

2020 is coming to an end and I won't be sad to say good riddance, sweep it out the door, and welcome in a new year!

Toilet paper, frontline workers, home schooling, lockdown, coronavirus, Covid-19, Zoom meetings, flatten the curve, stay home, pandemic, masks, quarantine, social distancing, self-isolate. These words filled up our days.

The year posed many challenges for all of us. For the MDDA, it also brought us opportunities to be creative and look for new ways to connect and support our community.

Though we couldn't meet in person, the digital world revealed a number of opportunities. We hosted our first ever virtual @Home Retreat replacing our traditional face to face yearly event with over 200 attendees from all over Australia and New Zealand.

The @Home Retreat was deemed a huge success. We were able to create a fun and engaging weekend for our members that included sessions for everyone regardless of their age or IEM.

We also hosted the virtual launch of the PKU Carers Compendium with the Royal Melbourne Hospital. The event was attended by more than 70 carers representing 37 patients living in supported care. Originally planned to be launched in Victoria and rolled out to other states in the coming months, we were able to launch the program and compendium nationally all on one day.

We held our LowPro Inspo Live cooking demonstration, where delicious bowls of lowpro Fried Rice were being cooked simultaneously around the country.

Fundraising was difficult for MDDA in 2020, so to all our wonderful members who took on #teammda challenges and fundraisers – we THANK YOU! We appreciate the enormous effort and amount of work you did in this challenging year.



To all our generous sponsors and partners, without your funding we wouldn't be able to offer the level of service, support and programs to the IEM community. Thank you BioMarin, Menarini, Cortex Health, Orpharma, Nutricia & Vitaflo. We look forward to working with you in 2021.

To our amazing members and volunteers, thank you for your support, you inspire us to continue the vision and mission of the MDDA.

We held our virtual AGM in November and welcome back all our Executive Team, Monique Cooper, Louise Healy, Paige Moore & Bianca Albanese. We would like to thank them all for their incredible leadership and support this year.

A special thank you to **Monique Cooper & Louise Healy**, their commitment to supporting the IEM community is immeasurable. They give countless voluntary hours to support the MDDA and our members, they bring professionalism, integrity, innovative ideas and inspiration to the team. We are lucky to be beneficiaries of their generosity. Thank you to Jo our compassionate Patient Pathways Nurse, Kerry our friendly MDDA Admin & Bella our Communications guru, what a year we've had!

So, while we move cautiously but optimistically into 2021, we'll bring the resilience, diversity, collaboration and compassion 2020 has taught us. We wish you all a **HAPPY, SAFE & HEALTHY Christmas and New Year!**

Jenny Briant & the MDDA Team

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MDDA Office Christmas closure:

*The MDDA Office is taking a break from the 21 December to 8 January 2021.
For the remainder of January our office hours will be reduced.*



MDDA @Home Retreat

10-11 October 2020

MDDA, along with many of our members, were disappointed when we had to postpone our Queensland Family Retreat due to the COVID-19 pandemic. However, we didn't want to wait for a full year before we were able to get together, so, it was decided that we would organise the first ever **VIRTUAL MDDA RETREAT**. The inaugural @Home Retreat took place 10th - 11th October 2020. MDDA delivered Australia's first ever 2-day virtual event/conference, with more than **40 sessions broadcasted live**. Over 200 members participated in the event where attendees were engaged throughout the virtual experience, replacing our traditional face to face National Family Retreat. The virtual @Home Retreat was deemed a huge success for members across Australia and New Zealand as we were able to create a fun and engaging weekend for our members that included sessions for everyone regardless of their age or IEM.

The program offered national and international educational and scientific sessions, panel discussions, virtual exhibitions, interactive workshops and networking opportunities via the 'Members Hub'. Through the collaboration and generous support from our valued partners we were able to reimagine the Family Retreat to convey this new program bringing the IEM community together to reconnect and share experiences, especially valuable in this current difficult time. Attendees were able to immerse themselves in a virtual space of inspiration, discussion, and creativity across the whole weekend.

Whilst we could never replace an in-person event, by using innovative technology, we did feel like we all participated in a truly unique and invaluable experience! We want to thank all our members who attended this event and hope that we have helped to further educate and connect to the IEM community and feel that they participated in a peer supportive event.

We would also like to express our gratitude to all of the health professionals, presenters, speakers and volunteers who took time out of their weekend for this event. We truly appreciate that they are all willing to give their time and expertise to enrich and educate all those attending the event, their contribution really helped make this event what it came to be!

Following is a summary of the scientific and informative sessions. Continue reading over the page for the fantastic anecdotes from our members about this great weekend!

Dr. Minal Menezes

Our first speaker to present was the wonderful Dr. Minal Menezes who presented on the '*High-throughput screening of potential therapy targets for protein metabolism disorders*'. Dr. Menezes is a Senior lecturer at the University of Sydney and leads the Phenylketonuria research at the Kid Research and Children's Hospital Westmead. Her research focuses on trialling novel treatments for PKU and she received the Early Career Kick Start Grant from the University of Sydney for her work on PKU. Dr. Menezes is a great



friend of the MDDA and we thank her for talking time out to present to us on such an interesting and important topic.

Anita Inwood

Long time friend and supporter of the MDDA, Anita Inwood is the Director at Queensland Lifespan Metabolic Medicine Service and the Metabolic Nurse Practitioner at the Children's Health Queensland Hospital and Health Service. Anita presented two studies at the @Home Retreat - '*Parenting & PKU*' and '*Quality of Life - Kuvan*' studies. Anita was instrumental in developing the model of a Metabolic Lifespan Service, the first of its kind in Australia. Anita lead the development of national evidence-based guidelines on the management of PKU and maternal PKU. Anita is a highly respected metabolic clinician both in Australia and internationally. Those of you who have met Anita, either at the Queensland clinic or from her attendance and presentations at many of our family retreats, will be aware of her passionate commitment to the best care for metabolic patients Australia wide.



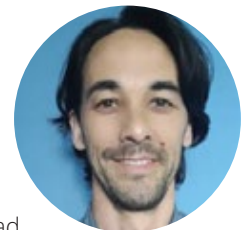
Dr. Elizabeth Barnby

By having this year's retreat virtually it has opened up the opportunities for us to hear from a speaker outside of Australia! MDDA welcomed Dr. Elizabeth Barnby to present live on the topic of '*Current Global Learnings of Tyrosinaemia Type 1*'. Dr Elizabeth Barnby is a Clinical Associate Professor at the University of Alabama Huntsville. Raising 2 children, now adults, with Tyrosinaemia inspired Beth to continue her education and research in IEMs. Dr. Barnby has an interest and extensive knowledge of inborn errors of metabolism, gene therapy, Hereditary Tyrosinaemia Type 1 (HT1), Genomic science, New drug discovery through molecular modelling, Tyrosine scavenger for HT1, Lentiviral vector gene therapy, Cognitive changes in HT1, Autism's relationship to inborn errors of metabolism and Murine models of disease. She has published approximately 9 manuscripts and has 3 articles in print regarding Tyrosinaemia. She hopes to publish new findings on a research project regarding Tyrosinaemia soon.



Dr. Michel Tchan

Dr Tchan presented on '*Diffusion Kurtosis Imaging Characterisation in PKU*'. Dr Tchan is a clinical and metabolic geneticist looking after adults with genetic disorders and inborn errors of metabolism. He is currently the Head of Department, Genetic Medicine at Westmead Hospital and responsible for the NSW Adult Genetic Metabolic Disorders Clinic. Dr Tchan's research interests include the neurological consequences of Phenylketonuria in adults, and clinical trials of novel therapies for genetic disorders.



Prof Ian Alexander

Prof Alexander presented on '*Emerging gene therapies for rare (non PKU) inborn errors of protein metabolism in Australia*'. Professor Alexander is a Professor in Paediatrics & Molecular Medicine, Disciplines of Child and Adolescent Health and Genetic Medicine at The Children's Hospital at Westmead, Head of the Gene Therapy Research Unit. Over the last 20 years Prof Alexander has played a central role in the establishment of the gene transfer/gene therapy field in Australia, and focused his research efforts on virus-mediated gene transfer and translational medicine. Professor Alexander is one of Australia's leading authorities on the development and use of recombinant viruses and has become a global leader in the development of liver-targeted gene therapy for metabolic/genetic liver disease (particularly urea cycle defects, UCDs).



Prof Mark Walterfang

Prof Walterfang presented on '*Psychiatric and Cognitive Aspects of Phenylketonuria: The Limitations of Diet and Promise of New Treatments*'. He has particular interest and expertise in the use of neuroimaging to aid in the diagnosis of complex neuropsychiatric disorders.



IEM Clinical presentation – Metabolic Dietitians & Nurses

Thanks to Anne-Marie Desai, Christine Fischer, Kate Billmore & Catherine Bonifant, we are truly grateful to have had these wonderful state metabolic dietitians and nurses participate in this event. We are most appreciative that they gave their personal time to share with us their knowledge, experiences and thoughts throughout their presentations. In addition, they made themselves available in the virtual Showcase to answer questions from attendees. The sessions were recorded so attendees were able to review the presentations throughout the event. A range of special interest topics were presented including:

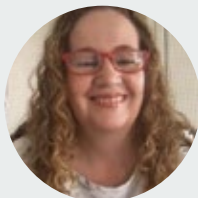
- *Guthrie Card, Finger Prick Testing & Tips* - presented by Christine Fischer, Metabolic Nurse, Royal Melbourne Hospital
- *Label Reading on a Low Protein Diet* - presented by Kate Billmore, Metabolic Dietitian, Westmead Hospital
- *"What's in my Formula?" Adults* - presented by Anne-Marie Desai, Metabolic Dietitian, Royal Melbourne Hospital
- *"What's in my Formula?" Kids* - presented by Catherine Bonifant, Metabolic Dietitian, Queensland Children's Hospital
- *Nutritional Dietary Tips* - presented by Anne-Marie Desai, Metabolic Dietitian, Royal Melbourne Hospital

Interactive Workshops

*The workshops were designed to provide hands-on information on specific topics and areas of interest.
The workshops were focused on health & wellbeing.*

Zest Adult Wellness

Louise facilitated a 2 hour Adult Wellness session using the modules of the ZEST program to check-in on our mental health and overall wellbeing. This session proved to be extremely popular with our adult members. Thank you Louise.



Teens Transitional Workshop

The Teens Transitioning Workshop described the key components of transitional care for IEM teens and their parents/guardians. 'Transition' refers to a child's move from paediatric hospital to the adult health care system and the process of teens taking on more independence and responsibility in their IEM management. Transition isn't something that happens overnight, and is a gradual process that involves preparing the younger person for the next chapter of their life - young adult hood. This session included a practical guide to help both teens and parents/guardians prepare for this exciting time in their lives.



Grandparents Discussion Forum

Last year at the Tasmanian Retreat MDDA offered a session for grandparents with an opportunity to come together to share experiences, ask questions and support one another. Many grandparents play a wonderful and supportive role in helping to raise our IEM kids. After seeing the value of this forum we were lucky enough to have Susi Hendricks once again run a session for grandparent/carers. It was warmly received and from the survey results greatly appreciated.

PKU Adult Advocacy Workshop

A workshop was held discussing tools we can use for effective advocacy, setting clear aims and objectives, constructive conversation techniques and ways for our community to take positive actions to advocate for new treatments and therapies.

New Parents Discussion Forum

Support provided from your peers can have a huge positive impact on your IEM journey and meeting new families is an important feature of MDDA's events and retreats. At the @Home Retreat we welcomed new parents into our community. A New Parents Discussion Forum was held giving those of newly diagnosed infants an opportunity to share their story and connect with other new parents.

Peekabu Kids Club & Teens Mentoring Session

The MDDA @Home Retreat was not only for our adults and parents, we had some fun interactive activities in store for the kids too!



PeeKabU Kids Club Virtual Scavenger Hunt Quest

This session was a lot of fun! Sunday afternoon we staged our exciting, innovative, fun-filled PeeKabU Kids Club, where our LowPro Teen mentors hosted the first of its kind - Virtual Scavenger Hunt "The Great IEM @ Home Quest". IEM kids and siblings from 5yrs onwards joined a team to complete the Quest. This was a fun and positive IEM mentoring and leadership experience for all kids and teens involved. Teams took photos and video's of themselves taking formula, bloodspots, fav lopro foods & pantrys, pets (snakes!) dress ups, MDDA teddies etc were all published to a gallery where plenty of prizes were up for grabs!

Member Hub

We all know that a major drawcard to our in-person events is the opportunity to catch up with friends, meet new people and build upon our peer support network. The Member Connect Hub was the perfect place to do just that! Attendees uploaded a profile picture (individual/family), answered a few questions about themselves to appear in the Hub where then we could meet and share stories and chat with other members during our designated networking breaks. The Speed Dating style event was a highlight – attendees were randomly grouped for 5 minutes in small 3 to 4 bubbles to meet and chat, who was going to pop up in your screen next?



Interactive Panels: Rare IEMS Advocacy Panel; PKU Adults Panel; IEM Kids & Teens Panel

Last year a big hit at our Retreat was the Q&A panel where kids got the opportunity to ask questions to our IEM teens. This year we hosted this panel online. Kids and parents were able to ask the teens any questions they had around school, diet, sports etc. Our interactive panels were no mean feat to pull off!

Key discussions were held where the attendees could type or ask questions live. There were funny anecdotes, stories and shared experiences. Thank you to Bianca and Susi for your amazing moderating skills.

Low Pro Showcase & Low Pro Cooking Masterclasses & Demonstrations

Nutricia and VitaFlo participated in the virtual Showcase providing resources and videos to be downloaded. Both low protein suppliers were available live to chat with attendees about any questions they had, website & ordering queries, providing tips & offering low protein food product advice. Masterclass cooking demonstrations were held with some delicious easy recipes to add to your low protein menu ideas.



My MDDA Retreat Experience

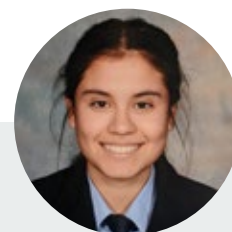
Due to the unforeseen circumstances of this year, unfortunately, the Queensland retreat had to be postponed to a later date. However, the MDDA was able to host the first-ever online retreat over the 10-11th of October!

This weekend was filled with fun and informative sessions. The interactive sessions run across the weekend such as the Q&A panel and the kids club allowed participants to have a taste of a retreat from the comfort of their homes.

As a kid, my parents have brought me along to a couple of the retreats as they thought it was important to meet kids my own age with PKU and hear the advice of older kids and adults who have lived with it. Fortunately, myself with a couple of other PKU teens were given the opportunity to help out at this year's virtual retreat by assisting with the kids club and answering any questions that either other kids with PKU had or parents. It also enabled the younger kids to meet other kids their own age as well as realise that they aren't alone.

I would like to thank the MDDA for organising yet another successful retreat during these challenging times.

Frances, PKU Teen



A big thank you to Bianca, Damon, Evie, Elena, Emma and Frances for participating in our IEM Kids and Teens Panel. We had some wonderful feedback from parents and other kids/teens as to how valuable this type of session is.

Major Sponsors



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In-kind supporters



MDDA thank our sponsors, in kind partners, speakers and volunteers that all played a key role over the weekend.

My MDDA Retreat Experience



Louise, mother to Caitlin (PKU)

The MDDA retreat has always been a highlight of the year for us in the MDDA community. For my 5 year old daughter Caitlin, who has PKU, a weekend getting on a plane to a lovely location and connecting with old and new friends in the MDDA community has become something to really look forward to.

Clearly with COVID-19 situation in 2020, this year's retreat was going to be different. Whilst disappointed that the retreat itself wasn't going to go ahead as planned in Sanctuary Cove, Queensland, we were excited about the prospect of a 'Virtual Retreat'. It is always an opportunity to learn more through the scheduled talks and discussions with other attendees.

The virtual event this year itself was so well managed, and an absolute credit to Monique and the others at the MDDA who worked so tirelessly to arrange the weekend. The registration process for the event was straightforward. Once the event kicked off online, the colour coded schedule helped to highlight which topics were relevant. It was also great to have the ability to look back over recorded sessions of ones that might have been missed.

The highlights of the virtual retreat weekend for me were the 'speed dating' – getting to speak to others for a short period of time - and the Scavenger hunt activity for the kids (and big kids like me). Caitlin and I came away from the weekend more informed about PKU and other IEMs, happy after re-connecting with the MDDA community and a renewed capacity to deal with anything related to living with an IEM (Inborn Error of Metabolism).

The event, as always, completely exceeded all expectations. Despite the challenges of COVID-19, there is always a way for our community to help each other, share knowledge and provide support to the newer members. Thank you again to all at the MDDA who make such a positive difference to anyone who either directly or indirectly is impacted with an IEM.

Caitlin and Lady had so much fun participating in our @Home Quest Kids Scavenger hunt. Well done on winning one of our prizes!



Bianca, PKU Adult

A major shift from our usual in-person retreats, flying or driving in to arrive at beautiful event spaces, this year we met our regular faces and new ones too from the comfort of our own homes.

The retreat was jam packed with talks from local and international researchers, dietitians and physicians across various IEMs. We had cooking demonstrations, low protein showcases featuring low protein products and educational sessions including "What's in our formula".

There was something for everyone. Kids and teens were involved in panel discussions, where it was realised we have many shared experiences but also unique ways of managing our conditions. Recipe ideas were shared, as well as tips and tricks for the daily ins and outs of our conditions. Teens and parents were involved in a transitional workshop, focused around the transfer of responsibility but also confidence in becoming your own self-advocate. Forums were held for parents and grandparents and panel discussions for adults to discuss topics such as health and well-being advocacy and coming back to diet.

And we can't forget the social events. Kids were involved in The Great @Home Quest, capturing some of the cutest pictures and videos of formula drinking, blood spot taking and low protein food cupboards. We even had a few special guests, lots of puppies and a snake! While we weren't able to share a drink in person at the end of the night, group chat rooms allowed us to all catch up.

A massive thank you is in order to all the hard working team behind the retreat, that was able to put on such an amazing event in the midst of the 2020 chaos. Each year's retreat is always such a highly anticipated event in the IEM community, and I think I speak on behalf of everyone in saying we were all so grateful it could go ahead.

It was great to see that a number of our members took advantage of our Social "speed meeting" sessions to catch up with some familiar faces!



MDDA Retreat



Sarah and Grant presented at our Virtual retreat as to what might be possible in the future with the help of an assistance dog. A topic of great interest for our rarer IEM's. Their son Isaac has Citrullinaemia.

Sarah, Grant & Isaac Dodds

A Life changing opportunity - an assistance dog

Our miracle boy, Isaac, has a very rare metabolic condition which could result in brain damage, coma or even be fatal due to high levels of toxic ammonia building up in the body. An assistance dog could help prevent this. Isaac has recently had several occurrences of high ammonia only discovered by routine blood tests and he was not showing any symptoms. We'd like to trial training an assistance dog to alert us when it smells high ammonia. This dog would also assist with other complex challenges in daily living functions enabling Isaac to have greater participation in family and community life and build his independence. We will share our experience of an assistance dog with the Australian and Worldwide metabolic associations and groups to help build up the body of evidence for this potentially life changing addition to our family. It's going to cost approximately \$40,000 not including ongoing costs.

An assistance dog could change Isaac's life dramatically.

To support the Dodds family and to support this research go to www.mycase.com.au/page/229672/a-life-changing-assistance-dog-for-isaac or email office@mdda.org.au for further information.



Advocacy Update

Plenty has been happening in the advocacy space since my last report. First and foremost MDDA has had a strong focus on our position that all IEM patients should have access to treatments that are safe and effective as soon as possible. We have continued to make representation to the sponsor organisation regarding sapropterin (Kuvan) and Pegpal (Palynziq) in Australia.

The Pharmaceutical Benefits Advisory Committee (PBAC) will consider sapropterin at the November meeting. Thank you to everyone who made a submission. The MDDA submission focused on the need for equitable access to treatment and the high burden of treatment currently faced by those patients using dietary therapy alone.

In addition to these activities the MDDA made several submissions to government inquiries and reviews to highlight issues of importance for our IEM community. These included:

- Submission to the Parliamentary Inquiry into approval processes for new medicines and therapies. Our submission highlighted the long wait Australian IEM patients have had to access therapies available overseas, the need to attract clinical trials for the rarer non-PKU IEMs to Australia, the need to invest in early stage research for the very rare IEMs to improve outcomes for rare IEM patients, the need for Australian medicine approval and funding processes to be fit-for purpose to evaluate emerging gene therapies – an important issue for our population with so many potential therapies currently being developed; and the need for approval processes to address the complexity of developing and measuring treatments for rare diseases. We will be

watching the inquiry as it progresses to public hearings and recommendations. Thanks to the amazing MDDA executive team who helped pull together the submission to be submitted immediately after the retreat.

- Submission to the Commonwealth's Government Preventative Health Strategy consultation. This submission highlighted the need for Newborn Screening to expand to diagnosis of rare (nonPKU) IEMs at newborn stage; to identify patients with rare lifelong conditions as a priority preventative health population in order to ensure that they have adequate support, including mental health and other clinical support, to help manage their condition throughout life and the need for all government systems to be able to adapt to respond to those living with rare conditions.
- Submission to the review of the Medical Services Advisory Committee (MSAC) guidelines, this committee is similar to the PBAC but reviews diagnostic, medical services, technologies and other complex therapies and makes recommendations regarding government funding. MDDA made a submission as we have heard from several sources that gene therapies are likely to be referred to MSAC. Our submission highlighted the need for patient involvement and input into submissions and decision making and that patient reported outcome measures need to be considered when evaluating gene therapies, especially if they are for very small patient populations, as is the case for all protein IEMs, especially the non PKU ones. Our goal with this submission is to influence the way future gene therapies and personalised therapies for IEMs are evaluated so that IEM patients have equitable access to treatments.



Louise Healy

Member Stories

Ben & Morgan (PKU Adult) Annabelle (PKU) 4 months

As everyone knows growing up with PKU or any IEM is hard, but I was lucky enough to share the struggle with my brother who also has PKU.

Throughout the early years I didn't seem to struggle a lot with controlling my diet as my Mum was very organized and always had food prepared for us, which back in the early 90's would have been somewhat difficult as there wasn't the range of low protein foods along with choices of formula like we do today.

When I hit my early teens, I went off diet for a few years as our family struggled with coming to terms with losing my Dad in 2006.

It wasn't until I was in my early 20's that I wanted to go back on diet as I always knew I wanted children and I knew I had to be healthy in order to bring a healthy baby into the world.

In 2014 I met my now husband Ben and we had the conversation early about children. After getting married in 2018 we started the process of getting ready to start the preconception diet in order to have a baby.

To begin with it was hard, as I had to be more restrictive than usual but after a few weeks it came easy and there was an end goal I wanted so bad. After 8 months of preconception and a few big hiccups along the way we found out that I was pregnant, and from day dot I had very bad morning sickness. After 11 weeks of morning sickness and not tolerating my formula or a lot of food I began to feel somewhat normal, and from there my protein allowance sky-rocketed.

From the start of the second trimester, I had a pretty seamless pregnancy, baby was healthy and we were both looked after by the most amazing Obstetrician. By the end of my pregnancy, I was consuming 68 grams of protein per day and I was on somewhat of a normal diet, eating steak, eggs, chicken, nuts most meals. By 38 weeks I was well and truly over being pregnant, luckily, I was induced at 39 weeks due to baby being on the larger size.

After a rather difficult traumatic 19-hour labour, our beautiful baby girl was born, Annabelle Mary Wilson weighing 9 pound 6 ounces.

The first few days in hospital were extremely hard between sleep deprivation and having difficulties with breast feeding, but by day four things were looking up. However, my meals were awful for the 9 days we were in there, I don't think I got one decent



PKU Mum & Bub

meal. All I asked for was a plate of steam vegetables and fruit but never got a meal I actually asked and constantly sent Ben to go and get foods that I can eat. This all led to me dropping a large amount of weight in very short amount of time. I think next time I will be bringing my own pre prepared meals. Because Annabelle would not latch due to being sore from a forceps delivery, I decided to express full time as my mental health was in a bad way, at the end of the day feed is best.

Like every baby, Annabelle had the heel prick and I did think they would push the results through with me having PKU, but I was informed that they cannot do so. Which was fine as there was a low chance of Annabelle having PKU, well so we thought.

Four days after arriving home I received a phone call from the Royal Children's Hospital saying that Annabelle has increased Phe levels in her bloods, I was in a state of shock and tried to hold back the tears whilst on the phone. The reason I cried was I didn't want my baby girl going through the struggles I have done growing up.

After a few days to process the news I was fine. The metabolic team at the Royal Children's Hospital has been amazing, no matter how many times I called in those first few week for reassurance they were so supportive and I cannot thank them enough.

Four months on Annabelle is a beautiful happy baby who is growing perfectly and thankfully sleeps like a little dream at night.

I'm sure there will be many challenges for her ahead but luckily for her she gets to share those struggles with mummy so she isn't alone.

IEM Food Grant

REMINDER: Patients with Phenylketonuria (PKU) must reapply for the IEM grant every twelve months. An application form signed by your metabolic specialist must be provided to the Department. Contact details and eligibility information can be found at the link below.

Payment Schedule 2021

The IEM food grant payment for 2021 is due by the Friday of the first full week of each month.
8 January, 5 February, 5 March, 9 April, 7 May, 11 June, 9 July, 6 August, 10 September,
8 October, 5 November, 10 December

Visit mdda.org.au/resources/iem-food-grant/ for more information



**Senada (Mum), Kenan (Dad)
Ilyas (Brother) 4, Naaila, (PKU) 4**

How was Naaila diagnosed? Newborn Screening. However, not until at 6 weeks old due to a mix-up with the original newborn screening card. This has thankfully had no impact on her.

What are the challenges you/family have faced from the point of diagnosis to now? For us, the hardest part was other issues, ancillary to PKU. Or at least we think may be linked to PKU. Naaila has broken her arms multiple times. We have some dental issues also. We are currently seeing the bone clinic to investigate if her bones are weakened, and the Dental clinic and some great child dentists to investigate if the dental issues are formula related. For us, the frustration lies in the lack of studies establishing the link between PKU and other health related issues due to the small patient numbers and perhaps lack of interest in a condition that can be "managed".

Treatment/grams of protein: Naaila is now on Kuvan and drinks Anamix Junior. Her diet is more liberal now at 20 to 25 grams a day. Still pushing it up with having recently started Kuvan so we haven't established a set amount. We aim to keep each meal between 5-7grams.

Describe your family/family life/adapting to a family member with PKU: As a family we don't let PKU stop us from anything. PKU has made our entire family healthier. We all eat a plant-based diet as a result and although the three of us can have some things Naaila can't, the base of our diet is identical – plant based. Kenan and Ilyas (her brother), will eat meat once or twice a week. I have not eaten meat since Naaila was about 18 months old.

It used to irritate me when people would say "oh so she is a vegan" when there were so many vegan things Naaila could not eat. However, when a diet is truly plant based, eating whole foods not processed vegan alternatives, it is easily adapted to a low protein diet, and in fact, not such a bad alternative to the modern Western diet! We've travelled overseas lots and even been in countries with very little PKU friendly foods, but we've made it work and I'm super proud of our family for that!

What does a general day look like for your family? With Covid restrictions at the moment, the adults are working from home. The kids are at grandmas across the road. We wake up early, the kids have breakfast, smoothies (always!) and either toast or oats/cereal. Naaila will have gluten free bread and a smaller serving of oats with lots of fruit through it. Limiting breakfast to 5 grams of protein. They then go across the road to grandma. A year ago their lunch and snacks would be packed for them. But now we are organised enough for grandma to know what she can cook for Naaila and she notes down how much she eats. They come back home 4-5pm and we usually have a quick walk or bike ride and then prep a quick dinner! Knowing what she ate for brekky and mum telling me what she had for lunch, I then accommodate dinner accordingly. The biggest change over the years has been teaching mum and her learning exactly what Naaila can and can't eat. Very proud of her! And it has made our lives so much easier.

How do you go about educating friends and family? Since Naaila was a baby I explained PKU as her liver cannot break down protein, and I would talk about the foods Naaila CAN eat. Now, all our close friends and family know exactly what Naaila can and can't eat and go out of their way in ensuring at any gathering there is an option for her (sometimes even beyond what I would be providing



for her!). Being European, we have a large family and see each other almost daily, so, they are all well-versed in PKU! My favourite part about our close friendship group is how comfortable they make us feel and always accommodate for Naaila without it ever being a big deal. (Especially because the kids in the group are of a similar age and the mums/dads ensure their kids are eating what Naaila is). For example all the kids will eat pasta while Naaila has low protein pasta, or if they are having a BBQ Naaila will have veggie patties and mushrooms ensuring food is cut up to look the same on everyone's plate. But we also make sure we don't stop other kids from having their steak or normal meal. It's more about always having an alternative for Naaila so that she never feels like she is missing out. They all know her favorite foods and have them ready to go! It's no longer a big issue. Everyone knows what Naaila can eat. With new people, we take responsibility for Naaila's food and explain why.

How do you explain PKU? As above, I just say the liver cannot break down protein. If Naaila is around I always try make it a fun thing by saying or naming all the yummy veggies and fruits we eat. Focusing on what we CAN not CANT, and at the end I say "that's what makes us super dooper healthy and clever!". Ensuring that both the person I am speaking to and Naaila (and her non-pku twin brother) can hear. I think it's really important if the child is around to involve them in the explanation. They hear and observe EVERYTHING! And just as we would feel uncomfortable if we were standing next to someone talking about us, they do too. So, I will often ask Naaila "do you want to explain to such and such what PKU/ low-protein tummy is?".

What is your child's favourite thing to do? To be honest, with COVID, watching people assemble Lego on YouTube Kids! and assembling Leggo herself. Pretending to be a cat with her twin brother is also a favourite pastime.

What is her favourite thing to eat? Broccoli, sushi, rice paper rolls, pumpkin, sweet potatoes, low protein nacho/pizza and we make these veggie tortilla wraps she gets to assemble herself which she loves.

How do you manage children's parties/events? All our close friends and family know and provide for Naaila. If it is someone not familiar, I try to manage her protein intake during the day to allow a bit more protein at the party. She still will not eat something that's not a "PKU" food. Every kid's party has chips and lollies! We just have a "special treats day". So it's not like I say ok have a sausage today because that's a "treat" - definitely NOT that!

When her tolerance was lower, I'd bring a 12 pack of mini vegan cupcakes (1 or 2 grams). Decorated to be exciting for kids. I'd offer

them around and usually other kids want one too and Naaila doesn't feel left out. There's always a dairy free, gluten free kid at every party, I find their parents and try to "prepare together" so at least one other kid is eating what Naaila is eating. I find a lot of gluten free and dairy free things are also low in protein. I understand this is easier with her more liberal tolerance.

What happens when you eat out? If eating out, we manage the rest of the day to be super low or no protein to allow her to eat some foods off the menu. There's always chips on a menu and some grilled veggies or steamed rice. I am no longer uncomfortable asking for something to be changed to suit Naaila. We even recently started taking vegan cheese with us to our local take away shop for them to use. We couldn't see anything on the menu other than chips which she could have, so Kenan popped over to the woolies next door got some BioCheese and had them change the recipe a bit to make it a mushroom, spinach and vegan cheese wrap. If you explain things people are accommodating, and if they are not, eat elsewhere.

Explaining it's not an "allergy" is the most important part. As kitchens will not guarantee no cross contamination. Luckily for PKU that's not a huge issue. When going overseas where every meal is really "eating out", we take with us a heap of low protein pasta, small jars of veggie pasta sauce, long life almond milk, cereal, pizza bases and dry snacks. We then explain it's not an "allergy" and sign a waiver usually and they will cook our foods for us.

How was your kinder in accommodating special requests?

Starting kinder next year and they have already been fantastic! Kinder will be sessional 8.30am to 1pm 3 times a week. So morning tea will be fruit, veg, crackers and dip. Lunch will probably be sushi or rice paper rolls or a sandwich - because I know she will eat that and it's yum cold!

What would you like everyone to know about managing the first few years with PKU?

That it gets easier. But I know until you see your child thriving, no matter how many times those of us with bigger kids tell you that, it won't make it easier now. Build a support network, ask for help if you need it. Learn as much as you can about nutrition (from reputable medical sources). Once the storm clears, try to focus your energy on something positive in every hurdle you face.

Most of all know that no amount of worry now, will change the future. It will just mean that when you look back on these first years, your memory will be a sad and negative one. Instead focus that energy into action and on the things that do bring you joy. Don't let a dietary restriction define the memory you have of the first years of being a parent to your precious bub.

Don't let fear creep up on you and spiral into thinking 5, 10, 15, 20 years ahead. This was my biggest struggle in those first years. I remember when I found out about the struggles PKU women face in conceiving a baby. And literally being up at night sometimes crying "how will Naaila have her own children? This is so unfair!". Then a friend said to me "But what if she didn't have PKU and she decided she doesn't want kids? Or what if she didn't have PKU but couldn't medically have kids anyway?" It kind of clicked that all these worries are just wasted time. We have no control over the future, you can just control the now. Everything is a matter of perspective. We get to walk into a hospital appointment with our baby and walk out with them in our arms. A lot of parents don't. A lot of parents don't even have access to a hospital for their kids. We get to see our kids grow up and a lot of parents aren't that lucky.

Any tips in incorporating living with an IEM/PKU into everyday life and ensuring it is as easy as possible? Getting kids involved into sports helps with accommodating IEM/PKU needs as those focused on sports are generally also better at managing what they eat and "keeping healthy". It helps them be more in tune with their bodies also.

A bit controversial.... but go vegetarian/plant based/vegan (whatever you can manage) yourself! Better for you, better for the earth and makes accommodating a PKU diet alongside yours so much easier. Your child seeing that you "don't eat" something that "others eat", also helps them see that "diet" is not what defines your life. It's just one part of our lives, it's not the centre of it!

Extra comments that you wish to share? I always thought having a twin brother who does not have PKU will be harder than not having a sibling or if he also had PKU. But he has become the best at managing Naaila's diet! He's such a little champion for his sister. Often stepping in to tell others "my sister can't have that but she can have this".

Patient Pathways - with Jo Campbell

MDDA urgently needs your assistance!

MDDA is aiming to educate health and medical researchers on what it is like living with an IEM.

Patient Pathways Program.

MDDA and 11 other patient organisations across Australia have been chosen to be part of a pilot program known as the Patient Pathways Program. The main objective is to hear your story and your patient experience to inform future health and medical research into your condition. This information is crucial as you would be improving the health outcomes of people with IEM's. You can impact how your condition is managed in the future.

You can do this via a quick phone call with our telehealth nurse, ph 03 9723 0700 or email pathwaysnurse@mdda.org.au to request a call at a convenient time for you. (Mon, Tues, Wed 9am -5pm)

This program does not replace the expert clinical care of the patients metabolic team. The nurse will not provide treatment advice. The Patient Pathways Telehealth Nurse provides practical and emotional support, education and connection with existing services including clinical trials. You can also find more information about the Patient Pathways Program on our website!



**Natalie (Mum), Tom (Dad),
Maddy (big sister) 12, Tessa (Tyrosinaemia Type 1) 11**

How was Tessa diagnosed?

Tessa was diagnosed at 9 weeks. Her heel prick test at birth wasn't quite right, so the doctors suggested it may have been due to Nat having a cold in the days prior to the birth. The second test a few days later was a bit better but still not perfect so the paediatrician said we'd keep an eye on things.

Tessa was mostly a happy baby, but didn't put on much weight. She had a beautiful big smile and bright blue eyes, but spindly arms and a round belly. While waiting for the next paediatric visit we were in and out of the GP as Tessa's stomach became more bloated. We went through the standard concerns of colic and irritability but it wasn't until we finally got to see her paediatrician that he took one look at her distended stomach and said that he was phoning us ahead to the Women's and Children's Hospital. We'll never forget his comment that it was most likely either a tumour or a metabolic condition. As our heads were spinning he said he hoped it was a tumour so at least we could remove it! The team at the hospital were fantastic, and pretty quickly came to the realisation that it was definitely a metabolic condition, and they were looking at SA's first case of hereditary Tyrosinemia Type I. Quite a few other doctors came to inspect this exciting new case study. We weren't exactly feeling like we'd won a lottery, but we were definitely relieved that we knew what was making Tessa sick & could fix it.

How do you explain Tyrosinaemia Type 1?

HT1 is when the liver is missing an enzyme to break down the amino acids phenylalanine and tyrosine. Untreated, the liver produces toxins rather than inert waste products, and the body slowly poisons itself. That bloated stomach in the early days would have ended badly, possibly in only a few more weeks.

What is the Treatment?

HT1 patients, otherwise known as tyrosinimaniacs, take a daily dose of Nitisinone, a miracle drug that started out as a herbicide, but since the early 90s has meant that HT1 is no longer a free ticket to a liver transplant. Combined with a low protein diet and nutritional supplements, 'maniacs monitor their phe and tyr levels through regular blood prick tests. Tess checks in with the fabulous metabolics team 3 times a year and has the occasional ultrasound and MRI to keep tabs on her liver health.

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

The biggest challenge is of course food, but there's also been a stressful holiday where we left her medication in the back of the taxi at the airport! It certainly forces us to be organised and plan ahead! If we have a day where we accidentally go over the 10g limit then we make the following day a bit lower and everything's fine. Her liver health and blood markers are all essentially perfect since those stressful first few weeks. Some literature suggests that impairment of cognitive abilities may be an issue with HT1 patients, but the studies and data are very limited. Plus it's very hard to know how an individual's brain powers would be without HT1, so we're not losing any sleep over this.



Describe your family/family life/adapting to having a family member with Tyrosinaemia Type 1.

We consider ourselves very normal. Modern day food allergies mean that most people don't bat an eyelid about Tessa's unique diet, and new products pop up with regularity in the supermarkets that have lower protein, so we try and see it more as a fun challenge to come up with different options rather than get too bummed about it. Tessa's a definite sweet tooth, and there's no protein in sugar, so there's always an upside

What does a general day look like for your family?

Pretty normal. Tessa has her Nitisinone with breakfast and before bed, and after each main meal she has a supplement gel that is mixed with water. Her classmates often mix it for her at school! Tessa's daily allowance is 10g of protein, so one meal is generally made with Nutricia or Cortex products (pasta, cereal, crackers etc.). Other than mealtime Tessa's day is just like any other 11 year old's.

How do you go about educating friends and family?

This year at school Tessa did a project explaining HT1, including making a model of an amino acid chain using balloons and ice cream sticks. The rarity of the condition is what wows most people, but once they understand it's not an allergy it becomes pretty straightforward to manage. Tessa is also very good with not eating something if she's not sure how many grams of protein are in it.

What is your child's favourite thing to do?

That's a hard choice between bike riding, her various team sports (cricket, soccer, tennis and athletics), scouts and watching fail videos on YouTube.

What is her favourite thing to eat/take to school?

Hot chips! When we go out for dinner we don't need to ask her if she'd like to see the menu. And preferably with some gravy! Her school lunch box usually has a sandwich using GF bread, and a heap of fruit and veg. What she looks forward to most though is the treat that makes it in there... usually a biscuit or packet of chips.

How do you manage children's parties/events?

We tend to make sure she has a few spare points by managing her protein intake before the party, and don't send her there hungry. Most parties have fruit and veggie sticks, plus our friends and family are fabulous and wanting to make sure that Tessa doesn't feel left out, so there's often lower protein GF cakes or biscuits.

Describe a usual mealtime.

Tess will have her own meal. As a family we didn't want to convert to low pro eating – Tess needed to grow up knowing she is different. She is pretty good with her fruit and veg, and we use plenty of low pro products to bulk out her meals.

What happens when you eat out? Advice for eating out?

Tessa's favourite food is hot chips, so they're pretty easy to come by. We once went to the fancy restaurant Hentley Farm in the Barossa, and phoned ahead about low protein options. What they produced was mind blowing. It was like Heston had been set loose in the kitchen and Tessa was served up all manner of cucumber foam, vegetable gels and ultra thin low pro wafers. It was Michelin star – tyro style!

How was your child's school in accommodating any special requests/requirements?

They've been great. Again the key is communication and all the teachers and tuck shops have been very accommodating. We tend to send Tess to camps and other events with her own stock of food, and teachers are good at organising to keep medicines safe and refrigerated.

What would you like everyone to know about managing Tyrosinaemia Type 1?

Just that it's manageable with planning and organisation of meals and snacks. Apart from food and the daily routine of tablets and supplements Tessa is a very typical 11 year old.

Any tips in incorporating living with an IEM/ Tyrosinaemia Type 1 into their everyday life and ensuring it is as easy as possible?

We've been lucky that Tessa has never really felt a victim due to her condition. We all have challenges in life, and we're super proud of how she takes this pretty major one in her stride every single day. It obviously is a big part of who she is, but she doesn't let it define her.

Zest Adult Wellbeing and Vitality Program

We are currently into the third series of Zest, MDDA's very own tailored IEM Adult Wellbeing and Vitality program. Zest aims to improve the mental, emotional and physical health of Australian adults living with an IEM. This series opened with the topic of "Mindfulness in Uncertain times" now more than ever it is important to check-in and adopt new techniques that help our overall wellbeing and mental health. Zest makes habit-forming life changes in areas identified as limiting individuals from achieving optimal health and management of their IEM. The Zest program provides a holistic and tailored approach to these challenges by addressing emotional, physical and social wellbeing.

The program is delivered via MDDA's online virtual events platform via a combination of web-based seminars, teleconferences, online forums, weekly goal setting and one-on-one coaching. The program is facilitated by Louise Healy (Program designer, coach and PKU mum). Louise has more than 18 years of professional experience coaching and facilitating programs for leadership, peak performance, change, stress management, relationship building and mindfulness. The fourth series is starting early 2021 and is free to Adult MDDA Advantage Members.

If you would like to register your interest in future Zest series please email office@mdda.org.au.



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MDDA thank our sponsors BioMarin and VitaFlo who support the Zest program. Without their support we would be unable to offer this exceptional program.

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 if you would like to check on the status of your annual subscription or would like to become a member of the MDDA.



Fundraising

A big thank you to one of our new MDDA members Chelsea Docherty, not only for her active role in our virtual @Home Retreat adults panel, but also for her recent fundraising efforts. Chelsea nominated MDDA for a charity soccer day through 'And People'. Along with her work colleagues and employer, 'Trend Micro', they have raised over \$5000 through givenow.com.au (The CrowdRaiser is open until April 2021).

NSW



We would like to shout out to 'And People' who organised the charity soccer day (www.andpeople.com) and 'Trend Micro' who will be matching employees donations

Thanks to Hayley Pash who also raised funds for the MDDA. Hayley organised a fundraiser through her Facebook page. We really appreciate all your efforts in supporting MDDA, your fundraising will help with future projects and initiatives.

WA

TAS

Pauline Blyth is the grandmother of a PKU teen and took it upon herself to do some fundraising for MDDA. Thank you Pauline for your Facebook fundraising efforts earlier this year.

#teamMDDA is a way for you and your family and friends to raise funds in support of the MDDA. You can do so by selecting MDDA as your chosen charity as you participate in an activity of your choice and raise awareness and funds for MDDA whilst doing something you love. Funds raised via #teamMDDA go straight towards providing greater resources and value back into the MDDA community and research priorities.

By signing up to a #teamMDDA challenge you are joining a group of remarkable individuals who are prepared to go above and beyond to achieve something for a great cause. If you are participating in a fun run, marathon or other outdoor challenge, #teamMDDA running singlets & T-shirts can be ordered (and personalised) via MDDA Marketplace.

visit www.mdda.org.au/help/teammdda and join the team



Need to get in touch?
Contact the pharmacy team on:

 02 9427 1755  pharmacyau@nutricia.com

Genetic Student MDDA Placement

Hi everyone, Emma, George and Devni here. We met a few of you at the @Home Retreat but for those of you who don't know us, we are currently Master of Genetic Counselling students at The University of Melbourne. As part of the course we were asked to complete a community placement in a support group and were fortunate to be placed with the MDDA.

We were mentored by Jo, Jenny and Louise, who as you all probably know, have a tremendous wealth of knowledge regarding everything IEM. We learnt so much from these wonderful ladies and will always appreciate their guidance, wisdom and many stories.

We were also lucky enough to be given the opportunity to help out with the retreat where we got to listen to so many of you! All your stories were so interesting, and gave us a whole new perspective on what it is like to live with an IEM. It also helped us to see first-hand the importance of support groups and how special the MDDA community is.

During this placement we also helped develop three different projects. George worked on a 'Diet for Life' project that aims to educate more individuals with PKU about the importance of a life-long low protein diet. Emma worked on a brochure that will help educate hospital staff on the dietary needs to those living with PKU. Devni worked on a video discussing the purpose of genetic counselling and the different patterns of inheritance. We hope these resources will help the MDDA members in the near future!

Lastly, a few incredibly kind members took time out of their days to have a chat to us about what it is like to live with an IEM. Those discussions were invaluable to us. As future genetic counsellors, it's important for us to truly understand our client's journeys and obstacles they may face, those chats brought us so much closer to that goal. To the members that spoke to us, if you're reading this, thank you so much.

Overall, we had a wonderful time with the MDDA and will be leaving with so much more knowledge and experience than we came in with. Thank you so much MDDA, we will never forget our experience with this wonderful support group! We hope to send many more members your way in the future!



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Nashi Pear Slaw - serves 1

Ingredients:

2 celery sticks
3 tbsp fresh lime juice
2 tbsp seasoned rice vinegar
1 tsp finely grated peeled fresh ginger
2 firm Nashi pears
2 spring onions
1/4 cup fresh coriander leaves
1/2 tsp finely chopped fresh hot red chilli,
salt & pepper

Peel the strings from the celery with a vegetable peeler and cut celery into ½ cm thick matchsticks.

Whisk together juice, vinegar, and ginger.

Stir in celery and remaining ingredients and salt and pepper to taste.

Let stand at room temperature 15 minutes before serving to infuse the flavours.

Method:

Cut Nashi pears into 1/4 inch-thick matchsticks.

Thinly slice spring onions diagonally and add to a large bowl.



Dolmades (stuffed vine leaves)

Ingredients:

200g packet vine leaves in brine
1 cup (250g) low protein rice
1 small onion, finely chopped
1 tbsp olive oil
2 tbsp currants
2 tbsp chopped fresh dill
1 tbsp finely chopped fresh mint
1 tbsp chopped fresh parsley
1/3 cup olive oil, extra
2 tbsp lemon juice
2 cups vegetable stock

Method:

Soak vine leaves in cold water for 15 minutes, then remove and pat dry. Cut off stems. Reserve some leaves to line the saucepan. Soak the rice in boiling water for 10 mins to soften. Drain.

Mix together rice, onion, oil, currants, herbs and salt &

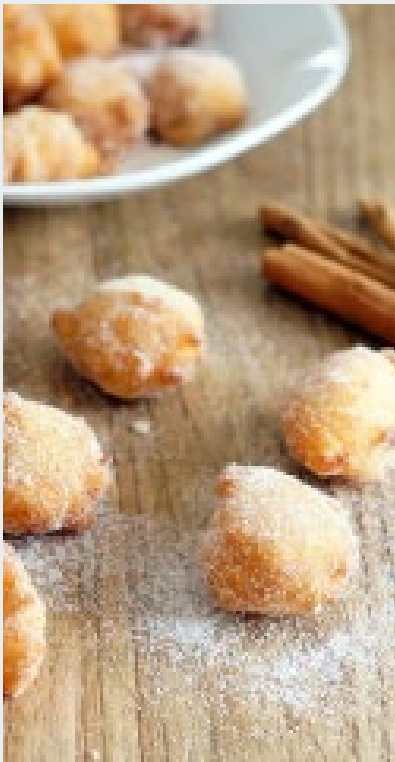
pepper in a large bowl.

Lay some leaves vein-side-down on a flat surface. Place 1 tbsp of filling in the centre, fold the stalk end over the filling, then the left and right sides into the centre, and finally roll firmly toward the tip. Repeat with remaining leaves.

Use reserved vine leaves to line the base of saucepan. Drizzle with 1 tbsp olive oil. Add the dolmades, packing tightly in one layer, pour the remaining oil and lemon juice over them and then cover with stock.

Cover with an inverted plate to stop the dolmades moving. Bring to the boil, then simmer covered, for 45 minutes.

Remove with a slotted spoon. Serve warm or cold.



Cinnamon Fritters

Ingredients:

Batter:

70g Nuttelex
1 cup low protein flour sifted
2 tsp baking powder
Egg replacer equivalent to 4 whole eggs
Oil for deep-frying

Cinnamon syrup:

1/2 cup brown sugar
1 cup of water
2 tbsp orange or apple juice
1 tsp ground cinnamon

Method:

Combine water and Nuttelex in medium pan. Stir over low heat until butter has melted; do not boil.

Remove pan from heat, add flour all at once. Beat until smooth using a wooden spoon.

Return to stove, heat until mixture thickens and comes away from the side and base of pan. Remove from heat, cool slightly.

Transfer mixture to a small mixer bowl. Add egg mixture gradually beating well between additions until mixture is glossy.

Heat oil in a deep pan. Gently lower heaped teaspoons of mixture into moderately hot oil, cook for 5 minutes or until puffed and golden.

Drain on absorbent paper. Serve warm with Cinnamon Syrup.

For Cinnamon Syrup, combine brown sugar, water, juice and cinnamon in a small pan. Stir until sugar has dissolved.

Bring to boil. Reduce heat. Simmer until liquid has reduced to 3/4 of its volume. Serve warm with cinnamon fritters.

These recipes and more can be found at www.mdda.org.au/recipes





Products

Always check the nutritional panel on products



noshu: Marshy Mellow snackles bars

Protein per 100g: 2.0g
Protein per serve: 0.4g
Serving size: 22g
Available from:
Coles & Woolworths



The Natural Confectionery Co: Vegan fruit mix

Protein per 100g: <1.0g
Protein per serve: <1.0g
Serving size: 25g
Available from:
Coles & Woolworths



Coles: Sweetened coconut condensed milk

Protein per 100g: <1g
Protein per serve: <1g
Serving size: 40g
Available from: Coles



Forager foods: Freeze dried apple wedges

Protein per 100g: 1.5g
Protein per serve: 0.3g
Serving size: 20g
Available from: select IGA
stores & online:
www.foragerfoods.com.au



Well & Good: Gluten free pastry flour

Protein per 100g: 1.5g
Protein per serve: 1.5g
Serving size: 100g
Available from: select
stores & online:
www.buyglutenfreedirect.com.au/



syndian: Italian sun-dried tomato vegan sausages

Protein per 100g: 2.8g
Protein per serve: 1.4g
Serving size: 50g
Available from: select
stores & online:
[www.syndian.com.au/
shop-online](http://www.syndian.com.au/shop-online)



Picasso Kitchen: Cauliflower pizza base

Protein per 100g: 5.3g
Protein per serve: 2.3g
Serving size: 42.5g
Available from:
Woolworths



Mylife : Bio Creamy

Protein per 100g: 0.5g
Protein per serve: 0.15g
Serving size: 30g
Available from: Coles &
Woolworths



Tutto Pasta: Vegan gluten free vegetable lasagna

Protein per 100g: 1.8g
Protein per serve: 5.6g
Serving size: 300g
Available from: Coles &
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Last orders to cover this period to be
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Ph: (03) 5229 8222



Cortex Health / Cambrooke

For orders to arrive pre-Christmas, order
before 18th December 2020
Limited dispatch over the Christmas,
New Year period. Re-opens 11 Jan 2021
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Ph: 1800 367 758



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Re-opens 4th January 2021. Deadline for
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Ph: 03 9863 7267



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2021 Queensland National Family Retreat

Sanctuary Cove
2nd - 4th July 2021

New Dates!

Stay tuned for when registrations open
at www.mdda.org.au

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

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