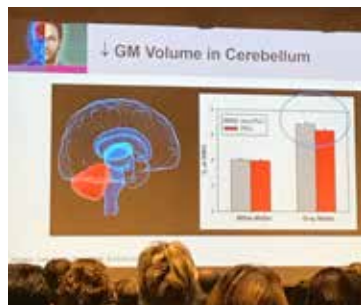


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# ESPKU 2017



When Evie was first diagnosed in 2007 it was hard to imagine coping with PKU much less where it would take our lives. Over the past 5 years being involved with MDDA, presenting at retreats on wellness and working on advocacy campaigns and meeting so many wonderful people in our fantastic IEM community, PKU has given us unimagined opportunities along with the challenges it brings. This year it gave me the wonderful opportunity to present at the ESPKU conference in beautiful Norway.

What an amazing experience. Norway itself is stunningly beautiful. While the conference offered the opportunity for me to learn so much and make many new connections with our international community. Attending ESPKU helped me in so many positive ways including:

- Feeling pride in the MDDA. I got heaps of great feedback about some of the things we are working on and I wanted to acknowledge Monique, Susi, Richard, Katy and Paige who had such great vision about how MDDA could build on strong foundation to bring the community together and offer more support services.
- Feeling lucky that Evie was born in Australia and as such she has regular and predictable access to treatment and expert specialist care. In some European countries access to clinical care and formula let alone low protein food is quite difficult and often unpredictable. It must be very stressful for people with IEMs and their families to live in these countries.
- Feeling hopeful about the amount of research into new and future treatments. Some are in final stages of trials and some in early stages of development but it seems to be there is quite a big interest in developing treatments beyond dietary management. I hope this means that in years to come a range of treatments will become available for all IEM's to help manage the diet and eventually hopefully there will be a cure.
- Feeling excited as a number of young people gave great presentations about the creative ways they had overcome barriers to travel for people with PKU and allied disorders. These young people are making paths and showing the way for the next generation of people with IEMs and really proving that having an IEM does not stop you from doing anything.
- Feeling privileged to be involved in further discussions about the proposed international PKU organisation. It is a great opportunity to really make a difference. To people with PKU all over the world. There will be more say about this over the coming 6 months.

As always it is great to spend time and share experiences with people who really "get" it and to see how different people and cultures adapt to the low protein diet and other challenges of living with an IEM. I thank Vitaflor for their support.

As a follow up to the conference I will host a virtual round table summarising some of the emerging treatment research and answering what questions I can about them. I will share what I know about the pathway to having pharmacological therapies available in Australia and some of the work Rare Voices Australia are doing to try and improve that pathway.

– Louise Healy



# End of Year Celebrations

## Queensland

**One of my favourite things about the Queensland Christmas party are the traditions we follow each year.**

This is the 8th year our family has attended the party and each year we go full of excitement ready for the things we know will happen – the lolly hunt, the water balloon fight and a visit from the Man in Red.

This year was no exception and it is a special way to start the Christmas season. It was great to see that familiar faces as well as so many new faces including some new members of the Queensland IEM family. We all bring a plate of low protein food and get heaps of great ideas for Christmas treats.

Thanks to everyone who came and also all the people who helped out with invitations, set up, clean up, lolly hunt, arranging for Santa to visit and water balloon filling. See you all next year!  
– Louise Healy



## South Australia

**Pancakes in the park was one of the reasons South Australian members got together on December the 3rd.**

Fun was had by all, no one left with an empty stomach. A big thank you to Sasha and Steve for organising. Members look out for another get together end of March/April.



## Western Australia

**The end of year celebration was held at Hyde Park, in Perth.**

It was wonderful to have a new family come along this year who shared some adapted low protein Turkish recipes and another family share some traditional Russian dishes. We would love to see more people at these events. If you are a WA member get involved and let us know what you would like to do. These get togethers are impossible without our MDDA state helpers, thank you Fiona and Scott Greer.



## Victoria

**Sunday the 26th November saw the Victorian members get together at The Grand Hotel Warrandyte to catch up and celebrate the year.**

The members and families enjoyed a low protein and regular gourmet buffet, sampling some of the new items on the daily Grand menu. They were delicious. It was wonderful to have some new families that attended the retreat this year come along and join in the festivities. Thank you once again to The Grand for providing the venue and fantastic food and a special thank you to Santa and his helper elf who provided some excitement for the kids.





## End of Year Celebrations (continued)

### Tasmania

**Risdon Brook Dam, Hobart, was the place where MDDA Tasmanian members met to celebrate the end of year.**

It was wonderful to have five PKU families attend the picnic on December 10 this year. Thank you to Pauline Blyth and Stacey Farrell for getting some of our Tassie members together. A visit by Elmo and the Cookie Monster provided some fun entertainment for the children, while the weather and venue were perfect for all to sit back enjoy and catch up with friends.



## Member correspondence ....

Dear Monique,

You may recall I was involved in the early work of establishing support groups for IEM sufferers. I was thus interested to receive and read the latest MDDA newsletter today and wish to congratulate you and your team for your wonderful input on behalf of those affected by an Inborn error of metabolism.

I was particularly interested to read the section on PKU worldwide & its implications of a united effort to improve help & advice internationally. It was really great to hear of the growth in activities & outreach of the support group here in Australia & indeed in many other countries now. WELL DONE.

Yours

Dorothy Francis



## Fundraising Updates

### Jamerry Nails fundraiser

Thank you to Nicholla Kinscher who recently held a fundraising nails nights. A fun way to help the MDDA while getting a little pampering in at the same time!



### Icy Pole Fundraiser & Dress Blue Day

**Recently Kaitlyn Greer aged 9 from Forest Crescent Primary organised a fundraising day for the MDDA. What a fantastic effort Kaitlyn, a big thank you from the MDDA. Here is Kaitlyn's report of the day....**

On Wednesday 25th October, I had a Icy Pole fundraiser and a "dress blue day" at our school (Forest Crescent Primary) to raise money for the MDDA. I did this because I care for the MDDA and love how it helps many people. I would like to thank my mum and everyone who helped me sell the icy poles, and everyone who bought one. I also want to thank the people in my class and especially my best friends

Charlotte Hall and Abbie Isles for all the support they gave me with my fundraiser. I am so happy and proud I got to raise \$229 from the Icy Poles (that's a lot of Icy Poles!) and \$441 from the gold coin donation dress blue day. We had such a fantastic turnout, even though the day was cold! We were so busy for about 40 minutes after school finished. It was total chaos. We raised a total of \$670. I can't believe I raised that much money for the MDDA and it was a fun and exciting experience.



## Congratulations!

### New Arrival – Baby Girl

**Anthea Margaret Kinscher**

born on 8/11/2017 at 12:32pm,  
weighing 2.86kgs



Congratulations to Nicholla, Joe & Max.  
Glad to hear Max is loving being a big brother!

(Extract from)

# Empowering Women in Engineering and Health – Meet Bianca Albanese

Oct 25, 2017

Original article published on the Let's Connect Women website by Jeromine Alpe | Oct 24, 2017 | Inspiration | Visit [www.mdda.org.au](http://www.mdda.org.au), news section to see the whole article

**LCW spoke to Bianca Albanese, Biomedical Engineer and PKU Advocate about what it means to be a woman in engineering and living with PKU.**

**LCW: Bianca, you're a Biomedical Engineer working for NeuRA – tell us what an average day looks like?**

**B:** I am involved in quite a bit of report and paper writing, ethics applications, statistical analysis and general meetings, but my typical day is quite exciting. It could involve heading to vehicle auctions to hunt for study vehicles and more recently, I have been involved in developing and designing in-built video monitoring equipment to monitor driver and child passenger behaviour. The most exciting part though, has to be my previous work conducting crash tests (pics). We also now have our own in-house crash sled where I am 1 of 3 researchers at NeuRA qualified to operate it. As part of our motorcycle work, I have run mechanical performance tests on motorcycle protective equipment, along with home visits to inspect motorcycle crash scenes and interview crashed motorcycle riders.

**LCW: Bianca, you've been living with PKU, a rare genetic condition since birth – can you tell us a bit more about that and how it's affected you?**

**B:** Phenylketonuria (PKU for short) is a rare (1 in 15,000 rare!) metabolic condition which means my body can't break down one amino acid, phenylalanine (Phe), found in protein. Everyone (yes, you included!) in Australia and most developed countries were screened for this condition since 1973 via a blood spot at birth. If left untreated, high levels of Phe in the blood become toxic to the body, causing severe mental retardation. Treatment has come a long way since 1973. It was once thought a special diet only had to be followed until the brain 'stopped growing' at 10. As years went on, cognitive deficits, declines in IQ, and many other problems were seen in these patients. Today, we live by the mantra 'Diet for life'.



Everyone's tolerance is different, but I am limited to only 6 grams of protein from food a day. That's equivalent to one egg, a tablespoon of peanut butter or less than a glass of milk. Shops and supermarkets don't really offer much by way of low protein foods, apart from fruits and vegetables. Thankfully there is a limited range of specially made (but expensive) low protein foods (pasta and flour) that we can source from overseas. Essential vitamins, minerals and other amino acids which we miss out of due to our restricted diet is supplemented by formula.

I must admit it was tough growing up in an Italian family, surrounded by amazing food that I unfortunately couldn't eat. Despite that, I didn't see my condition as a barrier to my dreams; rather just something I had to accept. Being diligent with my protein count, blood tests and attending specialist appointments all became routine and are now second-nature to me.

My path venturing into engineering, research and science has really fostered my interest in the treatment and management of PKU. There is still a lot that is unknown about living with PKU. It is a relatively young condition; at 27 I am within the first generation of 'diet for life' patients. A lot of patients, despite being on diet, still experience symptoms associated with PKU.

I am currently an executive member of the Metabolic Dietary Disorders Association (MDDA) which is an organisation that represents a variety of disorders affected by Inborn Errors of Metabolism (IEM).

They aim to support, educate and advocate for those living with an IEM. The MDDA holds retreats for affected families to bond, share experiences and educate about developments in research and management. They have successfully lobbied the Government regarding IEM management, fundraised to enable research, created a fantastic Australian IEM community and just recently participated in the formation of the first global association for PKU.

My drive for development and to create change led me to recently join the Metabolic Dietary Disorders Association (MDDA) as an executive member. The MDDA Despite the challenges I face day-to-day in living with this condition, I believe it has shaped me positively and provided me with a unique skillset and mind frame that fuels my drive to achieve and excel. Whether it be a medical condition or being a female in engineering, nothing should be viewed as a barrier to living your best life.

**LCW: You're a fierce advocate for PKU and promote both those with PKU and without to live a happy and balanced life – what are some of the ways you make sure you live a happy and balanced life?**

**B:** The most obvious for me is to eat right. I love fresh fruit and vegetables and love trying new recipes (though not always successfully) and new foods. I find being active a great stress relief. I play hockey competitively, I also play in social netball comps with my work friends and I love hiking on the weekends. I strongly believe in doing what you love and to build on your skills and strengths. Get involved in things! Follow your passions be it work, community or hobbies! I love attending MDDA retreats. They have fostered such a sense of community and support which brings nothing but positivity to our lives. I also love travelling, even if this is a challenge with an IEM. The sights you see and the experiences you gain make the extra effort worth it.





October 2017

# VIC FAMILY RETREAT

**Our largest ever family retreat was held this year in Victoria at Country Place, Conference Centre, Kalorama on the 6-8th October. We had over 130 attendees including new members and families to those who have now become regular faces at our events! Our retreats are all inclusive giving everyone the opportunity to connect, educate and share their own personal stories. This year we had adults, teens, children and families attend with - PKU, MMA, MSUD, Tyrosinaemia and GA1.**

Friday night was "Party Night" a fun, relaxed atmosphere with fairy floss & slushie machines, a photo booth, band and dancing. [Thanks to John & Darren from Vandecoy for providing the great live music!](#) It was terrific to see new connections being made and old friends catching up.

Saturday there was no sleeping in with the program starting at 8:30am. Kids were checked into kids club, teens were off on the ropes course and the adults settled in for an educational morning program. This year we were fortunate to have Metabolic Physicians, Dietitians, Therapists and Nurses provide informative sessions. You can read their profile and a brief outlines of their presentation on the following pages.

After a delicious lunch the afternoon included formula overview and display, also a hands on bloodspot testing and monitoring lessons for those brave enough to participate. Laser tag in the afternoon kept the teenagers and a few adults busy while others simply enjoyed exploring the grounds, shooting some hoops and kicking the soccer ball

around providing some down time and a chance to recharge batteries. Martin Heppel from the Resilience Project ran very popular sessions for adults, teens and children. Martin presented thought-provoking sessions pulling on his extensive experiences living overseas, challenging us all to choose adventure, happiness and fulfilling life experiences.

This year we went with a new format and kept all our cooking workshops and demonstrations to the Sunday. Participants were divided up with one group participating in an interactive low protein cooking challenge and others taste sampling the Low Pro interactive Cooking demonstrations from Cortex Health, Nutricia and Vitaflo. The Chef and Manager from the Grand Hotel Warrandyte certainly received an appreciative applause from the crowd for the amazing effort they have put in to creating a permanent low protein menu for their establishment. Attendees were most excited to actually attempt making some of the delicious recipes themselves.

Thank you to our wonderful sponsors, the retreat is made possible by their generosity both financially and by way of product support. [A very special thank you to Menarini, Vitaflo, Nutricia, Orpharma and Cortex Health.](#) Their ongoing support enables us to continue to provide these events. Thank you to all our product sponsors for your generous donations. The delegate bags were filled to the brim with quality products, tasty treats and lots of new goodies. The 'showbag' is a favourite take away from the retreat. Thank you to the Australian Government for providing funding under the National Disability

Conference Initiative for members and carers to attend.

These weekends are jammed packed with information, education and new experiences. A lot of first time attendees are unsure of what to expect - it can be daunting and might put you out of your comfort zone, but remember most of us have felt that too and it is with support, education and friendship that we get through. You will be guaranteed to go home with one thing new you have learnt, new friends and an understanding supportive network to help you and your family.

Our executive committee are truly amazing and make these retreats what they are. Their willingness to go above and beyond to ensure every retreat participant gains as much value as possible in attending our retreats. We can never thank them enough. They manage to prioritise and schedule MDDA into their busy lives, their dedication, collaboration, strength knowledge and direction enables the MDDA retreats to be the success they are.

[Thank you also to all those who volunteered and helped over the weekend.](#) MDDA relies on the generosity of our community to support our vital work. The skills, knowledge and enthusiasm that our volunteers bring to our organisation allows us to continue to run these successful events.

MDDA is about educating and offering choice and this was a great chance for IEM patients to see and hear what options and new products are available to them. We look forward to seeing you at our next retreat in 2018, all are welcome!



Innovation in Nutrition







*This was our first retreat attended as a family. It was very informative and the conferences were well thought out. Food (both low pro and standard) were great! Cooking workshop was fun.*



*MDDA retreat is the one event I look forward to every year. A combination of quality information presented in easy to understand terms, fantastic low protein food and the ability to connect with people with other IEMs makes the whole weekend great.*



*The retreat was amazing as always.. I love having the opportunity to learn from the Health professionals and catch up with my PKU friends over a relaxed weekend. Martin Heppell was my favourite session – FANTASTIC!!*



*I was super happy to be on this retreat this year, catching up with some old friends and making some new ones. Giving my life experience and hearing about people who have a different IEM was great. Learnt a lot, ate a lot and had a lot of fun.. Cant wait for next year!*



*Thank you for a wonderful weekend at the retreat.. WE feel so lucky to be part of the MDDA. We learnt so much and loved connecting with families who have children with some of the rarer IEM's as well as those with PKU and their families. It was a terrific experience. Thanks so much.*



YOUR ONE STOP LOW PROTEIN FOOD SHOP!



# Victorian Retreat Speakers

## Marta Rachman

My name is Marta Ines Rachman, I am Argentinean and I have lived in São Paulo, Brazil since 1976. I am divorced, fifty-three years old and I have a 21-year-old daughter currently completing a Cinema degree at University in Brazil.

I have got my bachelor degree in Business Administration at "Pontificia Universidade Catolica de São Paulo". I worked in the HR areas of multinationals for over 20 years and reached high levels in all companies I worked for. Currently working and as an HR Consultant and Independent Coaching.

I have been working at a NGO, SAFE Brasil, as a volunteer for the past 10 years, which focus on the support of PKU families. I got involved in this area due to my daughter's condition and I ended up becoming a reference.

### Session Outline

#### Meanwhile in Brazil

Marta provided a revealing insight into what it is like living with PKU in Brazil, and what her organisation SAFE Brasil does.



## Dr Avihu Boneh

Avihu graduated from the Hadassah Hebrew University Medical School in Jerusalem, Israel. His MD thesis focused on Glycogen Synthetase activity in Diabetes Mellitus. He trained in Paediatrics at Hadassah University Hospital, Jerusalem. He then did a fellowship in Biochemical Genetics at Montreal Children's Hospital and graduated from McGill University with a PhD in Experimental Medicine (Biochemical Genetics). His PhD thesis focused on signal transduction mechanisms in X-Linked Hypophosphataemia. Between 1989 and 1997 he worked as a consultant in Paediatrics with a special interest in inborn errors of metabolism at Hadassah Mt Scopus hospital, Jerusalem. In 1997, he took the position of Head of Metabolic Genetics at VCGS, MCRI and the Royal Children's Hospital in Melbourne, which is now the Department of Metabolic Medicine at the Royal Children's Hospital. His research interests include: 1) The natural history of inborn errors of metabolism; 2) Safe protein and calorie intake in diets for patients with inborn errors of metabolism; 3) The role of perturbation of Signal Transduction in the pathogenesis of Inborn Errors of Metabolism.

### Session Outline

#### Guidelines: All the things you didn't want to know

Avihu presented a general overview of the role guidelines play in the management of IEM's



## Clare Kreis

Clare has been working as an accredited practicing dietitian for over 10 years. She is currently working as the state-wide adult metabolic dietitian for the Queensland Lifespan Metabolic Medicine Service at Mater Hospital in Brisbane. She has been working with people with metabolic conditions since 2014 and has a strong passion for encouraging every individual to enjoy their food, create variety and focus on fresh fruits and vegetables. Clare has been recently nominated as the dietitian rep for the ASIEM group, and is happy to be here today to present of balanced eating with metabolic conditions.

### Session Outline

#### Making your protein choices count. What's on your plate?

Clare discussed the importance of nutritional content and portion control when managing a low protein diet and tips and tricks to assist with making healthy eating choices.



## Maureen Evans

Maureen is a senior dietitian at the Royal Children's Hospital where she has worked for the last 24 years. She has specialised in the area of inborn errors of metabolism over the last 14 years. She is about to submit her PhD thesis, which has examined the relationships between dietary intake and growth and body composition in children and adolescents across a variety of metabolic disorders where diet is restricted.



### Session Outline

#### Long Terms Effects of Medically Prescribed Diets on Growth and Body Composition in Children with Inborn Errors of Metabolism

Maureen's presentation outlined some of the results from studying children and adolescents with PKU and other IEM's.



## Evelyn Culhane

Evelyn is the Manager of Transition to Adult Care at the Royal Children's Hospital (RCH) and strives to ensure optimal care pathways for all young people and their families as they transition from the RCH, in partnership with all departments (including metabolic medicine), adult services, primary care and other key stakeholders. Evelyn and her Transition Support Service team deliver dedicated transition clinics with a holistic focus which empower and assist adolescents from 15 years of age and their parents/carers to successfully navigate the move from paediatric to adult care.

Evelyn also leads a number of collaborative and innovative initiatives including:

- The Royal Children's Hospital and Royal Melbourne Hospital transition initiative – developing better transition care across both organisations
- Developing a (transition) model of care for young people with intellectual disability and/or Autism Spectrum Disorder with mental health issues
- Developing excellent transition care for all patients with congenital heart disease across Australia and New Zealand

Apart from her wonderfully challenging role, Evelyn enjoys time with her two adolescent children.

### Session Outline

#### Transitional considerations & preparation – teens to adults

Evelyn delivered an interactive session for parents and carers exploring aspects for consideration during the transition process, what to expect with the move towards adult care, available supports and how best to prepare for this change as children emerge into adolescence and young adulthood within the healthcare setting.

## Flora Pearce

Flora has worked in a range of roles at Royal Children's Hospital (RCH) including teaching, staff supervision and clinical social work over a 20 year period.

She has been the Metabolic social worker for the past 13 years as well as operating a private practice as a couple and family therapist.

### Session Outline

#### Parenting experiences and tips for self-management and building independence in kids of all ages

Flora facilitated an interactive session with parents of kids with IEMs (of all ages), exploring and sharing personal experiences and developmental considerations with participants.



## Anita Inwood

Anita has been a paediatric nurse for 29 years. She qualified as a Metabolic Nurse Practitioner in 2015, having previously worked as a Metabolic Clinical Nurse Consultant in Queensland since 2003. She has been an executive committee member of the Australasian Society of Inborn Errors of Metabolism (ASIM) since 2005 and is currently the past Chairperson. She won a Churchill Fellowship in 2012 and gained the opportunity to work within the National Health Service in the United Kingdom. Her Fellowship was focused on lysosomal storage disease and transition. Anita works collaboratively in a multi-disciplinary team; her primary clinical case load is phenylketonuria as well as other IEM.

### Session Outline

#### Newly released National Guidelines for PKU(including Maternal & BH4)

Anita discussed the new guidelines as well as looking at protein counting & advances in treatments.



## Mia Normoyle

Mia Normoyle, RN, works as a Clinical Nurse Consultant for the Metabolic Department at The Royal Children's Hospital (RCH), Melbourne. She has over 10 years of experience in Paediatric nursing and has worked in two major children's hospitals in the United Kingdom and Australia. Mia trained as a Children's Nurse at Great Ormond Street Hospital (GOSH), London, United Kingdom. Mia started her career working on Rainforest ward at GOSH which specialised in Metabolic, Endocrine and Gastroenterology conditions. She was fortunate to move to Melbourne, Australia and work with children on Cockatoo ward, which also specialises in Metabolic, Endocrine and Gastroenterology. To develop her nursing skills, Mia completed the Advanced Course in Paediatric Intensive Care (ACPIC) on Rosella ward at RCH. She is currently studying with the University of Derby, to learn more about child development and develop her research skills. Mia is passionate about providing holistic care to the families and children with inborn errors of metabolism.

### Session Outline

#### Exploring effective bloodspot testing and monitoring of your IEM

Mia delivered an informative and interactive session exploring effective techniques for bloodspot testing and monitoring of your IEM. This session explored challenges and barriers as well as providing hands on advice and demonstrations to assist with accurate and effective bloodspot testing.

## Victorian Retreat Speakers (continued)

### Martin Heppell

Martin's background is unique. He spent a considerable amount of time growing up in Borneo (whilst his father studied an Iban Dayak headhunting tribe). He is heavily influenced by the morals and values that he and his family were surrounded by whilst living with the Iban.

He is passionate about children being given the opportunity to be raised in a positive manner that evokes confidence and a zest for life.



#### Session Outline

**The Resilience Project** delivers emotionally engaging programs to schools, clubs and associations and businesses and provides them with evidence based, practical strategies to build resilience.

Three key Strategies were addressed in Martins presentations

1. Gratitude (appreciating what you have, not begrudging what you don't)
2. Empathy (thinking of the needs of others/kindness) and
3. Mindfulness (being present in the moment, not becoming distracted by unhelpful or negative thoughts)

Martin shared stories of his own experiences to highlight these strategies and the ways that these can be used to promote positive mental health and their application in daily life and at home.

Martin presented a session for kids and parents, adults and older teens. Both sessions were about creating a cohesive approach to developing positive mental health, improved confidence and positive relationships.

### Peter Appleby & Brad Hawker

Peter Appleby, General Manager and Brad Hawker, Executive Chef Grand Hotel Warrandyte

The Grand Hotel Warrandyte, a local establishment located in the North/Eastern suburbs of Melbourne launched Australia's first low protein menu specifically catering for individuals with IEMs.



As the backbone to the Warrandyte township, the Grand Hotel prides itself on the ongoing support it provides to its many local community based groups, and is why it was a no brainer to extend themselves to do something unique for their local PKU community and provide them with a dining experience equal to other patrons.

The idea is powerful! Providing the gift of a normal dining experience for IEM and gives these families with prescribed medical dietary needs, the ability to enjoy an inclusive dining out experience together.

Brad has not only created a selection of delicious, restaurant quality low protein menu options, but has completely embraced the idea and studied the complex PKU dietary needs and been extremely thoughtful, creative and adaptive in his approach.

The menu options that Brad has been presenting are exciting, packed with fresh ingredients, color, and flavor and with all the nutritional considerations required for a PKU child or adult to enjoy safely,

The Introduction of a PKU friendly menu at the Grand is an Australian first, and it is hopeful that through its example, other venues around the country might follow suit

#### Session Outline

##### Phenomenal Low protein cooking

Brad and Pete hosted an inspirational low protein cooking workshop full of creativity and flavour and highlighting various features from Brad's lopro creations. During this session, Brad provided insight into the details behind his many creations and provided some tricks and tips for all to take home to their own kitchens.



# 2018 Retreat South Australia

Adelaide Hills Convention Centre, Hahndorf  
5-7th October 2018



# PKUNSW Updates

## End of year celebration

This was held on the 26th November at Borruso's Pizza & Pasta in Northbridge. It was wonderful to have over 40 people attending. From all accounts the pizzas were fantastic and the venue certainly went out of their way to provide a relaxed, delicious dining experience for PKU patrons and their families.



## Ladies High Tea Fundraiser

Twin Creeks Golf club, Luddenham, NSW was the venue for PKUNSW Ladies High Tea on November 20. Congratulations to all those involved. Champagne was flowing and the day was a huge success.



**Congratulations to the PKU Association, who were appointed a Founder of the Children's Hospital at Westmead, in recognition of their fundraising for PKU research.**

There were delighted to announce that they have raised over \$1 million dollars!

Well done to all members and supporters, who have been so generous over the years. The PKU community may be small, but together we can achieve great things.





# Families Living with an IEM

MSUD

Ruby Kirwan

Age: 8 IEM: MSUD

## What is your daily routine:

Get up, have breakfast normally coco pops, make coolers, drink one, brush teeth, brush hair put shoes on and go to school. Come home from school, have cooler and get changed, play outside, feed the dog. When mum gets home I have dinner, have a bath, last cooler and go to bed.

## How do you explain MSUD:

Maple Syrup Urine disease. When I was sick as a baby you could smell maple syrup in my ears. I have a special diet I can't eat much protein, if I have too much I can get really sick and go to hospital to stay overnight

## What is your treatment:

I count protein and if I don't know how much is in it I ask mum and dad. I have coolers 3 times a day with valine

## How did you go about educating the school/ teacher/classmates about MSUD:

My friend Ella knows and my teacher knows, but no one else at school. Why don't you tell everyone? because it's embarrassing

## Favourite subject at school?

Reading and whole class maths

## Any major difficulties ( what is hard at school)?

It's hard to tell everyone I have MSUD. Anything else? LEVEL 15 of blitz master

## Favourite food, snack?

Ice cream, chocolate, cream filled biscuits. Broccoli, corn fritters and hash browns

## What is your favourite thing to do in free time?

Watch TV, invite my neighbour over for a play, climb trees and play on trampoline

## What would you like everyone to know about growing up with MSUD?

That eating vegetables is probably more healthy than eating meat anyway. It's a bit different, and it's hard to ignore all the food I can't eat.

Fiona Kirwan -

A parents perspective

## How was Ruby diagnosed?

New born screening which was taken late at 4 days old. The delay resulting in slight brain trauma and haemofiltration to remove harmful toxins from her blood, and a 2 week stay at RCH Melbourne.

## What are the challenges you have faced from the point of diagnosis to now?

We initially thought she would be severely disabled and in a wheelchair, luckily her brain trauma reversed itself, and she does not have any effects of it. Being the first one born in Victoria in 16 years, we felt completely isolated and didn't fully understand what lay ahead. My husband travelled to America to a symposium where he met several people with MSUD and saw, with the right care and treatment, how normal their lives can be, this was very reassuring for us. My main struggle these days is trying to explain why she can't eat whatever she wants when she has the "why me" days, and "it's not fair, I just wanna be like you", it's heart breaking.

## What is your daily routine like:

Ruby makes her own cookies now, which is great, I help her mix up the valine supplement, and she measures 6 ml into three coolers for the day. I make breakfast for Molly and myself, Ruby usually makes her own toast or coco pops, wheat bix. I pack lunches, Ruby has a sandwich or noodles in a thermos. We leave for before school care, child care and work 7:45am and I get home at 5pm. I cook 2 dinners, one for us and one for Ruby, bath, cooler, bed, repeat. I work 5 days a week.

## How did you educate your family & friends?

Family was pretty easy as they have seen the whole journey, and the consequences i.e. Hospitalisation if not taken seriously. Although, my mum who cares for the girls often struggles to understand counting protein and still tries to give Ruby high treats like Paddle Pops!! Newer friends, and parents met through school, don't really understand. I think because she looks so well, and they haven't seen what can happen, and high levels and walking sideways doesn't happen immediately, it's hard to grasp.



## Tips from a parent

- > Be prepared
- > Keep an emergency box of coolers in the cupboard
- > Listen to those who know
- > Take each day as it comes
- > Join the Face-book support group

## What are the difficulties faced in explaining MSUD?

Many people just don't get it. It's very complex to explain, even keeping it simple it's difficult for people to understand the seriousness of it. She doesn't look like she has a life threatening illness, and we don't go out of our way to make it public knowledge. It's not an allergy, and no she won't "just grow out of it".

## Any advice for others?

Be prepared. We keep an emergency box of coolers in the cupboard for when life gets crazy and you forget to make it to the chemist. Listen to those who know, especially when it comes to cooking, Le Pro products can be very difficult to master in the kitchen. Take each day as it comes, especially initially when a newborn/ toddler is not enough stress, but one that has special needs and you're required to be a mathematician, a dietitian a nurse and a chef all at once! I love the Face-book group for its support, some days when it all just seems too hard, there are people who fully understand and can lend a sympathetic ear in the tough times. Thanks to all of you, and MDDA.



Jordan Blyth  
Age 13 IEM: PKU

**This was your first year at Newtown High school what were you most looking forward to about high school?**

Being with my footy mates because they went to different primary schools and trying new subjects that I haven't done before.

**Describe your first day?**

It was fun and I got to go to my home group and meet all the people in my home group.

**How did you go about educating the school/teacher/classmates about PKU?**

My carer had a meeting and they talked about how I should have my cooler with a teacher but then I went off having my coolers at school because I couldn't be trusted because I had done the wrong thing.

**How do you explain PKU?**

Well I tell people that I can only have 3.5 grams of protein a day even 4 if needed.

**Are there any major difficulties you experience at school?**

No not really I don't tell anyone about PKU unless they ask.

**What is generally in your lunch box?**

Fruit, pack of vegie chips, fruit bars, my formula, sometimes a few lollies and pasta salad.

**What is your favourite food.**

Corn and potato shape pasta mix – low protein and lollies.

**How do you deal with class parties and excursions?**

I take my own food or eat what has not very much protein in it at the party.

**What is your favourite part of school/Why?**

My favourite thing at school is to play sport with all my footy mates.

**What would you like to learn more about?**

To understand more about science and social science.



**What kind of books/movies do you like?**

I don't read much even though I'm a good reader and I like most movies particularly action, comedy and horror.

**What do you do for fun?**

Practise all sports like footy, table tennis, handball, basketball, and futsal and practice my running because I'm a good long distance runner.

**Has having PKU made participating in any sports/activities difficult?**

No, if I have my coolers before I play it gives me more energy and helps me more.

**What do you want to be when you grow up.**

I want to train hard and try work my way to the Olympics or play professional AFL for Collingwood.

**What is the one thing that you would like everyone to know about PKU and school life?**

That it's not contagious and I'm no different to anyone else. My cooler is just my medicine.

**Any tips for future kids/parents in making the transition to high school as easy as possible for a child with an IEM?**

Tell your teachers. Have a meeting with them and tell people and your mates that you are no different to anyone else and don't take any of their crap like bullying.

PKU

**Pauline Blyth - A Grandmothers story.**

Just a short story about Jordan (Jordy) Blyth and myself Pauline Blyth, Jordy's grandmother (and I'll do my very short story – as I have far more years of my life than I care to remember where I have suffered depression and anxiety, post-natal depression with my son Ricky (Jordy's Dad – 35 years old) and my daughter Rebecca (33 years old) Hence: the reason for this story.

Each time Jordy and I come to the MDDA retreats and I talk about Jordy being with a foster carer, I am often asked questions. Four years ago I was asked by a gentleman at the retreat in Melbourne “Why doesn't Jordan just live with you?” There is no short explanation to this question and just to come to the MDDA retreats for me is really hard as my anxiety really kicks in so it was always hard to answer (except this year.) So back to the question about Jordy with me (as I know that's on everyone's lips) its because of all the family dynamics that come into it - it makes it impossible for Jordy to be with me.

Jordy has lived with me earlier on but (Not because of Jordy) I had a nervous breakdown. When I got a little better, Jordy was home with me and this image will never leave me. Jordy was around 3 ½ years old on bended knees on my lounge next to me looking out the window with his hands (praying) saying “All I want is to be with my family” believe me it was the hardest thing I have had to do to hand him over to a Foster carer.

This is only a short story of Jordy's life, and I'm just so proud on how he has coped with all the changes in his life to date.

One thing that's given me a lot of peace of mind is all the help Jordy and I have received from the MDDA. I joined around ten years ago.

Jordy and I are really grateful for the help the MDDA have done to make sure we get to come to the retreats. A big thank you to the MDDA.



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



## Parsnip & Shitake Lettuce Wraps

### Ingredients:

3 tablespoons olive oil  
1 large shallot minced  
1 clove garlic minced  
1 cup diced parsnip  
1/2 cup shitake mushrooms thinly sliced  
1/4 cup water  
1 tablespoon soy sauce  
8 large iceberg lettuce leaves

\*Optional 1 teaspoon hot sauce of your choice

Portions 8  
Serving size 1 lettuce cup

### Method

Heat oil in large frypan then add, shallots and garlic. Stir gently for 1 1/2 minutes then add the parsnips and shitake mushrooms.

Stir every couple of minutes until parsnips and mushrooms are tender and browned. Increase heat to high and add 1/4 cup of water, and sauces. Stir constantly until all excess liquid has evaporated. Remove from heat and divide amongst lettuce leaves.

Serve immediately - enjoy!



## Apple Cranberry Slaw with Celery Seed Dressing

### Ingredients:

1/2 medium cabbage head  
1 medium red apple  
2 tablespoons onion  
1/2 cup dried cranberries  
1/2 cup canola oil  
1/4 cup sugar  
1/4 cup cider vinegar  
1/2 teaspoon celery seed  
1/2 teaspoon dry mustard

Portions 8  
Serving size 1 cup.

### Method:

Shred cabbage and chop apple into small pieces. Grate onion.

In a large bowl mix cabbage, apple, onion and cranberries.

In a small bowl or jar combine remaining ingredients to make celery seed dressing; mix vigorously.

Pour over slaw and toss.

## Spiced Roasted Apples & Blackberries

### Ingredients:

100 g milk free margarine  
4 medium apples  
4 tablespoons clear honey  
1/2 teaspoon ground cinnamon  
finely grated zest & juice of 1 large orange  
250 g blackberries

Portion 4  
Serving size 1 apple

### Method:

Preheat oven to 180 degrees. Core the centre out of the apples and make a cut into the skin around the middle of each apple.

Stand the apples in a shallow baking dish, large enough to take all four. Mix together the honey, cinnamon and orange zest, put an even amount into the cavity of each apple, then pour the orange juice into the dish.

Roast the apples for about 40 minutes, spooning the juices over them occasionally. Then when the apples are almost ready, spoon the blackberries around and over the top of each apple.

Return to the oven for 10 minutes or until the juices start to run. Spoon the blackberries and juices over the apples to serve.





# Product update



## Vege Deli Crisps: Turmeric & Cheese

Protein per 100g: 1.7g  
Protein per serve: 0.3g  
Serving size: 20g  
Available from: IGA & Coles



## Genius: Soft white rolls

Protein per 100g: 2g  
Protein per serve: 1.6  
Serving size: 80g -1 roll  
Available from: IGA, Coles



## Alimate: Mini wafer cones

Protein per 100g: 8.8g  
Protein per serve: 0.1g  
Serving size: 1.3g  
Available from: Coles & woolworths



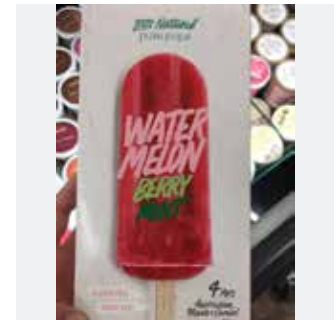
## Green Vie: Cheddar slices

Protein per 100g: 0.3g  
Protein per serve: 0g  
Serving size: 10g  
Available from: On-line Vegan Perfection



## Weis: Dairy free dark chocolate & coconut bar

Protein per 100g: 1.6g  
Protein per serve: 1.2  
Serving size: 70ml/80g  
Available from: Coles & Woolworths



## 100% Natural Pure Pops: Watermelon strawberry raspberry & mint

Protein per 100g: 0.5g  
Protein per serve: 0.4g  
Serving size: 80g  
Available from: IGA & Health food stores



## Green Vie: Feta style cheese

Protein per 100g: 0.3g  
Protein per serve: 0g  
Serving size: 10g  
Available from: On-line Vegan Perfection



## Monster Health Foods co: Free & Lo Muesli

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



## Community Co: Butter blend spread

Protein per 100g: 0.2g  
Protein per serve: 0g  
Serving size: 5g  
Available: IGA & Foodland

## 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)

## 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.



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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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