

MDDA Matters

Issue #73 - June 2021

We have many events and activities planned for the remainder of 2021. The coronavirus won't stop the MDDA from looking for new ways to connect our community! We have been hard at work setting up our new virtual Member Connect Hub which launched earlier this month. Page 4 details how you can get involved in this new initiative.

We are also preparing for MDDA's host role in the GAP (Global Association of PKU) virtual conference that will be held September this year. We look forward to your involvement in these events and make sure you keep checking in with our website www.mdda.org.au for updates.

A big thank you to the Welk's family (who feature on our front page) for organising a fundraiser for Rare Diseases Day this year. More about their fundraising efforts can be found on page 9.

Thank you also to those that have contributed to our Patient Pathways program in the past months. We know everyone's time is precious, so we really appreciate you contributing to this pilot program. A short phone consult with Jo will provide reassurance and potentially access to more support in managing yours or your families IEM. Not only that, your

answers will contribute to research and further understanding the needs and gaps of people with rare and chronic conditions. Consults with Jo, our pathways nurse are still available. For further information please see page 3.

Also in this edition of course you will find our favourite pages - our members stories, product updates and recipes. A big thank you to this month's families and individuals who shared their IEM stories.

With winter upon us, rug up, find a sunny spot, grab a cuppa and take a few minutes to see what has been happening in the IEM/ MDDA space.

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Patient Pathways
- with Jo Campbell

Schedule an appointment with our Pathways Nurse today!

Ph: 03 9723 0700

See page 3 for more information on how to book your free consult



Advocacy



Louise Healy, MDDA Vice President, has been busy representing MDDA at various events and continuing to provide a strong voice to government and other bodies.

Louise was a witness at a parliamentary inquiry into approval processes for novel therapies hearing on the 22 April 2021 on behalf of the MDDA and the IEM community. Louise had provided a written submission to the Standing Committee for Health, Aged Care and Sport Inquiry into the Approval Processes for New Drugs and Novel Medical Technologies in Australia and was asked to be witness at the inquiry talking about issues raised in the submission.

The purpose of the inquiry is to look into the approval processes for new drugs and novel medical technologies in Australia, with a particular focus on those for the treatment of rare diseases and conditions where there is high and unmet clinical need. Louise spoke about the long wait for access to new therapies our community experienced and the challenges of getting clinical trials for rare IEMs to Australia and the need for reform to resolve the issues. You can read the transcript of her evidence here: <https://bit.ly/3zxkbLw>

On Jan 29, 2021 it was announced that Kuvan was recommended by PBAC for treatment for maternal women living with PKU in Australia

The Metabolic Dietary Disorders Association is extremely pleased with the decision of the Pharmaceutical Benefits Advisory Committee (PBAC) to recommend the listing of Kuvan (sapropterin dihydrochloride) on the Pharmaceutical Benefits Scheme (PBS) for maternal women, who are responsive, living with phenylketonuria (PKU). We are, however, extremely disappointed that there is still no access for adults and recognise the frustration of our adult community.

The PBAC noted there is a high clinical need in a small patient population, and acknowledged the input received from individuals, organisations and health professionals in relation to the November 2020 submission. Further, the PBAC noted the strong consumer feedback describing the very high clinical need for access to sapropterin for any adult with PKU. The PBAC would welcome a major resubmission for this broader population

Whilst the outcome is a positive one for maternal women, we are pleased that the PBAC have noted the high clinical need for access to all adults with PKU. We intend to continue to campaign for access to all safe and approved treatments. We have written to the sponsor expressing our concern that the needs of adults remain unaddressed and drawing their attention to the comments from the PBAC regarding unmet need in the adult PKU population.

We want to thank everyone who submitted a consumer comment to the PBAC about how important it is for PKU maternal women and our wider PKU community to get access to this treatment on the PBS.

In addition Louise has made a submission, on behalf of the IEM community, to the Medical Services Advisory Committee, regarding changes to their guidelines, in particular flagging the need for consumer engagement for evaluation of gene therapies for IEMs that are likely to be assessed in the future.

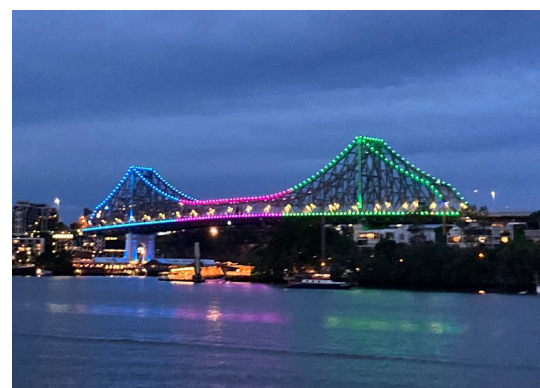


On the 28th February MDDA joined Rare Disease groups across the globe in acknowledging Rare Disease Day!

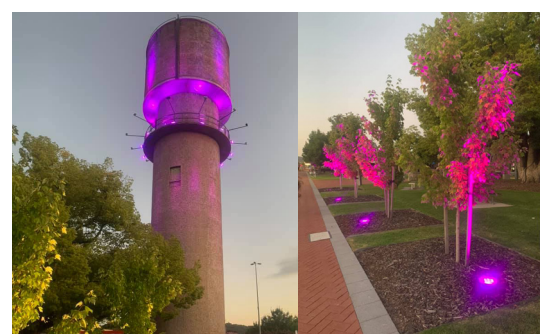
The main objective of Rare Disease Day is to raise awareness amongst the general public and decision-makers about rare diseases and their impact on patients' lives. The theme for Rare Disease Day 2021 was 'Rare is MANY, Rare is STRONG, Rare is PROUD'. We celebrate this day and reflect on the strength of every Australian living with rare genetic disorders known as Inborn Errors of Metabolism (IEM).

MDDA are proud to support our community who understand the uniqueness of those living with an IEM and understand the specific challenges that people affected with an IEM face every day.

To mark Rare Disease Day this year there were plenty of landmarks being illuminated in major cities and even regional towns. It was great to have some of our members share pictures of their cities/towns illuminated buildings and landmarks.



Brisbane, Queensland - Story bridge



Wodonga, Victoria - Water tower and surrounds

Patient Pathways & Information updates

Patient Pathways

IEM support health check with Nurse Jo

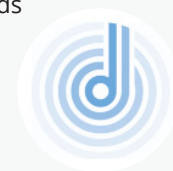
80% of people who completed a quick "patient pathways consult" with Jo accessed services and supports they did not know they were entitled to.

Jo will be able to provide practical and emotional support, education and can connect you to existing services including clinical trials.

You can also inform future research into your specific condition by telling Jo about the needs and the gaps you have identified in the treatment and management of your IEM.

Get in touch and book a chat with Jo at a time most convenient for you:
03 9723 0700 • pathwaysnurse@mdda.org.au

This program does not replace the expert clinical care and treatment advice of your metabolic team



Carer Allowance for a child under 16 years

Phenylketonuria (PKU) and other inborn errors of metabolism treated by medically prescribed diet to prevent neurological disability and/or severe organ damage are recognised disabilities and medical conditions eligible to receive carer allowance for a child under 16 years.

To receive the fortnightly supplement you must meet certain criteria:

- meet an income test
- care for someone whose care needs score is high enough on the adult or child assessment tools
- care for someone who'll have these needs for at least 12 months
- be an Australian citizen; permanent residence visa holder; protected Special Category visa holder
- you may be able to get Carer Allowance for more than 1 person you provide care for

A claim is required for the Carer Allowance (Child) Health Care Card.

Information and how to claim can be found on the Australian Government Services Australia website.
www.servicesaustralia.gov.au

Ex-Carer Allowance (Child) Health Care Card

You can claim this concession card to help get cheaper health care, medicines and some other concessions if you're a student and held a Carer Allowance Health Care Card before you turned 16. The card will not be issued automatically, you must claim the card and reapply annually.

To receive the fortnightly supplement you must meet certain criteria:

- are aged between 16 and 25 years
- are a full-time student
- had a Carer Allowance Health Care Card on the day before you turned 16 years of age
- meet residence rules

This card is not means tested.

A claim is required for the Ex-Carer Allowance (Child) Health Care Card and you must reapply annually.

Information and how to claim can be found on the Australian Government Services Australia website.
www.servicesaustralia.gov.au

Coronavirus (COVID-19)

australia.gov.au

For the latest official coronavirus news, updates and advice from the Australian Government.

- * check your eligibility and locate your nearest vaccination centre
- * Information about COVID-19 vaccines
- * COVID-19 vaccine information in your language
- * Health alerts & advice

Coronavirus Health Information Line: 1800 020 080



Virtual events

MEMBER CONNECT HUB

A welcome place for the IEM community to connect, share and learn.

June - December 2021

Our MDDA Member Connect Hub was launched on the 7th of June, and kicked off with our Launch Party. It was so nice to see your faces again and for the MDDA community to come together.

Our Member Connect Hub is an inclusive and interactive virtual platform that is extended to all MDDA members as a place to connect and meet with other members, gather in special interest groups and forums and attend virtual events and workshops. We have a great mix of informative and social sessions planned over the coming months.

Key Member Connect Hub Features

Member Connect Lounge

The Member Connect Lounge is a place where all members can go to discover who's who in the MDDA Member and IEM community.

Create your member profile in the directory and connect with others. Share information or stories, find people with common interests and conditions and create peer support networks of your own.

The Member Connect Lounge is open 24/7 and provides an interactive easy to use platform where you can connect and interact in a casual and ad hoc/impulsive way at any time of day or night. The ability to instant message, video chat or book a time to meet 1on1 or in small groups provide a great way for our members to connect beyond the realms of social media or other traditional forms.



Low Pro Inspo Virtual Showcase

The Low pro Inspo Virtual Showcase is an interactive resource Hub it's the place to go to find latest information of Low Pro foods, products, recipes and much more.

Member Connect Hub Virtual Events

Educational webinars, workshops, panels, peers support sessions, and 1on1 member interviews taking place regularly throughout the month.

Adults and Parents	EDUCATIONAL CONNECT FORUM'S	SPOTLIGHT SERIES	CONNECT GROUPS	VIRTUAL HAPPY HOUR
	Educational webinar style presentations, followed by Connect Group Chats & Breakouts	Intimate 1on1 or 'on the couch' panel style member interviews with audience interaction	Special interest peer support groups that convene regularly online in an informal setting	Casual Virtual Networking through the Member Connect Lounge and various Chat Rooms and our Connect 4 Speed Networking
	1.5 HOURS + NETWORKING 1.30PM TO 3.30PM TUESDAYS (BI-MONTHLY) TOPICS INCLUDE: MATERNAL PKU, PKU CARERS, SPECIFIC IEMS	45 MINS + NETWORKING 7.30PM TO 8.15PM THURSDAYS (2 PER MONTH) GUESTS INCLUDE: SCHEDULE TO BE ANNOUNCED SHORTLY	1 HOUR + NETWORKING 1.30PM TO 3.30PM TUESDAYS (1 PER MONTH) GROUPS INCLUDE: RARE IEMS, MATERNAL WOMEN, CARERS, GRANDPARENTS, NEW PARENTS, PKU ADULTS, PKU SPOUSES, PKU PARENTS	1 HOUR 7.30PM TO 8.30PM THURSDAYS (1 PER MONTH) CHAT ROOMS INCLUDE: HOSTED BY MEMBERS AS NOMINATED OR REQUESTED
Kids and Teens	TEENS LEADERSHIP WORKSHOPS	TEENS PANELS	CONNECT GROUPS	
	Our Low Pro teens leadership team get together for coaching and guidance to support their IEM management and guide our PeekabU kids with mentoring skills	Designed for Parents and other teens to come and ask questions of various IEM Teens	PeekabU Kids Mentoring Groups with Low Pro Teens (monthly challenges & show & tell)	
	1 HOUR 7.30PM TO 8.30PM THURSDAYS (1 PER SCHOOL HOLDS) TEEN LEADERS INCLUDE: LOW PRO TEENS 13 YRS+ CAN PARTICIPATE (ONCE PARTICIPATED IN A PANEL) AND ALLOCATED TO A MENTORING CONNECT GROUP	45 MINS + NETWORKING 7.30PM TO 8.15PM TUESDAYS (1 PER SCHOOL HOLDS) PANELISTS INCLUDE: ANY LOW PRO TEENS CAN PARTICIPATE	1 HOUR INC. BUDDY TIME 7.30PM TO 8.30PM TUESDAYS (1 PER MONTH) GROUPS INCLUDE: EACH GROUP CONSIST OF 2 LOW PRO TEEN MENTORING LEADERS WITH UP TO 6 PEEKABU KIDS	

We have an exciting series of different events and activities planned for this second half of 2021 so make sure you stay connected.

There is something for everyone!

Global PKU Virtual Scientific Patient Conference

10-11 September, 2021

MDDA are excited to host this first ever worldwide PKU patient conference, providing opportunities for all PKU patients from around the globe to hear from experts on latest science and research into the care and treatment of PKU.

A virtual conference allows the PKU patient community to attend virtually from anywhere around the world.

This event will be delivered in three key time zones to include participation across all Global PKU Support groups including the America's, Asia Pacific and Europe over a 12 hour time slot.

You will be invited to attend all three live streams where possible. 'On Demand' recorded sessions will be made available immediately following each event session for members of all Global PKU Support Groups.

Keynote scientific presentations will feature international speakers presenting on current PKU scientific priorities, outcomes & progress.

Thank you to our Platinum sponsors - BioMarin for providing this incredible opportunity. For sponsorship opportunities please contact MDDA.



Bridging the gap for PKU worldwide



Our Mums & Bubs forum was the first in our member connect hub series, and was held on the 8th June. This online event brought together PKU women who are new or expectant mums, and those that were thinking about family planning. Those involved heard from metabolic specialists and other PKU women as well as it providing a great opportunity to connect and share experiences. A big thank you to Anne-Marie from the Royal Melbourne Hospital.

Far North Queensland Clinic

Kim and Roy Large kindly represented the MDDA once again at the Far North Queensland Clinic that was held in Townsville 17th & 18th May and Cairns on the 19th May. The MDDA sincerely thank Kim and Roy for taking the time to volunteer and help spread the support of the MDDA and educate those newly diagnosed about the MDDA.

The clinic trip was kicked off with a dinner at the Townsville Cowboys Leagues Club on Sunday the 16th of May. They had a lovely turn out which included the Brisbane Metabolic Team, Dr David Coman, Anita Inwood and Dr Arty Selvanathan. It was great to have a relaxing dinner with all who attended, face to face. After Kim and Roy attended the Townsville clinic waiting room for two days welcoming IEM patients, they headed for a road trip to the Cairns clinic.

MDDA send our sincere and heartfelt condolences to Kim, Roy and their family for the loss of Kim's much loved father Allan shortly after her return from the FNQ Clinic.

There were many familiar faces but also lovely for Kim to meet some new families and welcome them into our MDDA community.



Member Stories

IVA

Victor, Shannon and Isovaleric Acidaemia (IVA)

Victor was born on the 8th of June 2019, weighing 3430g and measuring 50cms. At birth, detected beforehand with ultrasound, he had a small VSD (hole in the heart), which later closed over. That 'minor' problem became the least of anyone's concerns, after we were called in to our local hospital on Day 11 for a repeat newborn blood screening test, as his first one returned an abnormal result. On Day 12 the hospital called us back in again for him to be admitted, breastfeeding was ceased immediately, he was catheterised and put on a drip, then the next day we were flown to Westmead's Sydney Children's Hospital, where we received the shock of his diagnosis.

Victor has a rare genetic metabolic condition - Isovaleric Acidaemia (IVA). The incidence of IVA in Australia is approximately 1 in 200,000 births. It occurs due to an autosomal recessive gene being passed on to the offspring by both parents. A person with IVA is lacking a particular enzyme needed to break down one of the essential amino acids (leucine) in food. The enzyme defect results in the accumulation of isovaleric acid and other metabolites in the blood and urine which are toxic and harmful to the brain. If left unmanaged, this may lead to the person having a metabolic crisis as well as causing brain damage. *The aim of treatment of IVA is to keep the accumulation of isovaleric acid as low as possible by ensuring adequate intake of energy and providing a diet with a moderately decreased protein intake.*

We spent 5 days in Westmead where Victor was carefully assessed through daily blood tests. He was started on metabolic formula, Energivit, which he still takes to this day to supplement his diet so that he meets all of his nutritional requirements. By the end of the 5 days I was allowed to recommence breastfeeding which I continued to do for 11 months. By the time we attended the MDDA conference in Tamar Valley in October 2019, he was also having some regular supermarket grade formula, as blood tests indicated that he was able to handle, and needed, higher levels of protein in his diet.

At present, he is allowed one high protein (5g) serve per day, with the rest of his daily food intake being of low protein sources which don't have to be weighed. In addition to this dietary protein restriction, Victor takes 12ml per day of L-Carnitine which helps his body to excrete excess Isovaleryl CoA. We attend clinic with the Metabolic Team at Westmead every 6 months where they monitor his blood amino acids and carnitine levels but since the COVID pandemic began, this clinic is conducted by Telehealth Conference from my home and his bloods are taken from our local pathology centre and sent down to the team at their Westmead surgery.

The danger for him is if he becomes sick with either a high temperature, vomiting or diarrhoea, this can lead to him breaking down his own body protein, causing an overload of toxic metabolites. When this happens, the on-call Metabolic Doctor is phoned immediately and Victor's 'unwell' feeding plan is followed where protein intake is restricted even further and calories are increased until he becomes well again and his normal eating patterns return. He has had a couple of respiratory infections in his life with no adverse effects and just one hospitalisation when he had vomiting and high temperatures. Once again, our local hospital liaised with the Metabolic Team and they worked closely together to restore



Victor's health. We are so grateful to have the Westmead Metabolic Team managing Victor's life and know we can contact them at any time with any concerns that may arise as he grows.

Victor's initial diagnosis came as a shock, as none of our family had ever heard of such a condition. Not to mention, he is my first and only child and I was/still am a single mother. I didn't break down and cry though, as I felt that would be of no use to Victor. There was no other choice but to accept the hand we had been dealt, learn as much as I could about the condition and try to do my absolute best to take care of him by following the Metabolic Team's directions and ensuring he gets what he needs, medication-wise and nutritionally.

We also have wonderful family support which I am so grateful for and lucky to have. I cannot imagine our IEM journey without their ongoing love and support – shout out to Mum, Wendy and sister Biggle, who have dropped everything to come to our aid in times of need. To my other sister Vv, for all her help during that first 12 months that we were living together. Also to the men, they know who they are.

As for Victor's special diet it was no adjustment or cause of added stress for me, as I was already eating mostly plant-based well before Victor was on the scene. I am also a huge foodie and love cooking from scratch, so after endless recipe hunting for low protein options and finding the right substitutes for certain ingredients, it is always a pleasure to throw together something delicious for us to both share and enjoy. Mum also grows beautiful veggies, so I am never short of quality organic produce. We also never leave home without a snack pack of yummy home-made Victor-friendly nibbles.

He recently started two days per week of day care to have some added stimulation and socialising. The centre supplies his food and they have been most accommodating of his needs. He eats only low protein foods while there and I save his high protein serve to have at home, where I can monitor how much he has eaten.

At almost 2 years of age, Victor is happy, healthy and unstoppable. He loves his food and play and keeping the family on all of our toes. *I couldn't feel happier or any luckier for all the love, joy and life lessons this little human being has brought and continues to bring to our lives.*

Our family journey with Phenylketonuria (PKU)

Reflecting back on the past 5 years, I think our PKU journey started out quite similar to other families I have read about.

Initially when we received the phone call to come into the hospital to learn about our 8 day old daughter Olivia's diagnosis we were in shock and disbelief and when that wore off I think I in particular went through a grieving process for a period of time and then concerns about the future for her. My husband and I both had our own ways of coping and for him it meant not having to read up about the condition but just trust in the information we received from the metabolic team. I on the other hand, read the PKU guidelines in its entirety, researched PKU online, read about the different companies selling the low protein foods online and joined PKU groups on Facebook in order to be as prepared as possible.

I remember being quite anxious just before Olivia turned 6 months as I knew that this would be the time we would start solids which meant facing the overwhelming thoughts of having to prepare and weigh her food each day and start counting protein. I remember having a phone call with Louise Healy during that time who really normalised things for me and gave me many great tips and a place to start. *I have to say the first 12 months were definitely the most difficult but following that, it really has become second nature. I have often had a laugh with my mum about how we can rattle off what the protein count is in many different foods now....who would have thought.*

Olivia has grown into a confident, joyful and very active 5 year old. She loves swimming and dancing and has started Ballet through her school this year which she has loved doing with her little friends. She has had quite a smooth transition to Prep and we prepared for this by setting up a visit with her teacher before the school year started, talking through her condition with the teacher and providing the school with an information sheet about PKU with a photo of Olivia on this and also a list of the foods she can and cannot eat. I have asked the teacher to email me when there are cooking days or days when the school has free lunch days. I also keep a few cupcakes in the freezer in her classroom so the teacher can get one if they have a birthday in class.

Olivia has been on PKU Squeezies since she transitioned from her infant formula and despite trying samples of many other types of formulas (during times she was getting sick of the Squeeze) she has stuck with this one. At school Olivia has been having one at morning tea and has chosen to tell the other children in her class it is her 'yoghurt' drink as it resembles the yoghurt pouches. We have attended a few birthday parties already this year and I take along a cupcake for her and some treats but also check in with the other children's parents to let them know and find out roughly what might be served in order to try and match some foods. When Olivia first started day care I was certain that I would be able to make or provide similar food for Olivia however I quickly realised I did not have the time nor the skills to do this so Olivia took her 'special' food in her lunch box there instead. Now that she is at school, every child brings in a lunch box so thankfully there are no differences.

We get excited about discovering new recipes or finding new foods that are low in protein. I have had many baking fails and have still not baked a great loaf of bread – this is my goal. But the main things is we keep trying and we really enjoy trying to be creative and Olivia loves to help cook.



It seems as though she is always hungry but certainly doesn't go without. I have food intolerances and so does her brother so she knows that not everyone can eat everything. She seems to have a strong desire to smell and touch things though and I guess that comes with being curious about what something tastes like. We have given her little tastes of things here and there but nothing very high in protein.

I have to hide my heart breaking a little sometimes when she asks if she can have ham or chicken or something she has seen us eat when she gets older, or when I tell her that she can't have any more mashed potato or broccoli but we always make sure there are lots of low protein options she can have instead and she loves desserts and anything sweet so this is her main focus always.

Metabolic conditions, like many other significant medical conditions, can be so tough some days as you do not get a day off from it - it doesn't matter if it is your birthday or a special occasion or you are sick, you still need to think about it at some level. *I have so much appreciation for all of the parents of PKUers and the adults with PKU that have come before us as they have made it so much easier and more manageable for us with tips, advice, support and guidance. We feel lucky that PKU is a manageable condition and that there continues to be ongoing advocacy and support for research and treatment.*

We are so proud of Olivia and even though we have had many challenging PKU moments, she has been resilient and taken everything in her stride. A big factor with feeling confident in managing this condition now for Olivia has been the support from her metabolic clinic and the MDDA, in particular the Facebook group. It has been so helpful reading others' stories, recipe tips and where to find low protein products and it is such a welcoming space to receive or give support. I would truly be lost without it.

All the best, Natalie, Jason, Olivia and family xo

Member Stories

PKU

Living with Phenylketonuria (PKU) by Therese-Alena

How was I diagnosed? I was the last born of 8 children and I was diagnosed with PKU with the 5-day old new-born screening test. I still have the letter from the hospital with my results stating that I have PKU. My oldest sister and 1st born child Renee, was not so lucky as new-born screening was not conducted at the time she was born.

As far as I am aware she is not on diet and is still in assisted care due to being intellectually challenged. The part that hurts me is that Renee does not know who I am when I see her around the city as she shops each week. The best thing is that I know who she is, and it warms me inside that I know that she is doing ok and being looked after.

The challenges of growing up with PKU. Growing up I was unaware that I had PKU or what PKU was and how it affected me. All I knew was that I could not have certain foods and had to go to the hospital to see a doctor regularly. I knew inside that I was different, as I was always treated differently than my siblings that I lived with. PKU was never explained to me that I am aware of, I remember flashes of my childhood, like sitting out front of my primary school saying I did not eat a packet of Twisties to my mum with all the yellow around my mouth, I remember this but not eating the Twisties or what happened after.

I really wish I could write more on growing up with PKU, but I believe that due to being off diet for over 35 years and fluctuating on my blood levels, I have little to no memory of my childhood or growing up. I do have flashes of imagery in my head every now and then. I have some pictures of me as a child, I know it's me in the picture, but I have no memory of the event or being there.

Challenges as an Adult with PKU. I was taken off diet when I was around 11 or 12 years old. I remember my first meal off diet was at the Kmart food café "Holly's" in Rundle Mall. I had the meatballs; I think it came with chips but I don't fully remember. I believe my Mum took me there straight after the Dr's appointment for lunch.

I've had many jobs and relationships throughout my adult life, but due to concentration issues and not remembering tasks or routines, I have always been let go or dumped. I opened a gift store in Adelaide CBD but sold it due to a relationship breakdown in 2006.



Returning to Diet at age 43. I met my partner in 2007 and we got married in January 2010. After we were together for a couple of years Darren questioned me as to why I had the shakes all the time and could not concentrate; during this conversation and me thinking "great another one that is breaking up with me because of this PKU crap". I ended up telling Darren that I had PKU, but it did not affect my life...boy was I wrong! I did not see it, but he did, and he stuck around and researched what PKU was.

I knew that I had concentration issues and the shakes, but I did not think it was that bad or connected with PKU; I just thought I was not that intelligent. After Darren talking to me for several years and helping me discover a PKU Global Search for Adults off diet on Facebook. We started looking into what would happen if I returned to diet and how it would affect my life. I still did not understand it all myself, but we made an appointment at the RAH to discuss the options of returning to diet.

Since returning to diet Darren has said that he has drastically noticed that *my concentration issues have mostly disappeared, and my shakes have all but disappeared*, except when I have too much protein...my bad.

Managing my diet for parties/Events. Friends that like to entertain have researched PKU and what food limitations I have when they are planning dinners or events so that I can enjoy myself as well. My husband always researches menus before we go out anywhere for us or with friends so that I can pre-order or prep for the outing. I turned 50 in April, so planning a cocktail party had its challenges, but the Chef "Anthony" at the Arkabar Hotel assisted by creating PKU canapés as I had some PKUPEEPs attending.

Attending my first Retreat. After discovering and joining as a member with the MDDA, my diet and outlook on PKU has improved, as I know that I'm not alone anymore. I attended my first Retreat in Tasmania and connected with other members with PKU. I started to understand that I have support and joined the SA MDDA Community Chat group on messenger. Since then, I have also joined a smaller group that meet once a month for lunch and chat about our experiences and our lives. I have found that this group, we call ourselves PKUPEEPs, have kept my outlook on having PKU a positive experience as we can support each other and boost each other when things look down.

Zest Adult Wellbeing and Vitality Program

Zest aims to improve the mental, emotional and physical health of Australian adults living with an IEM. 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.

If you would like to register your interest for a future Zest series or would like more information please email: office@mdda.org.au

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



ZONE • ENERGISE • SOAR • THRIVE



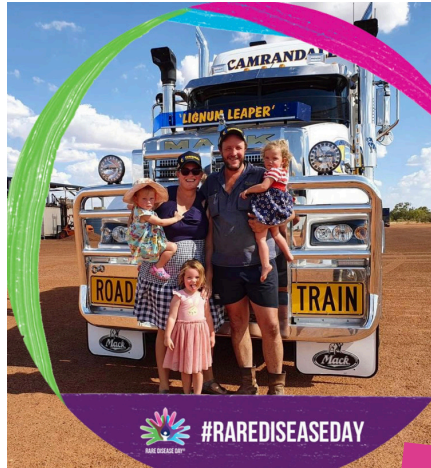
Fundraising



#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 can be ordered via MDDA Marketplace.

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



Living in the remote south west Queensland town of Quilpie, the Welk family used Rare Diseases Day to raise awareness and funds for PKU and for the MDDA.

The Welks and the Quilpie township raised over \$2300, this is simply incredible and we are most grateful for their bighearted generosity.



QLD

Also a big thank you to our MDDA Treasurer, Paige. Paige organised a birthday fundraiser through her facebook page and raised \$1,412

Volunteer knitters

A big thank you to some wonderful ladies, who answered our call out when stocks were low for our knitted IEM baby bears. Thank you to Anne Hellings, Laurel Tulloch, and to Jill Close who along with her lovely neighbours, Lynn, Gail, Bernice and Glenda knitted bears for us. We know how much our newborn babies and families love getting a knitted bear. Thank you all for your time and care in knitting these for our youngest members.



Dr Jim McGill receives 2021 Australia Day Honours

MDDA extend our most heartfelt congratulations to Dr McGill for his well-deserved award in the Australia Day honours. He is such a worthy recipient. MDDA were proud to be asked to provide a reference for Dr McGills nomination.

Dr McGill's gentle and gracious manner, his compassion and dedication, warmth and willingness to go above and beyond expectation to deliver the very best care to each of his patients will be missed. Many families shed tears on hearing of Dr. McGill's retirement from clinical practice.

We are privileged and honoured as an association to have had Dr McGill's support. As individuals and parents with a rare disease we already know that Dr McGill is more than deserving. He is already sadly missed in clinic and we thank him for the immeasurable difference he has made to our lives and to the IEM 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 2021

The IEM food grant payment for 2021 is due by the Friday of the first full week of each month.
9 July, 6 August, 10 September, 8 October, 5 November, 10 December





Cauliflower Provencal

Ingredients:

1 cauliflower
1 red capsicum
2 tomatoes, coarsely chopped
75ml vegetable stock
1/2 cup (75g) black olives, pitted and sliced
Salt and pepper to taste.

Method:

Cut off the leaves and stalk from the cauliflower, then break or cut the florets from the core. Arrange the florets in the top of a steamer over boiling water, cover and steam for 9–10 minutes or until almost tender.

Meanwhile, in a saucepan combine the red capsicum, tomatoes and stock. Bring to the boil over moderate heat, then cover and cook, stirring occasionally, for about 3 minutes or until the capsicum is almost tender.

Add the cauliflower and olives to the tomato sauce and toss to coat. Cover again and cook, stirring occasionally, for a further 2–3 minutes or until the cauliflower is tender. Season with salt and pepper and serve.



Aloo Jeera

Ingredients:

1kg new potatoes
2 tablespoons olive oil
2 tablespoons cumin seed
2 teaspoons ground turmeric
2 teaspoons curry powder
2 teaspoons sea salt
1 teaspoon freshly ground black pepper
Handful chopped fresh coriander

Method:

Place whole potatoes in saucepan with water to cover. Bring to a boil and cook until just tender.

Drain, and cut potatoes into quarters. Set aside to keep warm.

Heat oil in a large pan over medium heat. Add cumin, turmeric and curry powder and cook for 1 minute.

Add potatoes and cook until slightly crisp.

Toss potatoes with salt, pepper, fresh coriander.

Serve hot.



Sweet Potato & Pear Caramel

Ingredients:

1kg sweet potatoes, cooked, peeled and sliced lengthwise (scrub potatoes and cover with water, simmer until potatoes are almost fork tender, let cool, peel and slice)
4 pears, peeled, cored and sliced into wedges
1/3 cup brown sugar
1/4 teaspoon cinnamon
1/4 teaspoon nutmeg
1/4 cup melted Nuttalex
1/2 cup shredded or coarsely grated fresh coconut

Method:

In a baking dish arrange sliced sweet potato alternatively with pear wedges.

Sprinkle with brown sugar, cinnamon and nutmeg.

Pour over melted Nuttalex.

Lightly cover with shredded coconut.

Bake 180°C for 30 minutes or until hot and bubbly.

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



Products

Always check the nutritional panel on products



Special Medical Foods Suppliers



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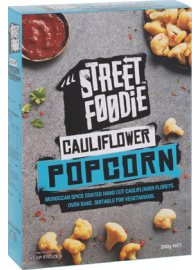
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www.orpharma.com/products/low-protein-food/
Ph: 03 9863 7267



PLATYPUS FOODS

Platypus Foods
www.platypusfoods.com.au



Street Foodie: Cauliflower Popcorn

Protein per 100g: 1.8g
Protein per serve: 0.9g
Serving size: 50g
Available from:
Woolworths



Genius: Stone baked Pita breads

Protein per 100g: 2.6g
Protein per serve: 1.6g
Serving size: 62g
Available from: Coles & IGA



Chris' Plant based Corn Relish

Protein per 100g: 1.5g
Protein per serve: 0.3g
Serving size: 20g
Available from: Coles



Proud & Punch: Coconut pops - coconuts for mango

Protein per 100g: <1g
Protein per serve: <1g
Serving size: 69g
Available from: Coles & Woolworths



Coles: Nature's Kitchen Jackfruit bites

Protein per 100g: 4.2g
Protein per serve: <1g
Serving size: 20g
Available from: Coles



Fibre One: Chocolate Fudge Brownies

Protein per 100g: 4.2g
Protein per serve: 1g
Serving size: 21g
Available from: Coles & Woolworths



Coles: Vegan Vanilla Bean frozen dessert

Protein per 100g: 1g
Protein per serve: <1g
Serving size: 60g
Available from: Coles



Birds Eye: Deli Roast Veggies

Protein per 100g: 1.7g
Protein per serve: 2.7g
Serving size: 157g
Available from: Woolworths



Sara Lee: Creamy Coconut Key Lime Pie

Protein per 100g: 2.2g
Protein per serve: 1.6g
Serving size: 75g
Available from: Coles & Woolworths

Grab yourself some merch, IEM products or gifts at
MDDA Marketplace



Looking for gift ideas, while helping support the MDDA?
Check out our online shop at MDDA marketplace for some great ideas.
www.mdda.org.au/marketplace



ARE YOU A FINANCIAL MDDA MEMBER?

Please contact us office@mdda.org.au if you would like to check on your status and continue to support the MDDA

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.

**MDDA
Membership
only \$35 per
year.**



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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