

MDDA Matters

Issue #71 - July 2020

2020! – What a year we will all remember. COVID-19 restrictions have meant that we have had to adapt and slightly change some of our MDDA plans, including having our office team all working from home. We are pleased,

however, that we were able to adjust with the times, and even though we made some changes, we have still been able to develop and offer the following programs; Zest, LowPro Inspo, MyLowProPal, Patient Pathways, and we have many more new and exciting (even virtual) programs in development. More information on these programs can be found in this edition.

Unfortunately, the restrictions have meant that our planned 2020 Queensland Family Retreat has had to be postponed. While disappointed about this, MDDA have new dates for 2021 and an exciting replacement “virtual” event.

Replacing our October 2020 Retreat will be **our first ever @Home Virtual Family Retreat - taking place across the same weekend as the initial dates in October.** This event will provide an opportunity for everyone to get involved and will include lots of fun and interactive online sessions, as well as a series of informative and educational presentations and workshops. Check out more information about this event in this newsletter!

The last few months have proved to be the perfect time to brush up on those cooking skills, and this newsletter features some tried and tested recipes from a member, who is a cooking sensation (thanks Sasha)! This edition also features information on our growing LowPro Inspo YouTube Cooking channel. So, no more excuses to get cooking!

Also in this edition, you will still find our member favourites with three member stories, one from a PKU Adult, PKU teen and a family with MSUD. Included is also the new product page. We love sharing any new low protein products you find so please let us know if you discover something!

At the MDDA we are always looking for innovative and exciting ways to support our members, and there are great benefits to joining our MDDA Member Advantage Program! As a MDDA member you are part of building a stronger future and community. As a financial member (for \$35/year per family) you will have access to our Member Advantage program, all areas of the MDDA website, special prices to our events and be kept

up-to-date and connected with support and resources. Please renew your membership and consider adding a donation to strengthen your impact. MDDA wouldn't be able to do half of what we do without your continuous and generous support, so thank you!

MDDA office staff are working from home and continuing as per usual. You are still able to contact us on the office phone or via email should you wish. **Our volunteer Executive Committee are, as always, unstoppable. They are continuing to work in progressing MDDA initiatives and developing us into a strong support group, as well as continuing with important advocacy efforts.** MDDA are always looking at improving services and opportunities for all IEMs.

This Newsletter edition is filled with great member stories, program information, product finds and recipes, so we hope that you enjoy it! As we move into winter we hope that you all stay safe and continue to be healthy. Thank you again for all your kind support!

in this issue

MDDA updates	2
Importance of Isolation	3
Launch of the National Strategic Action Plan.....	4
Member Stories.....	6
COVID-19 Advice Resource.....	9
LowPro Inspo.....	10
Fundraising.....	12
Celebrations.....	13
Recipes	14
Products.....	15
Contact Information.....	16

Updates

MDDA Family Retreat QLD Postponed to April 2021

After months of deliberation we have decided to postpone the 2020 National MDDA Family Retreat that was set to take place this year at the beautiful Sanctuary Cove in October.

As much as we would love to proceed with the event as planned, our concerns of being able to run an event of the same calibre, standard and safety, we felt would be compromised with the existing uncertainty around COVID-19 and the anticipated ongoing restrictions in place. It is our hope that by April next year we will be in a much better position to provide a FULL event program to the level of what we are all used to, and ensure ALL our members have the ability to attend.

The new dates have been set for **16-18 April 2021**, and coincide with the end or middle weekend of school holidays for most states. All event activities will still take place at the beautiful Sanctuary Cove, and in the coming months we will be reopening registrations for you to reserve your spot.



For more information about the Retreat postponement visit mdda.org.au/news-events/news

Zest Adult Wellbeing Program

Over the past 5 weeks MDDA has facilitated the second series of Zest, our IEM Adult Wellbeing and Vitality program. Zest aims to improve the mental, emotional and physical health of Australian adults living with an IEM. We decided to begin with the topic of 'Mindfulness in Uncertain Times' because we know that now more than ever it is important to check-in and adopt new techniques that help our overall wellbeing and mental health.

The program is delivered via a combination of web-based seminars, teleconferences, online forums, weekly goal setting and one-on-one coaching. We're getting ready to run a third series in the coming weeks and have decided that during these times of uncertainty and isolation that it would also be hugely beneficial to run a Zest session for parents and caregivers. Further information will be available soon.



MDDA @Home Retreat

Replacing our October 2020 Retreat will be an @Home Virtual Family Retreat, and will provide an opportunity for interactive online sessions, as well as a series of informative and educational presentations and workshops. There will be sessions for people of all IEMs and of all ages.

How the Retreat will Run

This Virtual Retreat will take place using a comprehensive online portal, so all you need to join is internet and a computer. Through programs such as Zoom and YouTube we will be able to listen to speakers, have 'round-table' discussions, workshops and other great opportunities! Whilst we will be physically apart, this technology will still allow us to come together as a community. We are even planning on still having the social aspects of the Retreat where you will be able to connect with old friends and even make some new ones!

Program Overview

Educational sessions, discussion panels & workshops:

- International & local scientific webinars
- Scientific poster displays & presentations - home testing devices, clinical trials, ASIEM clinical presentations (PKU & Other IEM based)
- Special interest panel discussions (Teens & Tweens, Newly Diagnosed, Grandparents, spouse/partners etc)
- Health & wellbeing workshops (Maternal Women, Back to Diet, Adults, Parents)
- Transitional Teens workshop

Interactive meetings & activities

- PeekABU kids mentoring sessions & chat room
- Interactive LowPro Inspo cooking master-classes
- Virtual expo and sponsors meetings hub
- Virtual Scavenger Hunt & Points Incentive
- Hands on Power talks (Guthrie cards, MyLowProPal App, volunteer opportunities, advocacy, fundraising etc).

More information about this Retreat coming soon, so make sure you keep an eye out for when registrations open!

Importance of isolation for the IEMS that have sick day plans



Victor has Isovaleric Aciduria (IVA) and is one of our members who needs to take extra care during these times.

For some rarer IEMs risk of decompensation due to viral infection is high and therefore a sick day action plan is common place.

Please read about the precautions to take for individuals with a 'sick day action plan' in regards to COVID-19.

Some people with inherited metabolic disease are at risk of worsening (decompensation) of their metabolic condition if they develop a viral infection. Any patient requiring a sick day plan, including individuals with urea cycle defects, fatty acid oxidation disorders, maple syrup urine disease, tyrosinaemia type 1, methylmalonic academia, glutaric aciduria type 1, isovaleric aciduria or propionic acidemia. These individuals may have specific supplements or medications to keep at home to use in the event of illness and metabolic decompensation.

Practical steps to take:

- Check that any medications or supplements that you keep at home are in date (not expired for use)
- Keep a copy of your written emergency guidelines handy to show to other healthcare professionals if needed

If you have other specific queries or concerns about your condition then please contact your own metabolic clinic team to discuss these further.

Virtual "SPECIAL INTEREST" Chat Groups

MDDA are hosting and facilitating a series of NEW Virtual Special Interest Chat groups - designed to focus on topics and areas of interest relevant to all. An opportunity to come together with people who are similar can really help with your IEM journey.

To get involved simply go to <https://www.surveymonkey.com/r/W3PDR9B> or call the office. Once we have enough interest we will schedule a session in our new and exciting online virtual community house we have created.

Volunteers Week

The 20th of May was the start of National Volunteers Week, an annual celebration and opportunity to acknowledge the generous contribution of all our volunteers!

At the MDDA we would like to give a HUGE thank you to our volunteer Executive Committee Team, Monique Cooper, Louise Healy, Bianca Albanese, Paige Moore.

These amazing volunteers play an integral role in our success. They drive every program, initiative, lead our advocacy campaigns and oversee the governance of our association whilst managing their own families, businesses, employment and studies. Please join us in thanking and recognising their amazing efforts!

To find out more about how you can volunteer please visit our website at www.mdda.org.au/help/volunteer.



Patient Pathways - with Jo Campbell

Jo has over 30 years of experience in nursing and has helped many patients navigate the complexities of the health care system. Jo has a diverse background across paediatric, adolescent, aged and family centred care with extensive experience in chronic healthcare.

To contact Jo **ph: 03 9723 0700** pathwaysnurse@mdda.org.au

Patient Pathways nurse can call you back at a scheduled time if you prefer.

Monday, Tuesday, Wednesday 9.00am - 5.00pm

This program does not replace the expert clinical care of the patients metabolic team. The nurse will not provide treatment advice. The main objective is to develop tailored care plans, provide practical and emotional support, education and connection with existing services.

You can also find more information about the Patient Pathways Program on our website!



Launch of the National Strategic Action Plan for Rare Diseases

MDDA were honoured to be invited by Rare Voices Australia (RVA) to attend the launch of the National Strategic Action Plan for Rare Diseases in February 2020. This was a milestone event held at Parliament House, Canberra, with the Minister for Health, the Hon Greg Hunt MP. MDDA and RVA have a collaborative long-term relationship sharing a passion for education, advocacy, awareness, support, holistic health and wellness for the rare disease community.

"RVA was commissioned by the Australian Government to develop the Action Plan on behalf of the rare disease sector. The Action Plan provides guidance and direction around key goals and priorities for Australians living with a rare disease. It sets out actions and activities, as determined by the sector, which could be introduced to improve the health and wellbeing of Australians living with a rare disease. The actions identified in the Action Plan are for consideration by a wide range of stakeholders, including governments at all levels, non-government organisations, the public and private health sectors, industry, researchers and academics, rare disease organisations and the wider community.

The National Strategic Action Plan for Rare Diseases is the first nationally coordinated effort to address rare diseases in Australia. Due to the great complexity, significant unmet need and critical urgency associated with rare diseases, systemic reform is required. While there are many different rare diseases, they share countless commonalities. Informed by extensive stakeholder consultation, the Action Plan addresses this common ground. It represents the views of the rare disease sector and outlines a comprehensive, collaborative and evidence-based approach to achieving the best possible health and wellbeing outcomes for Australians living with a rare disease. It is built on three principles: person-centred, equity of access and sustainable systems and workforce."

The National Strategic Action Plan for Rare Diseases (the Action Plan), with its three Pillars – Awareness and Education, Care and Support, and Research and Data – can be summarised into a Plan on a Page (see page 5).

Further information on the Action Plan can be found at rarevoices.org.au/actionplan.



MDDA Secretary, Bianca Albanese attended the launch



MDDA were delighted to congratulate Nicole Millis from Rare Voices Australia in person on the launch of the National Strategic Action Plan for Rare Diseases at this year's Rare Disease Day event at the Royal Children's Hospital in Melbourne.



Ph: 03 9723 0700

We need your voice, we want to hear from you. We encourage you to call the MDDA Pathways Nurse to share your patient experience on living with an IEM.

This information and data collected will be used to inform future research treatment and care across the health sector.

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.



Many Voices ONE GOAL.

YOUR NATIONAL STRATEGIC ACTION PLAN FOR RARE DISEASES

VISION:

The best possible health and wellbeing outcomes for Australians living with a rare disease.

CRITICAL ENABLERS:

Multi-stakeholder involvement and engagement

Collaborative governance and leadership

State, national and international partnerships

High quality, comprehensive collection, and effective use, of rare disease data



Pillar 1 AWARENESS AND EDUCATION

Priority 1.1: Increase every Australian's awareness of rare diseases including, where applicable, relevant prevention measures.

Priority 1.2: Ensure Australians living with a rare disease have access to information and education that enables them to be active participants in their rare disease journey.

Priority 1.3: Develop a national rare disease workforce strategy that responds to current and future demands, including the impact of genomics.



Pillar 2 CARE AND SUPPORT

Priority 2.1: Provide rare disease care and support that is integrated and appropriate for all Australians living with a rare disease, while being both person and family-centred.

Priority 2.2: Ensure diagnosis of a rare disease is timely and accurate.

Priority 2.3: Facilitate increased reproductive confidence.

Priority 2.4: Enable all Australians to have equitable access to the best available health technology.

Priority 2.5: Integrate mental health, and social and emotional wellbeing, into rare disease care and support.



Pillar 3 RESEARCH AND DATA

Priority 3.1: Enable coordinated and collaborative data collection to facilitate the monitoring and cumulative knowledge of rare diseases, informing care management, research and health system planning.

Priority 3.2: Develop a national research strategy for rare diseases to foster, support and drive all types of research for rare diseases, contributing to agreed priorities and systematically addressing gaps.

Priority 3.3: Ensure research into rare diseases is collaborative and person-centred.

Priority 3.4: Translate research and innovation into clinical care; clinical care informs research and innovation.

THESE PRINCIPLES ARE THE FOUNDATION FOR THIS ACTION PLAN:

Person-centred | Equity of Access | Sustainable Systems and Workforce

► Taking Action Together | Visit rarevoices.org.au/actionplan

Member Stories

Living with MSUD

Amanda & Tom Stella 7, Daisy 5 & Charlie (MSUD) 3

How was Charlie Diagnosed? When Charlie was five days old we received a phone call from the Metabolic Team at the Royal Children's Hospital (RCH) explaining that something had come up on his Newborn Screening Test and we needed to present at RCH Emergency Department as soon as possible. Upon arrival, his bloods were taken and Charlie was fed an unwell formula through a Naso Gastric tube, Charlie was assessed and he was diagnosed with Maple Syrup Urine Disease (MSUD). Shortly after, his blood results came back very high and he was taken to ICU where he was placed in a coma and his blood was filtered for 30 hours through hemofiltration. Thankfully, Charlie has no long lasting affects from his initial diagnosis. He is a happy and healthy child living with MSUD.

What is the treatment? Charlie's daily treatment is a low protein diet (currently 6 grams of protein) and formula made up of MSUD Anamix, Valine and ProZero. When Charlie's levels are elevated or he is showing signs of illness we commence an unwell regime. Charlie's unwell formula consists of MSUD Anamix, Valine, Isoleucine and ProZero made up to a total of 1.3Litres and consumed over 24 hours. Charlie often requires an NGtube to consume this quantity which we will also use at home if he is well enough. When Charlie is very unwell we present to RCH ED and Charlie receives treatment at hospital for a few days and sometimes up to a week.

What are the challenges you/family have faced from the point of diagnosis to now? Charlie has had many hospital admissions, we estimate it to be over 30 admissions so far. This has been quite challenging for Charlie and our whole family. We are very fortunate to have a wonderful support network of friends and family who make these times easier by providing food, emotional support and practical support (eg. Dropping our daughters off at school) to keep life as consistent and as easy as possible for us and our children during the challenging times. In particular, my Mum has been a wonderful support.

How do you go about educating friends and family? We have found social media to be a great way to share information about MSUD. There are a lot of great resources we have come across and we often share them on social media with family and friends. We are also very open with talking about Charlie's condition and we are always happy to answer any questions my friends or family have about MSUD. We believe education is very important to help keep Charlie well, in particular, education around nutrition and hygiene to avoid Charlie becoming unwell.

What is your family's favourite thing to do together? We love to go camping as a family.

Describe a family meal time. Family meal times are very special times for us. During our family meal times we discuss what went well during our day. We find that practising gratitude every day helps us to have a positive outlook on life, even when things become difficult. We eat a lot of similar meals eg. Risottos, pastas with lots of vegetables. We cook meat for the rest of the family separately and add it after Charlie's portion has been taken out. Charlie will have his own rice and pasta or noodles. Or potato gems if he won't eat anything else!



How do you explain MSUD?

We often find ourselves explaining the name of the condition Maple Syrup Urine Disease, as it is often the first question we get asked. When someone with MSUD is in metabolic crisis their urine smells like maple syrup. Which is where the condition gets its name. We then explain that MSUD is a rare, chronic, and life threatening genetic disease. I also like to include that Charlie is living a happy and healthy life on a strict diet.

What is Charlie's favourite food? Charlie's favourite food is potato gems!

How do you deal with parties/ going out? Charlie's big sisters are very protective of him and they do a great job of informing their friends if Charlie can't eat something. Charlie is also very good at asking what he can eat while we are out. If we are at a party with a lot of people we don't know, Charlie wears badges which say to not feed him as an extra precaution. Being organised is key! I usually call ahead to the venue and pack some food just in case there's no appropriate food available for Charlie.

What would you like everyone to know about growing up with MSUD? As parents of a child growing up with MSUD we would like everyone to know that some days are difficult. Charlie misses out on many things due to hospital stays or because other children attend parties or school even when they are unwell and pass illnesses on to him. We would like everyone to know that the choices we make for ourselves often affect others. We would also like everyone to know that although some days are tough, other days are wonderful! And even though Charlie has MSUD we believe he can achieve anything he wants to achieve. He is a happy and healthy kid capable of great things.

Any tips for parents/kids in incorporating living with an IEM/ MSUD into their everyday life and ensuring it is as easy as possible? We have found thinking ahead and being organised helps to ensure Charlie's everyday life is as easy as possible. We make sure we have an adequate supply of his formulas, medical supplies and speciality foods and have an extra bag of food packed when we go out. Our biggest tip would be to focus on the positive. Being grateful for our network of friends and family, the RCH, friends we've made in the MSUD community and our three healthy and happy children makes our everyday life living with an IEM feel easy because we know how lucky we are!

Phoenix & Lee-Anne 13 years old with PKU

We were so fortunate to have the incredible Dr Jim & Anita Inwood at (the old) Brisbane Children's Hospital as our PKU first point of call after that life changing phone call when Phoenix was 8 days old.

The reassurance I received in those first hours from our amazing team set us on a path to see PKU as a simple challenge & one of life's many, to overcome daily.

I heard how PKU was easier to manage than diabetes, with no daily blood test & insulin injection to give and far less dangerous than some nut allergies which may cause severe anaphylaxis. We have family members & friends with both these afflictions and while PKU is a daily challenge I can see how it is far easier to manage.

Following on this path I have brought Phoenix up to know 'we each have a thing' (eg medical, physical or mental condition) his 'thing' is PKU & we always do the best we can with what we have. At times when Phoenix was younger & complained about PKU or formulas or said "it's not fair", I'd remind him of our cousin in a wheelchair & our cousin with severe facial deformities & ask "is that fair? Which would you prefer to have?" It may sound harsh but life is full of challenges and I believe we grow through them.

I now know this grounding in living with PKU, initially set up by Dr Jim and crew, has put Phoenix in very good stead. This was confirmed when discussing his PKU life for this article. *In response to the question "What would you like everyone to know about growing up with PKU?" Phoenix replied "Its easy - don't worry its not stressful - unless you make it". I'm so happy he takes it in his stride and gets on with life.* I want to remind all the parents and carers out there, it will all be ok and it gets easier every year and all the stress I've personally felt really didn't help anyway!

Phoenix says Kuvan has been the best PKU improvement for him as he's been able to go from 6g to 20g of protein daily. We are both very excited to hear of all the new developments and trials taking place with gene therapy on the path to a cure. Phoenix said he'd love to not count his protein intake every day but he would still be a vegan because there is no need for us to eat animals.

With more people in general moving towards vegetarian and vegan diets there are a lot more products available now on supermarket shelves that are suitable for low protein diets. Phoenix loves as always every variety of hot chips for a main meal and his current favourite snack is Vegan Cornettos icecreams from Woolies at only 1g each!!! His favourite activities are Xbox and Virtual reality games.

There are certainly a lot more choices in formula available now but Phoenix is still happy with his 3 x Cooler 20 whites a day. He has tried all the other flavours but always comes back to his usual.

School life went ok as most schools support everyone eating their own lunch as many people have allergies etc. the tricky bit was at class parties and school fetes etc when Phoenix was limited to what he could eat and felt a little left out. At times like this Phoenix would 'save up' some grams of protein over a couple days so he could eat a bit more at the parties. Teachers were generally good but as they are often overworked or too preoccupied with a large class to remember PKU arrangements.



I found it best to always be proactive eg keeping a supply of low protein treats at the school for class member birthdays etc. And always getting the class schedule ahead of time to be prepared for cooking classes etc.

We now homeschool so it's easy to manage PKU at home & we've found the homeschooling community extremely accepting and understanding of Phoenix dietary needs at all our functions. Phoenix said the only challenge he can think of is packing for Scout camps, it can be frustrating as he had to write his own menu and pack & cook all his food individually, he'd prefer not to be separate from his troop.

I've found the very best holiday option for children & teens with PKU are cruise ships. All the staff were extremely helpful from booking us in to the chefs in each restaurant. They made it easy for us to take on board all special food and formula products and cooked any meal requested using our low protein pastas and bread mix and burger mixes. It was so easy and a real holiday for everyone (NO cooking NO dishes NO housework Yippee)

There is so much more support online now with many Facebook groups and lots of people sharing their experiences, so its easy to remind ourselves we are not alone and can easily reach out for advice and support. Remembering of course to always consult with your team of doctor, dietician, metabolic nurse for professional advice.

The biggest & best growth and support I've have seen over our past 13 years is the amazing forward movement of MDDA. With the tireless work of its awesome founders, great staff and the support from all us members. It has gone from strength to strength and there is so much more to come. Going to MDDA retreats is often the highlight of our year and I highly recommend attending at least one to all IEM families, take the whole extended family along. Not only is it very informative but incredibly heart felt with the friends we make and the stories we share. *Phoenix has loved every one we've attended and particularly enjoyed the kids break out sessions, especially in being reminded he is not the only one with an IEM by meeting his peers with whom he can relate, share experiences and brain storm ideas - its the best.*

See you all here in sunny Gold Coast QLD April 2021

Member Stories

PKU Adult

Susan

PKU Adult returning to Diet

Describe growing up with PKU / family life

Growing up with PKU at times was a challenge, especially at school. I was asked a lot about why my food was different and also with outings I had to take my own food. Back in the 60's PKU wasn't as recognised as it is now.

Were there any challenges you/family faced growing up and now any challenges as a PKU Adult

Challenges were the temptation of trying normal food which happened once or twice as a child. I find I have adapted well returning to diet which is now a lifestyle for me.

Why did you go off diet?

I received a letter from my Dietician on my 11th Birthday informing me I could go off diet.

What led to you wanting to return to diet?

After getting in touch with MDDA and doing a lot of research about the benefits of Diet for life. I wanted to feel better within myself.

Have you noticed any immediate benefits from returning to diet?

I have noticed my concentration is more focused, less anxiety and not as tired. Also it has improved my digestion and helped in losing some weight.

Do you find it easier now to educating friends and family about PKU then when you were younger?

I did find it easier educating friends and family about PKU when I was younger.

At school the challenge was mainly at lunch times when others would ask why my food was different once I explained why. They were pretty good though some would occasionally try and tempt me with the wrong food. I would have to explain why I couldn't have their food and what could happen if I ate it.

The workplace is easy as I work on my own and at night I eat before I start work. I explain PKU so it's easy for others to understand

What did you find was the most challenging things about taking the steps to return to diet?

The challenging things about returning to diet were the steps you had to take to return to diet. It was 3 to 4 weeks before I could start back properly etc appointments then I had to take samples of supplements pick which I like best. Then purchasing food took time as well. Once everything was sorted returning to diet was straight forward.

What would you like everyone to know about returning diet as a PKU Adult?

I would like everyone to know the benefits in your health and wellbeing when you return to diet.

Any tips in incorporating living with PKU into their everyday life and ensuring it is as easy as possible?

When I cook I freeze leftover food, I find it makes life easier and find you are not constantly cooking.

What was it like attending your first MDDA retreat?

I had the best time attending my first retreat, just glad to meet other adults with PKU.

Was this the first time you met other PKU adults?

The retreat was the first time I have met other adults with PKU.

Did you grow up knowing any other PKU children?

I grew up knowing mainly one other child with PKU who attended PKU clinics the same time as myself at the Royal Children's Hospital

The only time I saw others were at the PKU Christmas parties at the Royal Children's.

What is your "go to" low protein snack?

I like smoothies made with coconut milk, banana's and coconut yoghurt as a snack

Your favourite low protein food/recipe

Favourite food is pizza with chillies, mushrooms, zucchini, eggplant, pineapple.

What have you found most helpful in your journey returning to diet?

I find most helpful in the journey returning to diet is my health and wellbeing, it is a lot better also weight management.

Also meeting other adults with PKU and joining MDDA which makes you feel part of a community.



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 2020

The IEM food grant payment for 2020 is due by the Friday of the first full week of each month.

Payments due to arrive by: 10 July, 7 August, 11 September, 9 October, 6 November, 11 December

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





Metabolic Dietary Disorders Association

COVID-19 Advice Resource

Like everyone in Australia, MDDA had to quickly adapt as a result of the COVID-19 Pandemic. COVID-19 saw the MDDA Team working from home, brainstorming new ways to interact and support our community in a virtual setting and develop a COVID-19 Advice Resource on our website.

The purpose of the Resource is to consolidate and provide information that is most vital for our community and those living with an IEM. The information is collected from the Australian Government, the Health Department, as well as important information from our health professionals and low protein suppliers.

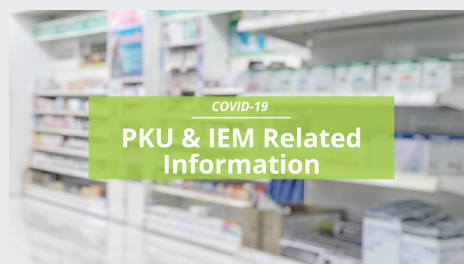
Information in our Advice Resource is provided under the following sections:



We report on key messages and updates regarding COVID-19 from the Australian Government.



Updates on Low Protein Supply including Food, Supplements and Medications.



Includes important information about COVID-19 and how it affects those living with an Inborn Error of Metabolism.



Answering all common questions that you might have regarding COVID-19.



Includes information on our Patient Pathways Telehealth Nurse for those who needed some extra support.



This section provides multiple resources that will help you and your mental health during these times.



We also included a section on other helpful COVID-19 Resources.

We have regularly updated this resource with important information that is relevant for our community and we will continue to update with any information regarding COVID-19 & IEMs that we receive.

Reminder: The most recent, accurate and up to date information from the government can be found on the Department of Health's Coronavirus (COVID-19) health alert. You should also always consult your metabolic clinics should you have serious health concerns.

If you would like to read our COVID-19 Resource, you can visit our website at mdda.org.au/coronavirus-advice



LowPro Inspo is MDDA's Low Protein YouTube Channel and a fantastic way for our community to share delicious LowPro meals with each other! Launched at last year's Retreat, LowPro Inspo includes cooking videos that open the door to Australian families showcasing the diverse range of diets of those living with PKU and other protein IEMs. The channel is initially focusing on low protein cooking and recipes, but we also envision it to evolve into including other inspirational content from MDDA, our members and affiliated communities!

Our goal for this channel is to bring the community together through the power of cooking and to inspire each other to make delicious low pro food. Whether you are a cooking fanatic, or a novice, there is something there for everyone!

We are continuing to build this YouTube Channel and have already uploaded some great videos from people in our community!

Latest LowPro Inspo Videos!



Watch Bianca learn how to make The Grand Hotel Warrandytes famous Veggie Nuggets from their very own Chef Ben!



Watch Finlay teach you how he makes his very own low protein bread and bread rolls!



Kylie shows you how she makes her delicious Thyme and Caraway Focaccia.



Want to cook along?

All of these great recipes can be found at **LowPro Inspo on YouTube!** So, make sure you check them out! More fun and delicious recipes coming very soon so make sure that you subscribe to the channel and keep an eye out!



COOK. LEARN. INSPIRE.



Want to get involved?

Have you got a favourite Low protein food? Whether it's a meal, dessert, breakfast or snack, why not film it and share it with our community!

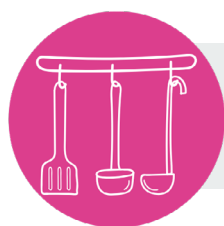
Become a LowPro Inspirator and film your favourite recipe! No expert filming experience needed, just a great recipe and some enthusiasm!

If you are interested email office@mdda.org.au and we will send you your very own starter kit (that might include your very own apron).

With everyone home during the COVID-19 Pandemic, we thought a great way to inspire our community would be to hold our first LowPro Inspo LIVE! An opportunity to all come together in our own kitchens and share a fun and delicious recipe!

MDDA Secretary, a resident Foodie, Bianca Albanese hosted the first session and showed everyone how she makes Cauliflower Fried Rice! Taking place on Zoom, and broadcasting live on Facebook, it was a fun time for everyone with some really delicious results.

To find out when out when our next LowPro Inspo Live is, stay tuned to our Social Media! Also, if you would like to host your very own LowPro Inspo Live, email us!



More information about LowPro Inspo can be found on our website at mdda.org.au/lowpro-inspo!

Fundraising



Thank you to Cameron, one of the store managers at Mango Hill Coles, QLD and his team, they raised \$245.25 for the MDDA.



Cameron organised a fundraiser and dress up - "show your stripes" for Rare Disease Day in February also raising awareness in his local community for rare diseases. Cameron has a 6 month old with Glutaric Aciduria type 1 (GA1).

#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



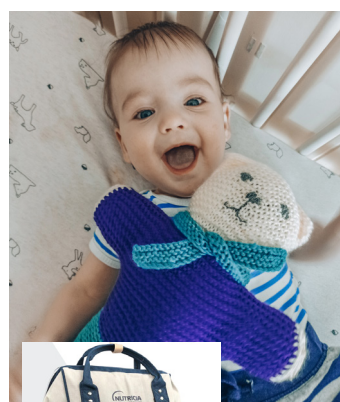
MDDA loves being able to send out our newborn "PeekabU" bags. We recently sent one to the Grasso family whose fundraising helped support this initiative along with our major bag sponsor Nutricia.



Welcome to our newest member - Ellis, who has Glutaric Aciduria type 1 (GA1).

Glad to see how much you love your MDDA teddy!

Special thanks to our wonderful volunteers, Ann Hellings and Laurel Tulloch who knit these for us.



If you are a member who has a child with an IEM under 18 months old & have not received your PeekabU bag, please contact the office to find out how you can receive yours.



cortexhealth

At Cortex Health, our mission is to help you "find your balance," which is why we aim to offer you a range of delicious low protein foods to add into your day.

Baking: Choc-Chip Cookie Mix, Chewy Choc Fudge Brownie Mix, All Purpose Baking Mix, MixQuick

Wide range of Pastas

Soups: Beef or Chicken Noodles

Snacks: Crackers, Cookies

Breakfast: Eggz, Vanilla and Cinnamon Hot Cereal

Meal Options: Chicken, Sausage or Burger Patty Mixes, Marinara Minis, Rice



Cortex Health Pty Ltd



@CortexHealth_Aus

Recipe for Cupcakes (Makes 12)

CUPCAKES:

- 2 cups Cambrooke All Purpose Baking Mix
- 2 tsp baking powder
- 1 tsp baking soda
- 1/4 tsp salt
- 4 Tbs butter, room temperature
- 1 tsp vanilla
- 3/4 cup sugar
- 1/2 cup non-dairy milk
- 1/2 cup water
- ICING:
- 2 cups powdered sugar
- 1/2 cup butter
- 1 tsp vanilla



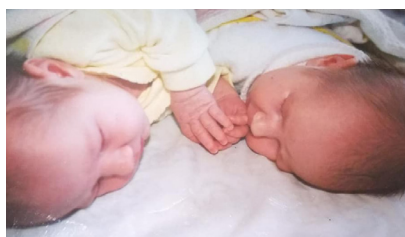
1. Heat oven to 180 °C and line 12 cupcake tins with paper cupcake liners.
2. In a large bowl, using an electric mixer set on medium-high speed, beat together the butter, sugar and vanilla until light and fluffy.
3. Add the rest of the ingredients until completely blended.
4. Bake for 22 to 27 minutes or until toothpick inserted in centre comes out clean.
5. Remove from oven to cool slightly, then remove from pan to wire rack to cool completely.
6. ICING: In a medium bowl, using an electric mixer set on medium-high speed, beat together the butter and sugar until light and fluffy. Spread frosting over the tops of cupcakes. Optional: add food colouring to colour icing or add fruit to decorate

Visit us at www.cortexhealth.com.au for more recipes and to see our low protein food range!

Celebrations



Happy 18th Birthday to Brooke and Natalie. They turned 18 on the 13th April. Thank you both so much for your help and contributions to fundraising, MDDA events and dropping into the office to say hi over the years. Your positive attitudes and active lifestyle in living with PKU make you great role models in our community.



Congratulations to Richard and Katy on the birth of Fletcher Matthew on the 15th of April. A little brother for Eden.

Thank you Katy for sharing your journey of being a PKU maternal adult.



MDDA Marketplace is the hub for all IEM products, merchandise and gifts.

Whether you want to don a PeeKabU hat, or purchase a compendium, all our many great products are available online to purchase - with proceeds going to the MDDA to help us continue to support our Member Advantage Program.



shop.mdda.org.au

Low Protein Burger Mix Recipe

SKEWERS

Makes 1 portion

Ingredients:

35 g **MEVALIA Burger Mix**
45 ml water
1 tsp oil
salt, pepper,
chili powder to taste
1 clove garlic (pressed)
100 g cucumber
60 g potato (1 exchange)
30 g cherry tomatoes



Preparation:

In a bowl mix well together the burger mix, spices and garlic. Add the water, oil and allow to rest. Meanwhile immerse 6 wooden skewers in water. Slice the potato and halve the tomatoes.

Divide the burger mix dough into 3 portions of equal size.

Take the skewers out of the water and dry. Wrap three skewers with the burger mix dough (press on well) and thread vegetables onto the other skewers.

Brush the six skewers with oil. Preheat a grill and fry the skewers for 8-10 minutes. Garnish with cucumber and serve.

Tip:

- Alternatively serve with ketchup or toasted MEVALIA Pan Carré.
- The skewers can be taken to a barbecue in the summer.

For more Mevalia recipes visit **Orpharma.com**



All low protein foods should be consumed under strict medical supervision. Please speak to a healthcare professional before making changes to your diet.



Veggie Patties

Ingredients:

1 large zucchini - slice lengthwise then slice across keeping it thin. (grated is too fine and allows too much moisture to come out during the cooking process.)
2 carrots - Julienne (grated is too fine and allows too much moisture to come out during the cooking process.)
1/2 red onion diced
1/4 cup gluten free plain flour
Handful of kale finely chopped
Handful fresh parsley finely chopped
1 tsp chicken stock powder
Approx 2 cups low protein flour

2tsp baking powder

1/4 tsp turmeric

1 - 2 tsp curry powder of your choice

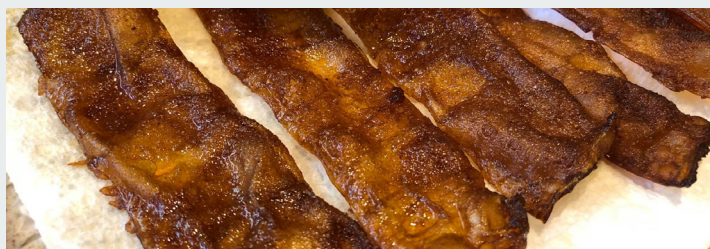
200ml milk substitute

Method:

Mix all ingredients together. Mix will resemble thickness of biscuit dough.

Shallow fry patty size portions then allow to sit on paper towel until ready to serve.

Store cooked patties in fridge for few days, great for lunch boxes.



Low protein Rice Paper "Bacon"

Ingredients:

Marinade

2 tbsp BBQ sauce

2 tbsp coconut aminos (soy sauce substitute)

1/4 tsp salt

3 tbsp oil

1 tsp coconut flour

1/2 tsp paprika

1 tsp maple syrup

Couple drops of liquid smoke (can be left out if you don't have it)

Rice Paper Bacon

4 sheets rice paper

Baking paper

Method:

Preheat oven to 200°C. Mix all marinade ingredients together.

Place baking paper on baking tray.

Soak 1 sheet of rice paper for 5 seconds in boiling water and put aside. Soak another sheet for 5 seconds and place on top of other sheet. Sheets should now be stuck together. Using a pair of scissors cut into bacon size strips.

Dip the strips in the marinade then place on baking paper.

6. Cook for 5-10mins until bubbled and crispy. Watch carefully as can burn very quickly.



Low protein Crème Caramel - Makes 4

Ingredients:

Caramel top:

100g white sugar

3 tbsp water

1 tsp vinegar

Custard:

60g white sugar

15g wheat starch

3g Agar

2 1/2 cups of any suitable milk replacement

1 tbsp vanilla essence

Method:

Ensure all ingredients are measured and ready as this recipe requires multitasking and working quickly.

In a saucepan mix together the 100g of sugar, water and vinegar. Cook until all sugar is dissolved stirring occasionally. Once dissolved allow to boil until sugar turns caramel colour

(approx 8mins). You will need to continue to watch as it will go from ready to burnt very quickly.

Whilst the sugar syrup is boiling add the remaining sugar, wheat starch, agar and milk replacement into a saucepan. Whisk together. Heat the milk mixture and continue to whisk. While the milk is coming to the boil check on your sugar syrup. The syrup should have changed colour. Evenly pour into ramekins making sure it covers the base of each.

Come back to your milk which should have come to the boil. Whisk and add vanilla. It should have slightly thickened and be like a very runny custard with no lumps. Take off heat and pour evenly into the ramekins on top of the sugar syrup.

Allow to cool for 2-3hrs in fridge. Once set run a warm knife around the edge to release the seal and then turn out onto a plate. Enjoy

Special thanks to Sasha Cranwell for these delicious recipes!



Products

Always check the nutritional panel on products



McCain: Veggie Fingers

Protein per 100g: 4.32g
Protein per serve: 4.32g
Serving size: 100g
Available from:
Coles & Woolworths



Table of Plenty: Mini Rice cakes - Triple Berry Yoghurt

Protein per 100g: 6.4g
Protein per serve: <1g
Serving size: 14g
Available from:
Coles



The Jack Man: Nude Jackfruit

Protein per 100g: 2.4g
Protein per serve: 1.8g
Serving size: 75g
Available from: Coles,
Online: TheJackMan.com.au



Sabrini: Punjabi Samosa

Protein per 100g: 4.4g
Protein per serve: 2.0g
Serving size: 45g
Available from:
Coles & Woolworths



Blackstone Snack Co: Prawn Chips

Protein per 100g: 0.8g
Protein per serve: 0.2g
Serving size: 20g
Available from: Aldi & Coles



Mr Chens: Rice Noodles

Protein per 100g: 0.1g
Protein per serve: 0.1g
Serving size: 137.5g
Available from: Woolworths



#FROPRO: Classic Vanilla

Protein per 100g: 1.4g
Protein per serve: 1g
Serving size: 69g
Available from: Woolworths



Latina fresh: Gluten free Lasagne sheets

Protein per 100g: 4.4g
Protein per serve: 2.1g
Serving size: 47g
Available from: Coles &
Woolworths



Birds Eye: Sweet Potato Rice

Protein per 100g: 0.9g
Protein per serve: 0.7g
Serving size: 75g
Available from: Coles &
Woolworths

Special Medical Foods Suppliers



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Ph: (03) 5229 8222



Platypus Foods
www.platypusfoods.com.au

2020 Queensland National Family Retreat

POSTPONED!

New Dates!

Sanctuary Cove
16th - 18th April 2021

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

Contact Us

Address

Suite 4, 6 Thomas Brew Lane
Croydon VIC 3136

PO Box 33
Montrose VIC 3765

Phone 03 9723 0600
Freecall 1800 288 460

office@mdda.org.au
www.mdda.org.au

Executive Officer

Jenny Briant
jenny@mdda.org.au

Administration Assistant

Kerry Tulloch
kerry@mdda.org.au

Communications

Isabella Hendricks
isabella@mdda.org.au

Patient Pathways Telehealth Case Management Nurse

Jo Campbell
Ph: 03 9723 0700
pathwaysnurse@mdda.org.au

Committee of Management

President

Monique Cooper
(PKU Parent VIC)
monique@mdda.org.au

Vice-President

Louise Healy
(PKU Parent QLD)
louise@mdda.org.au

Treasurer

Paige Moore
(PKU Parent VIC)
office@mdda.org.au

Secretary/Public Officer

Bianca Albanese
(PKU Adult NSW)
secretary@mdda.org.au

Health & Wellbeing

Susi Hendricks
(PKU Parent VIC)
office@mdda.org.au

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

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