



MDDA NEWS

Newsletter of Metabolic Dietary Disorders Association

Issue 58



IEM Food Grant Victory bringing the IEM Community together

Welcome to our bumper edition MDDA news. With so much going on in the past six months we have many great stories to share with you. So grab a cuppa, settle in and enjoy!

Winding back to early May 2015, our year had got off to a busy one, we had just come off a very successful **Western Australia retreat IEM youth camp**, and were busy working through our many initiatives, including working with affiliated groups endorsing their great work with the **National Rare Disease Plan** and **Newborn Screening Policy Framework** which were well underway.

Our submission for Nitisinone for Tyrosineamia Type 1 was in the process of review along with our **FSANZ Food Labelling** 'per serve' submission, and planning had commenced for our August QLD retreat.

On 21 May, 2015 our attention took a very sudden turn, as we were confronted with the announcement of the IEM Food Grant cessation. This decision came as a shock to the entire IEM community including metabolic clinics across the country, and MDDA went into immediate campaign mode with the Channel 9 news on our doorstep the following morning. The next 71 days saw an entire IEM community mobilised with "guns ablazing". A massive

effort was made from members far and wide and our community truly bonded in such an incredible way. On July 30, 2015 Minister Sussan Ley announced the reversal of the decision live on 2UE radio Sydney, resulting in a ground breaking victory for MDDA and the entire IEM community. The **IEM Food Grant victory** will go down in history as another great moment for our community and I am so impressed and proud of how deep everyone dug. People far and wide stood up for our rights, and together we became a voice to be reckoned with!

Whilst I don't wish for such a situation to ever present itself again, I feel grateful in many ways of the closeness this event brought our small IEM community, the connections it formed, and the freedom it provided to many of us to be able to share our stories and educate our country and politicians on the challenges and sometimes heartbreak faced by people with IEMs.

I look forward to us generating even more awareness on IEMs in the future and encourage everyone's involvement in our **"Newborn Screening Thankyou"** campaign we intend to launch in 2016. In the meantime, I hope you enjoy this edition.

Monique Cooper, President MDDA

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Donations over \$2.00 are Tax Deductible

MDDA 2015 Year End Events

VICTORIA end of year family fun night AGM and HT1 round table discussions Saturday 14 Nov 2015

5:00pm - 8:00pm

Inflatable World,
160 New St Ringwood
A night not to be missed!



A brief AGM presentation will take place at 5.30pm, followed by dinner and games with a very exciting special guest soon to be announced! Special note for Tyrosinaemia families – An exclusive Tyrosinaemia round table and kids play date is scheduled from 4-5pm prior to this event hosted by MDDA.

RSVP by 4 November to office@mdda.org.au
Gold coin donation prior to 5:30 otherwise normal entry fees apply. Pizza (including low protein) available for \$1 per slice
Drinks at bar prices on the night.
Please bring socks to wear on the inflatables.
Thank you to Nutricia and Menarini Australia for supporting this event.



Notice of 2015 Annual General Meeting

The Annual General Meeting of the
Metabolic Dietary Disorders Association
(ABN 99 021 391 381)

will be held on

Saturday 14th November,
5:30—6:30 followed by dinner and games
Inflatable World,
160 New St Ringwood, VICTORIA

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

Monday 9th November 2015.

Nominations for General Members are called for in all States and Territories

MDDA Low Pro Cook @ Home days

The MDDA is calling all budding low protein cooks to consider hosting one of our new concept low pro cook @ home days.

You can get involved as either a host or a participant.

To be a host is simple...

- ⇒ Have access to a decent size kitchen (at home or elsewhere) to host the occasion.
- ⇒ Contact MDDA to select a date and format that suits (limited hosting opportunities exist so apply first via MDDA).
- ⇒ Come up with some inspiring low protein recipes (Nutricia products along with a Coles voucher will be supplied to cover the costs of ingredients)
- ⇒ Work with MDDA to plan and promote your day (invitations will be sent on your behalf to local members)
- ⇒ On the day; document your recipes and take plenty of photos and video for us to upload to our website for others to enjoy (guidelines for this will be provided).

Unable to host? Keep an eye on our website and facebook group for advice on where our first round of cooking days will be held, and come along and participate. Not only will you be inspired with some great cooking tips & ideas, you will meet new friends and take home some yummy meals for your family to enjoy.

To find out more or apply to be a host visit the event section of the MDDA website. Brought to you by Nutricia.



NSW End of Year Picnic - All welcome Sunday 28th November

10.30am onwards

Centennial Park (*Meet off Dickens Drive in the area south of the Brazilian Fields, in between the area marked Lachlan Reserve & Loch Ave, Sth Area*)



Enjoy a relaxing day out with the family, activities and a picnic lunch. Bring a plate of low protein food to share with other families & friends. A picnic lunch will also be provided.



RSVP to info@pkunsw.org.au for catering purposes.

QLD Clinic & MDDA Christmas Party Sunday 22 November 2015

10:30am - 2:30pm

Taylor Range Country Club, Ashgrove, Brisbane.

Please bring your lunch, togs, towel, hat and sunscreen and a plate of your favourite low protein food to share, and a gift up to the value of \$20 for any children attending with you. There will be a lolly hunt, water bombs and a visit from Santa.

If anyone is keen to help out can you please email Louise Healy — louise@mdda.org.au. More information can be found at www.mdda.org.au under Event tab.

RSVP 13 November louise@mdda.org.au.
Thank you to VitaFlo for sponsoring this event.



SA and WA Dates to be announced soon!

PKUNSW & MDDA joining forces



The MDDA and PKUNSW are continuing to work together on joint initiatives and events along with representing the PKU and greater IEM community on important Government Policy advisory matters. Having "One Voice" for IEM's in Australia is a key priority for both organisations, and in recognition of our collaboration, PKUNSW News will now become a regular feature of the MDDA News publication. In addition the MDDA is granting reciprocal membership rights to all PKUNSW members, providing them with ongoing access to this publication along with the many other benefits that come with MDDA membership.

PKU Research at the Children's Hospital at Westmead-Update

We continue to make steady gains on the PKU research front.

A major milestone:

We are excited to report that Naz Al Hafid has now submitted her PhD thesis, which is currently being examined. Naz spearheaded many of the test tube studies and most of the PKU mouse studies relating to our GM probiotic treatment for PKU. Fingers crossed! Because of the skill set that Naz has developed over the last few years, she has become a very valuable member of the team, and accordingly we are about to re-employ her as a postdoctoral research scientist on our GM probiotic project.

Nonsense Read-through therapy for PAH:

It turns out that the human liver cell lines we had appear to have poor PAH (the PKU enzyme) activity, and so will not be of any use to us for our studies. There are a number of companies which offer liver cell lines

for research purposes, and Minal is going to look into this. The alternative is to consider the development of a "nonsense" PKU mouse, and this will ultimately be important when we want to test potential nonsense read-through drugs.

Progress with our GM PKU Probiotic:

Because Naz was busy preparing her thesis over the last few months there has not been any new experimental work to report. However, we have had very active discussions with potential commercial partners, including companies that have particular expertise in the development and regulatory submissions of GM probiotics as therapeutics, and those that sell PKU medical food products.. A partnership with one of these companies has the potential to attract the necessary drug development expertise, capabilities and capital required to develop and commercialise our GM probiotic.

Donations in support of our PKU research:

Our PKU research team joined in the festivities at the recent PKU Ball, which was a great social success, and a wonderful financial success. We were delighted to receive a very substantial cheque from Mirella Nicomede and her team, representing the NSW PKU Association, at a thank-you function on 17th July in the Board Room at the Children's Hospital at Westmead. In addition, I was delighted to receive a cheque supporting our PKU research efforts from the incoming President of the Rotary Club of Pennant Hills, Ian Chappel.

We are deeply humbled by the enthusiastic support of the PKU community and look forward to our continued engagement with you.

*Prof John Christodoulou AM,
Head, PKU Clinic*

Reciprocal rights for PKUNSW Members

MDDA is pleased to announce we will be providing reciprocal rights to all PKUNSW members effective immediately.

This step ensures PKUNSW members receive the many benefits that come with being an MDDA member, including receiving all future MDDA member communications and newsletters as well as access to MDDA's member only online facebook forum and membership portal soon to be relaunched.

Pinnacle Bread—NSW

Anthony and I regret to advise that we will no longer be offering the service of sending Pinnacle flour to members. It has become too difficult and time consuming, especially when the Pinnacle Bakery often cannot supply enough boxes for our needs as well as others – requiring a second order and pickup. We suggest that families and individuals who wish to continue using the bread mix try to make their own arrangements with Pinnacle Bakery to purchase a bulk quantity at a discounted price.

Meredith & Anthony



PKU Gala Dinner

The PKU Association of NSW Inc 3rd Annual Gala Dinner was held on Saturday 13th June 2015 and this was another successful night at Ottimo House, Denham Court. This is our main fundraiser to raise funds for the PKU Research project currently underway at the Children's Hospital at Westmead led by Professor John Christodoulou.

Thank you to everyone who has supported events such as the Annual Gala Dinner, PKU Awareness Walk, City2Surf and other fundraisers & individual donations. Bridie Melham & Mirella Nicomedes presented Prof Christodoulou, Head of PKU Research with a cheque for \$120k on the 17th July 2015.

Bridie Melham

WA Family Retreat and Youth Camp

Our WA Family Retreat was held April 17th - 19th at Point Walter Recreation and Conference Centre on the banks of the gorgeous Swan River. The setting provided a beautiful backdrop for our retreat offering families and individuals an opportunity to come together and share experiences, information and support.

WA held our first weekend Youth Camp where youths aged 10-17yo were able to stay on-site with their parents choosing to either bunk in with mum and dad or sleep in the communal bunk room.

A jam packed youth program focused on developing independence, building peer support networks, challenges, a 'little' education and most of all loads of fun. It was engaging watching on as friendships developed over the weekend. We would like to thank Paul Melham for taking on the task of Youth Camp Supervisor. Paul's energy and care ensured the camp ran smoothly and was enjoyed by all.

The retreat program began with Louise Healy leading us through a session on Mindfulness & Cultivating Resilience. Anyone who has had the opportunity to sit in on one of Louise's sessions knows that you will always come away with new ways of dealing with your

thoughts and emotions. Kath Harrigan - Dietitian from the Princess Margaret Hospital led a session on Health & Wellbeing tips for adults & kids and answered questions about choice in formulas and food. Saturday afternoon saw a Cooking Workshop 'Invention Test'. Thanks to Fiona and Vanessa for organising this fun filled activity. Check out the MDDA website gallery photos for pictures. The teens were extremely competitive and surprised many of us with their cooking skills!

A few highlights of the weekend included two 'Chocolate Fountains' both low pro & regular... yummy. Saturday late afternoon kicked off literally with an impromptu kick to kick of the footy, a game of chasey and for many others of us just basking in the late afternoon sun, (maybe), having a wine, beer or soft drink and connecting on all sorts of matters. After dinner we gathered around a campfire (which turned into a 'bonfire') where we shared our experiences of living with an IEM, we heard many heart-warming and emotional personal stories. Sunday lunch was enjoyed at the Point Walter Café. This retreat also saw the largest gathering of adult PKU men attend. We are looking forward to heading back over to the west!

WA Family Retreat - Member Feedback

Many thanks we enjoyed a wonderfully welcoming weekend away. Met lovely people, gained valuable information and had fun.

Jane

As PKU parents it is so valuable to be networking and talking about our experiences with PKU adults, other parents, other IEM families and health professionals. Hearing everyone's story and how they opt to manage and deal with it is so beneficial. Plus we feel it opens up some of the challenges we may see our children experience (emotionally, physically) down the track in life. The retreat is a real break from routine. After all - where else can you go and not have to think about packing so much food with you and then not have to cook!!

Maria

Connecting with adults with PKU is a great way to get a different perspective other than as a parent and of course the ideas tips and networking with other parents is invaluable

Nicky

WA Family retreat was a relaxing and enjoyable experience for the entire family. The grounds were lovely and provided a safe and stimulating environment.

Shelly

A great experience that allowed us (parents) to connect with those in a similar situation and our child to mix with kids of a similar age and condition

Louise



Sponsor of the WA Family Retreat 2015

MDDA would like to acknowledge our major sponsor VitaFlo for their generous financial and product support for the Retreat.



Thanks to Nutricia for their financial assistant and product support at the WA Family Retreat.



Product sponsors

Thanks to all our product sponsors of the WA Retreat who kindly donated their products for our showbags, cooking challenge and low protein menu.



WA Family Retreat April 2015



WA Youth Camp April 2015



ITEM AWARENESS MONTH - ACTIVITIES

May 2015 saw our members and friends organise and participate in fundraising events to bring about awareness. A big thank you to these people. This fundraising money is used to help continue to update our information brochures, kits and factsheets to assist new members learn about their metabolic condition. It also allows us to continue to evolve our website and to better connect with and support our members. With the IEM grant lobbying occurring as well, it saw our members band together and reach out to all in our community, members of parliament and local MP's, local papers, TV reporters all with the aim to help them understand what living with an IEM means.

Fundraising campaign SA

Being a mother of a child with PKU I have often found myself looking to others for support. Support from family, friends, dieticians and of course the MDDA.

To help return some of the support back to the MDDA, with the help of my amazing work 'Terri Scheer Insurance' we decided to undertake on a fundraising campaign. We have held a number of small fundraisers in our office raising a little over

\$800 so far. Our two greatest successes have been a low protein morning tea where I asked people to bring in or make something that would be suitable for someone on a low protein diet. My daughter Elaynah (2yrs old Classic PKU) also came in and it was so great for her to be able to sample so many of the foods people had made. We also held a market stall which people donated food, jams, craft items and many other items for people to purchase with all funds being donated.

But this isn't the end of our fundraising, we are currently in the process of organising an amazing race type of event which will be held around the Adelaide CBD ending up with a bbq in the park. Once all of the details have been determined we will be extending the invite out to the SA metabolic community and their family and friends.

It has been so rewarding for me and my work to help support such an amazing organisation who has been such a support to our family. I would strongly suggest that if you also work for a great company like mine, get on board and start your own

fundraising for the MDDA. No matter how small your idea or donation is, it's amazing how much you can do when you rally together.

Sasha Johnson



Fundraiser walk QLD

On Sunday the 3rd of May Tarnya (has son Tyson 3 PKU) and myself (daughter Esta 18 months PKU) decided we would like to organise an awareness fundraiser in spirit of PKU awareness month that kicked off on the 1st of May.

In organising this we really wanted to just raise awareness in our community as we've found so many people know nothing about PKU and other IEM's or even what the heel prick test is done for.

We had so much fun organising our walk which started at Jack Evans boat harbour and went all through Coolangatta.

Along the way we handed out a little booklet the MDDA did up for us to the locals about PKU.

The most amazing part of the day was that we had so many people come from all over Gold coast and even Brisbane. This included other members and their families from the MDDA so it was a great way to connect and meet some of them.

We were super excited that we raised \$700 that we donated to the MDDA for them to put towards resources and research.

Next year we hope to be more organised and organise something even a little bigger.

Tennille Stewart



ITEM AWARENESS MONTH - ACTIVITIES cont

Item Awareness month also saw one of MDDA ambassadors' continue his fundraising efforts for us. Dean Tulloch started running in 2011 to raise money and awareness after his best friend's son was diagnosed with PKU. He completed the 7 day Gobi desert ultramarathon in 2011 and has continued running since. This year Dean travelled to South Africa and saw his fundraising efforts climb to over \$50,000. A huge thank you Dean from the MDDA and all our members.

Race Report—Comrades South Africa

In September 2014, I decided to enter the world's largest attended ultra marathon. The ultimate human race Comrades.

I had heard so much about this race but really knew nothing about it. Here's what I knew. *Comrades is an ultramarathon between two cities in South Africa.* Firstly, the port city of Durban (or Durbs as my neighbour calls it) - the largest city in the Kwa-Zulu Natal province. The other is Pietermaritzburg (or Maritzburg as everyone calls it). The distance between the two cities is approximately 88km. So I needed to train.

Training for me was essentially between January 1st and early May. So around 4 months. In that time I ran the Two Bays (28km), Wangaratta Marathon (42km), Maroondah Dam (30km), Rollercoaster Run (43km), Canberra Ultra (50km) and Brimbank (50km). There were many runs in between (as well as physio visits for nagging calf injuries!!!). One of the hardest training runs was out in the Yarra Valley. Starting at Healesville, I ran towards Yarra Glen, then towards the Chocolate Factory, back on Old Healesville Road back to Healesville. Then uphill for some 13km to Toolangi. This was Comrades Training after all. That run was about 42km.....and really smashed me. I was ready.

Comrades alternates direction each year - one year they run up from Durbs, the next they run down from Maritzburg.



This year, 2015, was the 90th running of the event - and an up run. And when I say up - I mean up.

There are five key hills you need to run over on the up run. You know they are a little nasty when they name them. Yep, they are called the Big Five - Cowies, Fields, Botha's, Inchanga and Polly Shortts. These hills are legend in South Africa and they are referred to by name. People will say to you - "watch out for Inchanga. Nasty". Inchanga? Is this a type of leopard? I was in for something.

I arrived in Durban on the Thursday before race day, which was Sunday. After grabbing a rental car from the airport and realising that the speed limit in South Africa is something that nobody really cares about, I safely made it to the Expo. This was a chance to stock up on some Comrades specific t-shirts, socks, towels, sunnies, hoody - yep, that was about it. The expo was huge - *let's not forget this race attracts 20,000 entrants!!!*

For the next few days before race day, I relaxed in a city called Umhlanga Rocks. From my hotel I watched the ocean and the promenade where I had a couple of warm up runs before race day. Run 1 was about 8km and after negotiating the shaky bridges that rose over creeks (I'm sure I was safe from Hippos) the toughest thing to avoid were the monkeys that lived in the trees near the beach. Run 2 was 6km the day before Comrades. I got back to the hotel Saturday morning - dripping wet. Durban is very humid and was already pretty warm by 10am. Time to relax.

The night before race day, I laid out my gear to make sure I didn't forget anything. It seemed a social media thing to do - to lay your clothes out, take a photo, and send it out to your friends. So I joined in. It is actually an important thing to do because if you are not ready and you forget something - it could mean disqualification. So I had the Aussie singlet, shorts, socks, calf sleeves, my trusty Mizuno runners, Championchip (this sends your race times back to the computer and is the key things to have with you), sunnies, Comrades hat (no logos thanks, Comrades do not tolerate Nike, Adidas, 2XU etc Hats must be Comrades, or plain!), International



tent wristband, pacing chart wrist band - and my three good luck charms. My kids had given me some pre-race gifts which I wore around my wrist and neck. 2 bracelets (complete with silver frog) and a necklace (complete with silver dolphin tail). I was all set.

The hotel was fantastic. We had muffins and bananas all set for us and a car to transport us from Umhlanga to downtown Durban at 4am. *As you arrive close to the start line, you suddenly realise that you are about to be a part of one of the greatest running experiences on earth.* We are all divided into Corals - and I was in Coral C. This means I qualified with a sub 50km ultra time of 4hr 25min (I qualified by 9 seconds!!!!).

The city was an absolute buzz and had a festival atmosphere. We watched as large images of runners were beamed all over the city buildings. And we took our hats off as the South African national anthem was blasted from the PA system. We were just getting started. The remaining 10 minutes before the 5:30am start are legendary. First - they play 'Shosholoz' - and EVERYONE sings. Shosholoz is folk song that originated in Zimbabwe and was made popular in South Africa. It is really South Africa's second national anthem. The song is about hardship of working the mines - but also a song of hope and solidarity. Talk about goosebumps. Following Shosholoz we moved into Chariots of Fire. You will never hear a louder Chariots of Fire in your life. By now we have all welcomed each other, shook hands with each other, embraced each other. *Because over the next 12 hours we will stand together as one, from many political, socio-economic and religious backgrounds. For one day nothing else matters but this race.* It is beamed into the lounge rooms of all South Africans who unite as one to watch this race. The Ultimate Human Race. 5:30am - we're off.

We take off through the streets of Durban. The first part of this race is consumed with dodging fellow runners and making sure that you don't trip over anything. My first priority was to get to the foot of Cowie's Hill, which was about 17km away. I was conscious of my calves as I

IEM AWARENESS MONTH - ACTIVITIES

Race Report—Comrades South Africa cont

always worry that they could cramp at any point in time. So I kept a steady pace. As the sun started to come up, I arrived at Cowies in 1hr 45min. And began the climb. One of the key things I recall is how the locals support the race. Apart from the freeways (where the overpasses are packed with well wishers) the rest of the race is jam packed with supporters. Locals who simply come out to cheer you on. The morning locals in Westville are in the dressing gowns, with their BBQ's sizzling away as they eat their brekky with a cuppa and cheer you on.

By now we are mid morning and I am going through many beautiful towns. But before I get to half way I've got to tackle two majors - Fields Hill and Botha's. The crowds through Pinetown, Kloof, Inanda and Hillcrest really got me through. Amazing people, screaming your name - screaming Go Aussie! Go Bruce! (in South Africa, they call Aussie men 'Bruce' and Aussie women 'Sheila'). I was reminded a few times that the Wallabies would be fixed up next time we go to war playing Rugby. After negotiating Fields and Botha's I arrived at Drummond - the half way point. 4hours 35min had passed - I was happy considering the fact that we were soon to hit 28C/29C, I was sweating like mad - but still very much at a pace I was comfortable with.

As I passed Drummond, I stopped at Arthur's Seat and tipped my hat. Arthur's Seat is a hole that has been cut out of a bank and was the favourite resting spot of Arthur Newton - a five times winner of Comrades. Legend has it that Arthur used to sit there and have a nip of whiskey during the race !!! If you tip your hat or leave a flower, you will have a good second half of the race. So tip my hat I did.

Soon after Drummond I began the climb up Inchanga and ran through Harrison Flats towards Cato Ridge. *I was 58km in and had 6 hrs 14min on the watch.* Was beginning to feel it. One thing to note was the hydration. There were opportunity to get fluid every 2km - which is amazing. I was alternating between water, Energade and Coca Cola. The one thing I couldn't stomach was the salted potatoes. Yep - People would be standing there with little potatoes covered in Salt - you get some carbs - and some salt!!!! I found it really hard to eat these and stuck to my fluids as well as some Gu gels that I had stashed in my Calf Sleeves. From Cato Ridge I had 30km to go. Keep pushing.

From Cato Ridge you run through Camperdown and soon reach the highest point on the course. This is very exciting to me because it basically means it is all downhill from here right ? Wrong. First I

had to run through Lion Park. Can you believe you run through a place called Lion Park after running for 70km ? Then (for fun I guess) the race hits you with Pollys. But before Pollys - there's Little Pollys. Yes - you need to run up a big hill - which a lot of people think is the famous Polly's Shortts. It is not - it is the baby brother. Then you hit Pollys.

Polly Shortts is about 2km long and is very steep - it is really only the elite top 10-20 runners that can run this monster. So I, like everyone around me - walked. At this point of the race the heat was taking its toll, but not overly so. I had a block of ice that I had managed to get and had this resting on the back of my neck. It didn't take long to melt away. From the top of Pollys there is about 8km to go. *As I run past this checkpoint they are blasting out Bon Jovi's Born To Be My Baby (my favourite 80s Jersey rock song) and I immediately thought of my buddy Dean Cooper and his son Charlie, who has PKU. We have sung this song for the past 25 years. I had not forgotten that we were again raising money for the MDDA with this event.* I was pumped. It was go time. My time was 9hr 03 - and with just under 8 to go I was determined to run a sub 10hr Comrades.

The next 8km were filled with jubilation and pain. The road was packed with well wishers. "Not far to go - come on!!!" they would yell. "Come on Dean - you can do this" I would hear. I would acknowledge everyone I could - just too exhausted to talk to them. So a simple nod and a wave. I had one eye on the road and one eye on my watch as I was determined to run sub 10. I was running past water stations, dousing my head in water, a bit



of Coke, some Energade - and go. This was my ritual. And there it was - Pietermaritzburg stadium.

I had to run beside the stadium for a good km before entering. It was packed. It was noisy. I could hear the announcer on the PA and had one lap inside on the stadium grass before crossing the finishing line. I was soaking this up. *With 100m to go I could hear the announcer call my name - "Dean Tulloch from Australia in his first Comrades". I couldn't stop smiling and crossed the finishing line, covering 87.7km in 9:52:37. Done. Literally.*

I hugged one of the marshals as my medal was hung around my neck. I was spent. **So what did I learn ?**

- **Comrades is nasty.** You need to respect it and run to a plan. If you go out too hard you are likely to 'blow up' and risk not finishing.
- **Be true to myself.** This has been my mantra for the past 7 years. It is my compass as I navigate the world with my family and it always comes back to me when I run.
- **You can do anything.** Don't let anybody step in the way of your dreams. Surround yourself with people who will help you achieve yours.
- **People are amazing.** in November 2010 we came up with a plan to run in crazy races to raised money for the MDDA. *With Comrades, we have hit \$50,855. What am amazing community we can live in when we all pull together.*

So what's next for me ? I'm not sure. My immediate focus is to have a glass of champagne to celebrate the reinstatement of the IEM Food Grant. After I have done that, I will look at the running calendar and pick a few local events in the next 12 months. Maybe Comrades in 10 years for the 100th running.

My family and I will continue to support the MDDA with any events where we can. Thanks so much to all of you who have helped spread the word on my running and indeed contributed to the fundraising. I think you are all amazing and inspire me to get out there and pound the pavement.

Watch this space for the next event !!!!

Dean Tulloch

QLD Family Retreat and Youth Camp

Over 40 families participated in the recent MDDA QLD retreat and Youth camp held at Alexandra Headland, Sunshine Coast in August.

The weekend provided an excellent opportunity for new and old friends to gather and share information and ideas whilst enjoying some time to relax and socialise with family and friends.

Our IEM "Grommets" had an absolute blast enjoying the facilities of the campsite including traversing the rock climbing wall and hitting the beach to try their hand at surfing - with some great talent displayed! Thankyou Paul Melham for again supervising this program over the weekend.

The catering at Alex Park exceeded all expectations with our chef Peter Corkery and his team whipping up some delicious dishes for us all to enjoy with heaps of variety and flavour. Thank you Bridie Melham for managing this, you did an amazing job.

MDDA and PKUNSW Presidents Monique Cooper and Andrew McDonald provided an update on progress the two organisations are making towards an eventual merger, and also had the opportunity to jointly present and thank **MDDA executive committee member Louise Healy for her outstanding contribution in leading the IEM food grant reinstatement** campaign which resulted in an incredible victory after a 71 day intense government lobbying and social media campaign.

Attendees also enjoyed an evening of trivia with thanks to PKU team and newlyweds Tim & Bianca who kept us guessing with a suite of challenging questions for all – even a bit of IEM trivia!

Overall the retreat was a great success, and the MDDA thanks everyone that was involved in its organisation and support.

The next MDDA retreat will be announced in our next newsletter and is expected to take place in October 2016 in NSW.

Recipes

Some delicious and easy recipes were demonstrated and tasted over the weekend with thanks to MDDA members; Kylie Doonican, Shanna Driussi, Carmen Esparon and Bridie Melham. The following are a few highlights of what was created with full detailed recipes available in the recipe section of our MDDA website.

Salads: Asian Inspired noodle and Roast pumpkin & Beetroot salad

Mains : Cauliflower fried rice, savoury slice

Sweet: Carrot Cranberry Muffins

Teens: Belgian Waffles, Pancakes, cheese toasties



Thanks to our major sponsors for the QLD Family Retreat & Youth Camp



Innovation in Nutrition



Thank you to our product sponsors



QLD Clinic Insights



The MDDA was fortunate to have Anita Inwood – Metabolic Clinical Nurse Consultant, and ASIEM Chairperson, along with Clare Kreis, Dietitian, Danyelle O'Brien, and Tania Roper, from the QLD Metabolic Clinic, who were kind enough to give up their Saturday and join us at the QLD retreat to share their insights and some dietary management tips and best practices.

Anita announced the brand new national protein counting guidelines for PKU in Australia, that have just been signed off on by ASIEM and soon to be rolled out nationally.

In addition Anita spent time with our other IEM's updating them on latest research surrounding their particular IEMs, and also chatted with our teens group, facilitating a very productive discussion on transitioning from adolescence to adulthood

Metabolic Dietitian-APD, Clare Kreis presented on "Healthy Habits for a Healthy Low Protein Diet", and provided some very useful tips and tricks to develop a better mindset in diet management.

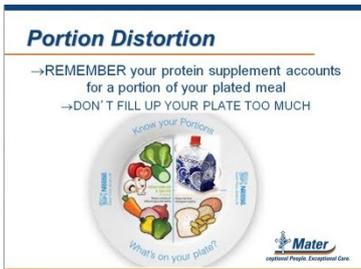
Clare presented a number of slides focused on the newly revised Australian Healthy Eating Guidelines, adapted to a low protein IEM diet. Much discussion was had around balancing daily nutritional requirements across your meals, and portion control including being mindful of our supplements acting as a portion of our meals, and adjusting portion sizes accordingly.

Some healthy and well balanced sample meal plans were provided also low in carbohydrates and sugars, with the suggestion to not be afraid to add spices and flavours for greater taste and enjoyment.

A panel discussion was held with the clinicians, where we discussed the variations in dietary management across various IEMs. Another interesting topic was also the nutritional composition of the special low protein foods and formulas.

The MDDA wishes to thank Anita, Clare, Danyelle and Tania.

For a copy of Clare's full presentation please visit the resources section of the MDDA website.



Standard National Guidelines for PKU in Australia

The MDDA is pleased to announce the release of newly agreed national 'protein counting' guidelines for PKU in Australia.

This announcement comes following MDDA and PKUNSW formally submitting a joint request to the Australasian Society for Inborn Errors of Metabolism (ASIEM), back in July 2014, to consider the rollout of a Standard National Framework for Australia. This initiative followed suit with both Europe and the US, where a call for national guidelines is also underway.

The submission drew attention to the variety of different methods being utilised by PKU families around the country when it came to counting the protein composition of common foods. Through drawing on specific examples, the submission highlighted many of the inconsistencies, and the confusion and concern it created amongst individuals.

Monique Cooper, President of National PKU Support Group, MDDA, said, "With the prominent use of social media within our IEM community, and regular attendance at national events, the differences between state methodologies has

become glaringly obvious, and become a constant obstacle for our community and organisation".

"Basic differences in the counting of staple daily food items such as sweet potatoes, tomatoes and mushrooms causes regular confusion amongst members, with a simple recipe resulting in multiple calculations of protein content - making it near impossible to confidently share food ideas amongst the group without controversy", Ms. Cooper added.

In addition to the "protein counting guidelines", ASIEM has released the first national set of Maternal PKU Management Guidelines, providing maternal women across the country with a detailed and consistent framework to follow in consultation with their metabolic clinicians.

PKUNSW president Andrew McDonald welcomed the news, stating, "It is great to see ASIEM facilitating effective collaboration amongst our national metabolic experts. Maintaining an effective support network for such a rare condition, that is regulated by state boundaries, is limiting, so this initiative brings us one step closer to working hand

in hand with MDDA in supporting a truly national PKU community".

Following the finalisation of the PKU maternal guidelines, ASIEM has announced they now have a working team in place to progress national PKU guidelines for everyone, and look forward to keeping us up to date on its progress.

The MDDA and PKUNSW thank ASIEM for their efforts in seeking effective and consistent guidelines for all PKU management across Australia, and look forward to seeing the benefits of greater consistency come to fruition.

Please visit the resources section of the MDDA website for a copy of the guidelines.

The MDDA strongly advises all individuals to consult directly with their metabolic clinician before making any changes to their current protein counting methodology. These guidelines are a recommended framework only, and specifics may vary on an individual basis as advised by your dietitian.

QLD Family Retreat August 2015



QLD Youth Camp August 2015



A PKU Love Story- Bianca & Tim

Where did you meet?

After meeting way back as toddlers at a PKU appointment, playing together in the waiting room (as recounted by our mums), the next time we would cross paths would be at the PKU NSW Camp in 2000. It wasn't until the 2006 NSW PKU Camp that we both caught each other's eye.

Could you believe you both have PKU?

Seeing as we met at the PKU camp, it was no surprise to us that each other also had the condition. It made dating a lot easier. No trying to work out if you can eat at a restaurant the other had picked, no problems sharing meals which actually posed a problem for Tim when I picked off his plate!

What part has PKU played in making your relationship stronger?

I think the fact that we both have PKU means we have this unique understanding of each other. We know first hand all the challenges that each other faces in a day, but also the little triumphs too – who else would share in my extreme excitement when I come home to break the news that I'd found a new low protein snack in the supermarket?

Where was your first date? Who asked who out?

For our first date Tim took me to the movies to watch Borat. It was verryyy nice. I was probably a little oblivious to his advances at first. We always kept in contact and chatted to each other, but it wasn't until a couple of years later that we went on a few dates again and Tim finally asked me out. He made sure I was vulnerable by scaring me silly watching Paranormal Activity first before asking the all-important question. I excitedly said yes and here we are happy and married over 5 years later.

How are meal times? Who cooks the best PKU food - what is it?

Meal times are great! We both love to cook so the whole "Who cooks better?" is a big debate. We both like to think we pretty good. Tim makes a great pasta sauce, but only after stealing my recipe and improving on it somehow (he keeps that a secret!). I love to experiment, which sometimes ends in a disaster but other times adds a yummy new recipe to our repertoire.

Where/how was the wedding proposal?

The wedding proposal was at sunset point in Thailand, it's a beautiful headland that has 270 degree views of the Andaman sea. We went on a sight seeing tour that day with a personal driver, we stopped off at the big Buddha, the Phuket Botanic Gardens and Wat Chalong Temple



before we made our way to the beautiful sunset point. Just as all the fishing boats were making their way home and the sun was setting over the ocean, Tim hopped down on one knee and asked Bianca to be his wife. (She said yes!)

What was on the menu at your reception?

The menu was standard for an Italian wedding, twenty-six courses. There was pasta, meat, fish, seafood, antipasto and many, many other things. I don't think anyone ate for weeks later.

Did you have any obstacles with the venue in catering for your PKU restrictions?

No, the venue was great in catering to what we wanted. We explained beforehand exactly what we would like. We received some great food including rice paper rolls, vegetarian antipasto, pasta, a vegetable stack and some sorbet for dessert. We were only able to eat a bite every few minutes though and missed out on most of the food as we were so busy talking to all our guests.

What is the most memorable part of your wedding day?

The most memorable moment may sound cliché, however when the church doors opened and I saw my beautiful bride it took everything I had to hold it together. Words fail to describe the culmination of emotions of which you feel at that moment.

What do you look forward to most about sharing your lives together?

The simple things in life, new experiences and sharing them with one another, taking the time to take in as much as we can.

Bianca & Tim Buecher

ANNUAL MEMBERSHIP IS NOW UP FOR RENEWAL

RENEW TODAY \$35

go to: www.mdda.org.au/renewal

donate go to:



A Youths perspective on living with an IEM

Taylah Shier (age 14)

IEM: PKU.

On living with PKU:

I don't find the diet hard to manage but sometimes it can become difficult to keep within my protein allowance. I don't believe that PKU stops me from doing anything though. I'm asked a lot if me not being able to eat things like meat or having smaller portions upsets me but truthfully I haven't known any different so it doesn't bother me.

School:

Being able to keep my PKU on track has allowed me to perform well at school. My best subject is Science and I thoroughly enjoy it. At primary school my teachers and the office staff were amazing when it came to me having my formula or just being aware about my diet and the effects. As soon as I settled into primary school the questions about my PKU had started to happen less often.

Explaining PKU to others:

When I began high school last year the questions such as "What are you drinking?" started to happen again but I have my short speech about my PKU memorized perfectly (after explaining it so many times) or if I'm not in the mood for explaining it I just say I have a special diet. My close friends are really informed about my diet and no one ever really makes a big deal out of it. Once people understand my PKU it just becomes a normal occurrence.

The difficulties in attending camps/parties

As part of my specialist program at school my class attends a few camps each year. My PKU has never stopped me from attending any of these events even when we are at camp grounds without electricity or running water. I generally take an esky full of frozen water bottles so I can have cold water for my formula, premade or packaged snacks and maybe a can of spaghetti or something to put on the BBQ. I believe there is always a way to cater for events such as parties or camps without feeling different to everyone else.

Family life and cooking:

My Mum has played a very important role with me having such a positive view on PKU. Since I can remember I have been involved in making food decisions, cooking meals and treats and writing down my daily protein intake in a diary with the help of Mum when I was younger. Now I can do all that by myself and this has made living with



PKU somewhat easier for me. I make bread fortnightly, do my own Phe level finger prick, cook dinner and other foods daily and count my own protein intake. I think these are all good skills to learn. Mum has always encouraged me to cook a variety of food so I don't get bored with what I'm eating. I enjoy cooking and adapting recipes that are suitable, yummy and look like what everyone else is eating.

In the future:

I hope to someday make a recipe book full of PKU recipes so that other people can enjoy and manage it comfortably as well. I know from my own experiences in the kitchen some recipes don't work out as well as I would like but I like to look at it as a challenge.

Words of advice:

For other kids and teens I think it's important to have a few favourite foods, finish up your formula even if it is a bit gross and to take part in some cooking but most importantly don't let having PKU stop you from enjoying things like parties. **We are people with PKU not PKU people, PKU does not define us as a person.**

Taylah Shier

New Arrivals



A beautiful baby girl
Congratulations to the **Dwan Family** on the arrival of **Kennedy Marce** Born 1st May 2015



A gorgeous baby boy
Congratulations to the **Poole family** on the arrival of **Liam** Born 13th April 2015

71 days that changed the FACE of IEMs in Australia

On the 21st May, 2015 the Australian Federal Government announced that the IEM Food Grant program would cease at the end of 2015 as part of the national health budget cuts being rolled out. Neither MDDA nor medical professionals from the Australasian Society for Inborn Errors of Metabolism (ASiEM), were consulted in the decision to cut the grant and thus the announcement came as a surprise to everyone.

The MDDA spearheaded the inception of the IEM Food Grant back in 2001 (as a monthly support payment) through strong campaigning to the federal government, and since then individuals have relied on the payment to assist with covering the hefty costs of the specialised medical foods required to prevent serious health implications.

Upon confirmation of the cut, the MDDA immediately moved to mobilise our member community to take action and stand up for what was an ill informed decision impacting on the health and livelihood of 985 Australians.

After 71 days of effective campaigning, on the 31st July 2015, the MDDA welcomed with open arms the news that the Federal Government had **reinstated the IEM Food Grant for all recipients**. This announcement ended the uncertainty hundreds of families across Australia were facing and re-instated our faith in the Australian Government support of the rare disease community.

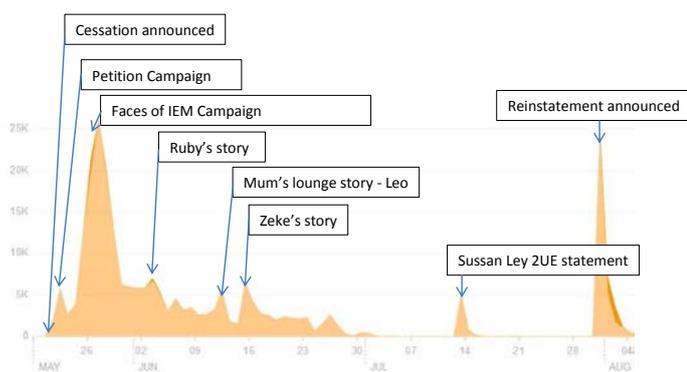
71 Days of momentum

It took 71 days for the MDDA to pave the way to victory for the IEM community. A member centric campaign was key to our success as we rallied together to ensure one voice for all IEMs nationally.

Both social media and mainstream media were leveraged along the way, and major breakthroughs were made in these areas adding weight to our political campaigning and ensuring our small voice was heard loud and clear.

Key highlights of our 71 days are captured in the following timeline. We wish to emphasise that so many individuals and organisations were involved in so many ways in assisting us with our cause that it is impossible to capture or name them all, nonetheless to say we are truly grateful for every single person and the role they played in supporting our plight.

The MDDA 71 day IEM Food Grant social media ride



The secret ingredients...

- ◇ **Responsive:** A quick acting MDDA team who responded immediately to the issue and got the whole community working proactively together and speaking one voice from the very beginning
- ◇ **Resourceful:** Early media and govt. opposition intervention helped to maximise awareness and dominate discussions surrounding health budget cuts.
- ◇ **Relentless:** The progressive flood of letters, phone calls, submissions and visits to local MP's, senators, federal MP's and Departmental heads ensured our matter was brought forward for debate in Parliament.
- ◇ **Respectful:** Strong social media and political campaigning focused on 'educating' not 'slandering' the government.
- ◇ **Unified:** Broad engagement and participation by the IEM community across the country strengthened our message through numbers and ensured our small voices became one larger voice.
- ◇ **Collaborative:** A single and unified front presented by MDDA in collaboration with all IEM stakeholders and affiliated rare disease and special dietary organisations, ensured our matter was dealt with.

The outcomes...

- ◇ **A broadened support network:** Unprecedented organic social media growth through the extended networks of our community, family and friends.
- ◇ **Increased member engagement:** Engagement heightened as members old and new came together to support one another and fight for our cause.
- ◇ **Bonded a community:** Relationships prospered and new connections formed as we shared our FACES of IEM stories and learnt of so many heartaches, triumphs, challenges and dreams amongst us all.
- ◇ **Increased public understanding and awareness:** Awareness of IEMs amongst our nation grew, providing many for the first time with genuine empathy and understanding of their condition.

The result...

VICTORY: A very sweet (low protein) victory for all!!! The IEM food grant was reinstated on 30 July 2015 for all recipients, stating a much clearer understanding of the challenges faced by people living with an IEM were now understood and appreciated by the government.

The MDDA would like to thank Minister Sussan Ley and the Australian Government for their reversal of this decision.

Thank you

In addition the MDDA thanks every committee member, family, individual, stakeholder and organisation who joined us in our plight. Our community is a much stronger and more unified group having been through this experience.

This is our 71 day story....

71 days that changed the FACE of IEMs in Australia cont

DAY#1 May 21 IEM Grant cessation announced

985 individuals with rare disease to have monthly support payment cut, placing treatment via strict medical diet financially unviable for many.

MDDA notifies and rallies members and IEM community.

MDDA sends letter of appeal and request to meet with Minister Ley and Dept. of Health.

Member call to action: Nationwide MP letter campaign commences immediately.

DAY#2 May 22

National media coverage (Ch9 & Ch10) with MDDA in Vic & SA.



MDDA change.org petition launched.

PKUNSW, HCU Network, Rare Voices Australia, Dietitians Association of Australia, Genetic Alliance Australia come on board in support.

ASIEM and metabolic professionals consulted for medical advice and guidance.

HCU Network brief Bill Shorten – grant raised in live cross on health budget cuts.



DAY#3 May 23

Member call to action: Petition drive Social Media campaign kicks in.

Petition status: 3000 signatures received.

DAY#4 May 24

Member call to action: Local & national media drive.

Local media coverage commences.

Petition status: 5000 signatures received.



DAY#5 May 25

MDDA launches national member survey for data collection and mobilises members.

MDDA provides official media release with accompanying information including key messages for member driven media.

Big names such as Denise Scott and Michael Woodhead join the cause and share our petition.

Member call to action: Join the discussion on Q&A with Joe Hockey and Twitter with Minister Ley.



DAY#6 May 26

FACES of IEM campaign commences.

MDDA meets with Department of Health, Opposition Minister for Health Catherine King and Minister Sussan Ley's advisor in Canberra.

Opposition and media meet with IEM member families.

Petition status: 7000 signatures received.

Social media supporters reached 25,000 in just 5 days.



DAY#7-10 May 27 - 30

Member call to action: Local member and senate cross bench campaign.

MDDA contacts and speaks with key Senator cross benchers and other influencers.

Department of Health respond to member letters discouragingly.

Petition status: 10,000 signatures received.

DAY#11 June 1

MDDA presents submission to Minister Ley – providing statistical, financial and medical research, benchmarking and evidence justifying the case for grant existence and reinstatement.

Ministers (including opposition Minister for Health Catherine King and Laurie Ferguson amongst others) apply pressure in question time in parliament.

DAY#12 June 2

Minister Ley's office commences outreach to families to understand the issues – means testing is raised as a possible solution to some.



Kevin Hogan MP, and other MP's meet with Minister Ley and provide reassurance to MDDA and members that action will be taken.

MDDA rebuts incorrect media and gov't statements made with factual information.

DAY#13-19 June 3-9

MDDA seeks input from members on means testing consequences and continues to collect data to strengthen our case.

DAY#20 June 10

MDDA meets with Senator Wang.

MDDA meets with local representative Michael Sukkar MP at MDDA office and discusses MDDA's concerns with the grant cut on the greater IEM community.

DAY#22 June 12

Prime Minister accuses MDDA of a scare campaign and reinforces same misinformed reasons for grant cut – outraging and discouraging members further.

71 days that changed the FACE of IEMs in Australia cont



DAY#24 June 15

MDDA Media Release – Response Prime Ministers Scare campaign accusations.

Minister's office appoints a dedicated senior advisor to manage the issue and be the central conduit for MDDA.

Petition status: 12,000+.

DAY#25 June 16

MDDA supplies feedback sought direct from members on concerns with means testing the grant.

DAY#28-35 June 19-26

MDDA submits further cost analysis assessment to Senator Wang and Minister Ley.

2UE Radio station with Justin Smith covers the story on his Drive program.

MDDA provide the department with some breathing space and time to review the materials provided, consider all points raised and talk with families affected by the cut.



DAY#35 June 25

Michael Sukkar MP meets with Minister Ley and advises MDDA a positive resolution is near.

DAY#36 June 26

Minister Ley speaks on 2UE and acknowledges an error has been made and steps are being taken to correct it.

2UE continue to cover the story and interviews MDDA along with several IEM family members and individuals on his Drive program – soliciting great public support.

DAY#37-40 June 27-30

2UE and other media outlets continue to cover the story and apply pressure for a reversal.

Ministers advisor updates MDDA that final decision is pending beaurocratic sign off before any announcement can be made.

DAY#41-51 July 1-10

HCU & Rare Voices meet with PM's office and key government heads.

AMA comes on board in support of MDDA.

2UE Radio coverage heightens with Justin Smith.

MDDA continues discussions with Minister's office and request to meet.

Members continue applying pressure on local MPs and other government representatives.

DAY#51 July 10

Minister advises MDDA that a solution is Imminent and makes public statement reassuring all that the case is being considered carefully .



DAY#54 July 13

MDDA provides official member update on expectation of a positive resolution.



DAY#61 July 20

MDDA submits further request to meet with Minister Ley in an attempt to discuss options for a positive outcome.

DAY#69 July 28

MDDA receives response to request advising a decision has been made and announcement is imminent – no meeting will be necessary.

DAY#71 July 30

Ministers office contacts MDDA to advise of the decision.

2UE contacts MDDA (and various members) to standby for comment following an announcement to be made by the Minister at the commencement of his show.

Minister Ley announces the reinstatement of the IEM Food Grant – in its initial form.

#IEMFOODGRANT REINSTATED



THANK YOU

VICTORY ACHIEVED!

The MDDA wishes to acknowledge the enormous commitment of time and energy put into this campaign by the MDDA executive team, in particular president Monique Cooper, Advocacy Director Louise Healy and Executive Officer Jenny Briant, along with the valuable support from HCU Network Founder and President Tara Morrison.

Special thanks also to the PKUNSW committee, Megan Fookes Executive Director of Rare Voices Australia, Diane Petrie Executive Director of Genetic Alliance Australia, Anette Byron, Senior Policy Officer, Dietitians Association of Australia and ASIEM Chairperson Anita Inwood along with the greater IEM medical community.

To our media specialist Elizabeth Bardwell who gave her personal time and expertise to our cause and helped our media campaign soar to unanticipated heights. Whilst many media got behind our cause, Justin Smith from 2UE personally took it to a whole new level (with thanks to MDDA member Nathan Tickle), and for this we will be forever grateful. He turbo boosted our plight, gaining broad public attention and support quickly and was instrumental in bringing the victory to a final and very positive close.

Last but not least we thank The Hon. Sussan Ley, Minister for Health, and the Australian Government for taking our concerns seriously and eventually reversing the decision.

Join our IEM faces campaign to say thank you



Information updates

Rare Voices Summit

In March 2015, the MDDA attended The National Rare Disease Summit in Melbourne, where approximately 100 representatives from rare disease support groups, along with medical, government and pharmaceutical representatives came together to drive a "National plan for rare disease".

The summit was hosted by Rare Voices Australia, the national alliance of people living with a rare disease, providing a unified voice to improve the lives of all Australians affected by rare diseases.

The Summit reviewed a Draft Communique, which lists the key principles and objectives of a National Rare Disease Plan. The MDDA has formally endorsed this Communique and it can be found on our website.



Anamix change of formula

Effective 1st June, 2015 an upgraded Anamix Junior range replaced the previous Anamix Junior range which is due to be discontinued on 30th November 2015. If you are a consumer of this product range please ensure you are working with your dietitian on an effective transition plan.

Labelling Review Recommendation 17: Per serving declarations in the nutrition information panel update

FSANZ has completed its evaluation report on this recommendation. At this stage we anticipate the Australia and New Zealand Ministerial Forum on Food Regulation (Forum) will consider the report late this year. Subject to the Forum's agreement, the report will be publicly released on the website, probably late 2015.

Nitisinone Update

– for Tyrosinaemia Type 1 individuals

On 30th September Menarini Australia was advised by the PBAC that Orfadin (Nitisinone) for Tyrosinaemia type 1 has been deemed suitable for the LSDP (Life Saving Drugs Program). They are working with the department to gain the earliest possible listing, and the MDDA will keep members posted on progress. In the meantime this essential medication continues to be provided to patients directly via hospitals without any change.

WA Clinic Update

Following recent concerns raised to MDDA by IEM adults based in Western Australia, and a subsequent visit by MDDA to metabolic clinics around the country, it became apparent that there was a gross disproportion of resource available to service the clinical needs of the Western Australian adult population effectively. Over the past six months the MDDA has been working closely with local IEM adults and the very knowledgeable and dedicated metabolic team (Catherine Manolikos and Damon Bell who are based in Perth) in order to seek opportunities to extend upon the flexibility of their existing funding model to enable a greater service to be provided to patients.

We are very pleased to advise our efforts have been rewarded, and through the provision of factual information from patients and best practice information sharing from other clinics, the WA Adult clinic hours and resources have been extended and further advice will be provided to all adult patients in due course.

QLD Clinic Update

The QLD Minister for Health, Cameron Dick MP wrote to the MDDA on September 21st to advise that Queensland is preparing to launch a statewide Lifespan Metabolic Medicine service, which will provide multidisciplinary healthcare support to people with IEM disorders. This service will also support adults with IEM disorders.



Congratulations and a big thanks to Katie who took her mum on the 5km Color run on the 12th of September in Adelaide. Thank you for your wonderful fundraising efforts and for raising awareness in your community.



St Mark's
Anglican Community School

Thank you to St Mark's Anglican Community School for their donation of \$1000 raised through the annual "Show us your colors day". It is wonderful to see this is now a tradition at the school and is in its seventh year.

Spring Recipes

Low Protein Arancini

Ingredients

- 4 cups chicken stock (1g protein)
- 1 tablespoon vegetable oil
- 1 brown onion (finely diced)
- 2-3 garlic cloves (to taste) crushed
- 330gm Loprofin rice (1.3g protein)
- 2 teaspoons Orgran egg replacer mixed with 4 tablespoons of water and 1 teaspoon of flour
- 40g low protein cheese grated, (the stronger the flavour the better (count protein accordingly))
- 17 small cubes of low protein cheese such as Bio-Cheese or Notzarella

Ingredients – for Crumbing

- 360g Dried low protein breadcrumbs (can place fresh breadcrumbs in oven and bake until crunchy)
- 100g low protein flour
- 4 teaspoons Orgran egg replacer mixed with 8 tablespoons of water
- Vegetable oil for deep frying

Method

1. Heat the chicken stock to simmering temperature
2. Heat oil in a large saucepan over medium heat. Add the onion and garlic and cook, covered, stirring occasionally, for 5 mins or until the onion is soft
3. Add the rice to the onion mixture and cook, stirring for about 5 mins. Reduce heat to low and add ¼ cup of stock. Stir constantly until liquid is fully absorbed. Continue to add stock ¼ cup at a time, stirring constantly and making sure liquid is fully absorbed before adding next ¼ cup stock,



until rice is tender yet firm to bite and the risotto is creamy. (this will take about 20 mins)

4. Stir in the grated cheese and set aside to cool. Once cool stir through egg replacer. You could add some herbs here, thyme or fresh basil, for extra flavour
5. Place breadcrumbs on a large plate and flour in a bowl. Mix remaining egg replacer into a bowl. Use wet hands to shape approx. 2 tablespoons of the risotto mixture into balls. Press your thumbs into the centre of the ball to make an indent. Place a cube of cheese into the indent and then mould the mixture around the cheese to enclose. Repeat with remaining risotto mixture.
6. Roll the balls in the flour and shake off excess. Dip in the egg replacer, then in the breadcrumbs. Place on a large plate and place in the fridge for 30 mins to chill
7. Add enough oil in a large saucepan to reach a depth of 5cm. Heat oil to 190 degrees or a piece of bread dropped in turns golden in 10 seconds. Add 7 risotto balls to the oil and cook, turning occasionally for 4-5 mins or until golden. Use a slotted spoon to transfer to a plate lined with paper towel. Repeat with remaining balls reheating oil between batches

Grilled Vegetable Bruschetta

Ingredients

- 2 large cloves garlic
- Low protein bread of choice
- 1/3 cup olive oil
- 1 small zucchini, cut lengthwise into 1/2 inch thick slices
- 2 medium tomatoes, cut into 1/2 inch thick slices
- 1 medium eggplant, peeled and cut into 1/2 inch thick slices
- 3 tablespoons chopped fresh flat-leaf parsley
- 2 tablespoons chopped fresh basil
- 2 tablespoons balsamic vinegar
- Salt and pepper

Method

1. Place whole garlic cloves in small saucepan with the oil and heat gently for 2 minutes to flavour the oil. Discard the garlic cloves and set oil aside
2. Preheat oven to 180 degrees. To make bruschetta brush the bread lightly with some of the garlic oil; toast in the oven on a baking sheet for 10-12 minutes or until just turns golden, turn the slices halfway through cooking time. Remove from oven and set aside.



3. Prepare grill. Brush vegetables on both sides with the oil. Grill vegetables on both sides until lightly charred but still firm, about 3-5 mins per side. Remove from the grill.
4. Cut vegetables into bite-size pieces and mix with the herbs and vinegar. Season to taste with salt and pepper and serve on the bruschetta toast. Enjoy!

(adapted from "Apples to Zucchini " cook book)

NSPKU Conference 2015 - Glasgow

The 2015 NSPKU Conference outside Glasgow, Scotland was an eye-opener for my 12 year old PKU son Lachlan. As if the food buffets full of beautifully presented Low Protein foods weren't exciting enough, he couldn't believe the lineup of PKU people reaching outside the conference room each meal! He was spoilt for choice and spent the next three days with a feeling he'd never properly had before – the feeling of being stuffed full of such a variety of foods he couldn't stop eating!

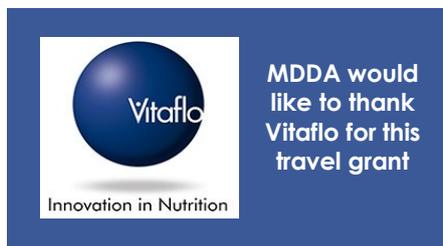
Lachlan has attended various PKU events, met other PKU children and adults and eaten foods from PKU buffets before, but never on this scale. Although he knows his condition is rare and understands the basic science of hereditary conditions, it is still a difficult concept for a child to comprehend. He has asked if there will ever be another PKU child at his school or in his soccer team, or even living nearby. He wondered at the idea of never randomly meeting other PKUs. And then he walked into a hotel conference with more PKU people than he had ever seen! *That moment of realisation, knowing he is not alone, meant so much to him.* He wondered at the numbers for days afterwards, reminiscing about "the Westerwood" and all the people who "know about PKU".

Lachlan and I were very fortunate in receiving the Vitaflo Travel Grant from the MDDA for travel to the NSPKU Conference in March. We were looking for a variety of information and experiences for Lachlan as he enters his teens and this conference had several child and teen sessions aimed at helping PKUs to understand the components of food, healthy eating, food selection and the options available both in supermarkets and from Low-Protein food providers. There were guest speakers from the NSPKU community discussing study, sports and friendships with examples of managing all of these in your PKU life. There were also several sessions reporting on scientific research and progress with trials so we felt this conference could be



very beneficial in moving Lachlan into the next phase of his PKU management with confidence.

Confirmation of our success in receiving the grant caused a great flurry of excitement and activity in our house – we had just ten days before the conference began! It was a crazy week of planning and preparing but when our departure time arrived we were confident we were well prepared for the journey. We had made a last minute order to Nutricia for par-baked bread rolls and wafers plus had a prescription for Vitaflo's Express 20s filled and sent ready for the trip. I also pre-selected the fruit platter and vegetable platter options for the flight to ensure Lachlan would be served foods at meal times. We were able to supplement these with some individually wrapped crackers, biscuits and cakes we had brought with us. While we knew the first few days of PKU food would be supplied at the conference we needed to be prepared for our sightseeing days afterwards. We needn't have worried as the food samples we were given at the conference more than fed Lachlan for the rest of the trip and stocked our pantry for the foreseeable future! We used an entire large suitcase to lug it all around the UK and bring back into Australia – all declared and accepted by customs.



On the first evening we were overwhelmed by the number of companies displaying their products for the conference. We spent time trying foods and discussing the options available from these companies each day, learning something new or discovering new products each time we ventured into the room. *Lachlan took part in some R&D product sampling for Vitaflo's new cooler flavours and felt very excited to have the opportunity to rate future flavor options for his preferred formula.* Some new products from the Cambrooke range also gained his tick of approval. I was very interested to learn that this company was named after the owners two PKU children "Cameron" and "Brooke". I knew Fate Special Foods was named after Eileen's PKU daughters Faye and Kate but I had no idea Cambrooke foods was also a family run, PKU inspired business in the USA!

The lovely ladies from Mevalia introduced Lachlan to their range with some product sampling topped with supermarket guacamole squeeze, something we'd never thought to try before. We've since



bought some here in Australia for a quick addition to crackers and sandwiches. Mevalia also stock a range of sliced bread which Lachlan thoroughly enjoyed and proceeded to eat all around Scotland and London after the Conference! With so many companies providing low protein options in the UK, the NSPKU were able to organize each meal to be designed and provided by a different company and the Westerwood Hotel Chef did a wonderful job following the recipes and instructions for the food preparation! Recipe cards and booklets were provided with each meal, giving some creative ideas and new takes on old favourites. It was handy to test the texture and taste of the various pastas and breads over the course of the conference. The meals also provided an excellent opportunity to meet new people and share ideas and stories of our PKU experiences around a table of your own choosing each meal.

I was impressed with the attendance of families and children to many of the sessions available. It was obvious the annual NSPKU Conference is an opportunity for families to connect each year and strong bonds had formed over the years of attendance. Whole families came for the fun of the holiday (especially at the inaugural Conference hosted in Scotland - considered quite a coup to the local Scottish families). Although the UK is much smaller than Australia they have never previously held a Conference in Scotland, preferring instead to alternate between the South and the North of England only. *Our own MDDA has addressed this issue for many years now and held Conferences and Retreats in cities all over Australia and deserve recognition for this tremendous effort.*

Smaller children were able to attend some special outings to a local zoo and the Resort facilities throughout the day, allowing their parents the freedom to select those activities and sessions most appropriate to their needs and current situations. The PKU sessions for young people were run by psychologists,

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dieticians and PKU young adults, providing informative and realistic information on the management of PKU in a young person's life. *Lachlan thoroughly enjoyed the dietician's session on food components, recognising the fat and salt content of a variety of products for a greater understanding of maintaining a healthy diet while choosing low-protein foods.* He was also interested to hear the scientific reports on the laboratory trials for BH4. While he is a classic PKU and doesn't have much hope for these products being of use to him in the near future, he was interested to hear about the procedures and tests, the research pathways and potential for breakthroughs at some point. I think he found the notion of a mouse with PKU quite interesting!



Eileen Green's Fate stall was abuzz throughout the conference. She had a variety of her recipes prepared for everyone to try, along with recipe sheets and free booklets to complement her original Recipe book.

Lachlan enjoyed all of her foods but especially loved her pancakes with fresh blueberries on the Sunday morning! The foods she had planned for her buffet night were also a hit and the hotel chef had great success in following her directions to prepare the recipes she'd left. Most of us have heard that UK residents are able to order their Low-protein food products for free through their Health system and this routinely makes us all green with envy. My conversations with families and young adults at the Conference confirmed the positive impact this has on their ability to stay on diet.

Families are able to experiment with recipes without the cost of each cup of flour or pasta hanging over their heads.

The variety of Low-Protein suppliers in the UK is also enviable. While there appeared to be some favourites, the continuing existence of this number of companies, alongside newer companies and products breaking into the market, shows individual

tastes require more than one option to be satisfied. I can only dream of this in Australia, at this stage, but hope to see an increase in suppliers and products in the future.

Our experience in Scotland at the NSPKU Conference has made an impact on both my son and me in many ways. From information gathered to a feeling of comradery, this trip was beneficial in ways we are still discovering. I cannot thank the MDDA and Vitaflor enough for this wonderful opportunity.

Kylie Doonican



Katy Drewitt - Adult IEM get together

Every March Richard and I take our annual holiday and this year we decided to take Eden and head north, to the Gold Coast. We thought this was a good opportunity to put a call out for some of the MDDA family to have a catch up while we were there.



Nicholla and Joe Kinscher made the trip from Lismore and stayed with us for the night which was lovely as we got to spend a bit more time with them. We had quite a laugh preparing food for the gathering, throwing together some veggie burgers in my Thermomix. Nicholla also made some bread and we even had a production line going making veggie kebabs!

Carmen Esparon and her daughter, Cierra, Rachael Cook, Renee and Matt Flood and their son Harry all came to enjoy a catch up with friends while enjoying some yummy Low Pro food.

Although the weather was lovely no-one, (except Richard and Eden!) took the opportunity to go for a swim, but the kids loved having the backyard and play equipment to run around and play on. Meanwhile, we adults were quite happy sitting back and swapping stories of success and frustration, which included chatting about pre-con/pregnancy, as 3 of us are mothers and Nicholla was on pre-con. Sometimes just knowing that you aren't the only one who cries when your loaf of bread doesn't turn out is all you need. You are NOT alone.

I'm so grateful for my MDDA family and having their support means the world to me. It's been described to me once as "feeling like I've come home", which I completely agree with. I would love to have more of these informal catch ups.

If you want to organise one in your area, contact the MDDA office on (03)9723 0600 or email office@mdda.org.au

Many thanks to Vitaflor and Nutricia for donating low pro foods to use for our catch up. Also I must thank Carmen for her delicious Green Bean and pumpkin salad and Renee for bringing a fruit platter.



Product Updates



So Good Coconut Milk
Protein per 100g: 0.2g
Protein per serve: 0.5g
Serving size: 250ml
Suitable for: All
Available from:
 Woolworths



Blue Diamond Almond Milk with Honey
Protein per 100g: 0.5g
Protein per serve: 1.2
Serving size: 250ml
Suitable for: All
Available from:
 Coles & Woolworths



CocoCola Life
Protein per 100g: 0
Protein per serve: 0
Serving size: can/bottle
Suitable for: Children & Adults
Available from: Coles & Woolworths



Has No – Gluten free Six Seeds Bread
Protein per 100g:
Protein per serve: 2g
Serving size: 50g
 2 slices
Suitable for: All
Available from: Aldi



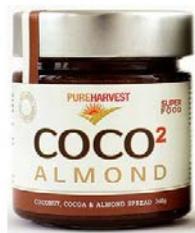
Macro Thai style Carrot-Dip
Protein per 100g: 2.1g
Protein per serve: <1.0g
Serving size: 20g
Suitable for: All
Available from:
 Woolworths



Creative-Gourmet – Gluten free Crêpes
Protein per 100g: 3.2g
Protein per serve: 1.6g
Serving size: 50g
Suitable for: All
Available from: Coles



Chan's-YumCha Shitake Dumpling
Protein per 100g: 1.1g
Protein per serve: 0.4g
Serving size: 37.5g
Suitable for: All
Available from: Coles, Costco, Woolworths



Pure Harvest COCO2 Almond spread
Protein per 100g: 7.3g
Protein per serve: .7g
Serving size: 10g
Suitable for: All
Available from: Health food stores



Kraft Cashew Spread
Protein per 100g: 5.0g
Protein per serve: 1.1g
Serving size: 22g
Suitable for: All
Available from: Coles

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