

MDDA Matters



Issue #70 - November 2019

TIME TO SHINE was the theme at this year's retreat, encouraging us to embrace and celebrate everything that makes us shine and together find our inner sparkle.

MDDA want to shine a light on everything good that is happening with IEMs today! As a rare disease patient population, the time has never been greater for us than right now. With many advances in clinical trials, research and genetic science leading the way, new opportunities will present, and the hope for a brighter future exists for all individuals living with an IEM.

This newsletter features our National Retreat held recently in Tasmania and a showcase of our exciting new initiatives and programs that we've been working extremely hard throughout the year to bring to you - including our new [Member Advantage Program](#).

It has been an incredible year for the MDDA and we are proud to be making a real difference to the lives of all IEM families throughout Australia. We have been very successful in advocating for our community throughout 2019. We have influenced decisions within the government and external stakeholders to improve services and opportunities for all.

[Advocacy](#) is about being active, telling our story, lobbying decision makers and developing campaigns. Working together we know we can make a difference. With this newsletter we've enclosed a copy of our Annual Report, and encourage you to find the time to read and reflect on the many wonderful achievements from our very active team and the positive changes we have made to our community.

Christmas Parties are being held around the country to celebrate the year with all members and friends. If you haven't already RSVP'd check out the MDDA website to find details of your states event.

On behalf of the team at MDDA, we would like to take this opportunity to thank all of our valued members and wonderful volunteers for their dedication and support over the past twelve months, each one working hard to exceed expectations and helping to make the biggest difference possible. [We wish everyone a very Merry Christmas and a Safe, Healthy and Prosperous New Year in 2020!](#)

MDDA Office Christmas closure: 20 Dec 2019 - 7 Jan 2020

MDDA Christmas Events

Saturday 16th November

TAS - 12pm Tailrace Park, Riverside

Saturday 24th November

QLD - 10:30am Taylor Range Country Club, Ashgrove

Saturday 30th November

NSW - 12pm Bayside Pantry, Woolongong

Sunday 1st December

WA - 12:30pm Kwinana Adventure Park, Walgreen Crescent, Calista

VIC - 12:30pm The Grand Hotel, Warrandyte

Saturday 14th December

SA - 6pm B.Social Restaurant, Oakden

For RSVP & further details visit mdda.org.au/events

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Advocacy Update

Another busy period in the advocacy space has included a range of advocacy activities to try and ensure that everyone in our community has access to treatments, services and clinical trials to get the best possible health outcome. These activities have included:

- Writing to the sponsors and a teleconference with representatives from Pharmaceutical Benefits Advisory Committee to identify ways that MDDA can continue to work to achieve access to sapropterin for adults.
- Providing advice and support to families considering a loading testing for sapropterin responsiveness for their child.
- Participating in an Australian Government Drug Utilisation Subcommittee review of sapropterin for patients with BH4 deficiency.
- Working with MMA families to bring a clinical trial for a new MMA treatment to Australia.
- Liaising with metabolic clinicians and referring clinical trial enquiries for a range of protein IEMs to them for review and advice.
- Liaising with pharmaceutical companies who have, or are in the process of establishing clinical trial programs for protein IEMs in Australia.
- Working with the Australian Tyrosinaemia Type 1 community and the Life Saving Drugs Program expert panel on the review of Tyrosinaemia Type 1 treatments currently subsidised by the Australian government. Thanks to Koby Poole and Fadwa Azer who attended a consultation with me on behalf of the Tyrosinaemia Type 1 community. MDDA encourages all families who access treatments on this program to participate in this review and ensure that the government understands the needs and challenges of families in accessing the treatments.
- Providing UCD families with information about treatments for Urea Cycle disorders and providing a written submission to PBAC regarding these treatments.
- Visiting Canberra as part of ongoing advocacy by Rare Voices Australia to have the needs of rare disease patients better recognised in the NDIS. During this trip MDDA representatives met with the Department of Health and



Associate Professor Carol Wicking, Director, Rare Voices Australia (QLD) and Louise Healy at Parliament House

key MPs, or their advisors, on issues of importance to our community, these included: access to treatments that are available overseas, the difficulty for rare disease treatments to be listed on the PBS, attracting clinical trials for protein IEMs to Australia and support for rare disease research.

- Finally, one important advocacy project we hope to launch by the end of the year is a Clinical Trial and Research Registry and Tool Kit. The kit is intended to help people considering participating in a trial with their decision-making process. In addition, Jo Campbell, our Patient Pathways Co-ordinator will be available to discuss any questions or concerns people considering participating in research or a trial may have. The Registry will allow you to express an interest in receiving information from the MDDA about any clinical trial or research that may be relevant to you or your family member.

Watch this space if you are interested in being involved in advocacy for access to treatments for adults. Thank you to everyone who has been involved in consultations, discussions with clinicians, providing written submissions or working closely with MDDA to promote the needs of a specific IEM. It has been a busy but rewarding time in the advocacy space.

Louise Healy – Vice President MDDA

Future Genetic Counsellors learn from MDDA Experience



As some of you may know, our names are Erin and Anastasia and we are Master of Genetic Counselling students at The University of Melbourne. As future genetic counsellors, we will be providing information and support to families who may have a genetic condition.

Over the past few months we have been lucky enough to undertake a community placement with the MDDA. During our time with the MDDA, we helped develop a resource about transition to the adult healthcare system for teenagers and their parents/guardians. We were also able to attend the 2019 Family Retreat. It was a fantastic way to end our time with the MDDA. It was a pleasure for us to witness your sense of community and really confirmed for us the importance of a group, like MDDA, in providing lifelong support to those managing a chronic genetic condition. We want to sincerely thank the MDDA and all MDDA members for welcoming us into your community and allowing us the opportunity to learn from your experiences. Your stories are something we will certainly carry with us throughout our lives and our future practice.

Tasmania Family Retreat



Tamar Valley Resort, Grindelwald, Tasmania 4-6th October 2019

At this years National Family Retreat we had over 140 members, health professionals, guest speakers and key stakeholders join in the experience. It was the perfect setting for a weekend of learning, connecting and sharing stories with others.

The following pages include a brief outline of some of the interesting and informative sessions that were held at this event.

Transitional Workshop for Young People and Parents/Guardians.

These sessions were delivered to describe the key components of transitional care for young people and their parents/guardians. Transition refers to a young persons move to the adult hospital system. Even though the formal process happens around 18 years of age, the transition process starts earlier at around 13 years of age. A pilot resource as a handbook was created for both groups.

Health services define adolescents as a specific client group with their own specific health care requirements. The research shows adolescents seen alone with health clinicians promotes disclosure and increased independence and control for the teenager/adolescent. Research has also shown that when the hospital, young person and their parent/guardian works through the transition process together, the young person stays engaged with clinic and moves into young adulthood feeling more confident managing their condition.

The aims of the transition process are:

- To provide high quality care for the young person. The care needs to be individualised and relevant to their unique needs as teenagers.
- Encourage the young person to develop skills in communication, decision making, assertiveness, self-care and advocacy, maximising the young person's potential to achieve their life goals (educational, social) regardless of their health condition.
- Provide support to the parent/guardian to gradually shift responsibility from you to your young person. The intention is for the parent/guardian to be confident their young person has the skills to take on the next stage of their lives.

The paediatric hospitals have a Transition Co-ordinator that you can asked to be referred to. Their role is to provide support and deal with any issues you may face while transitioning to adult health services.

The MDDA Transition booklets for our young people and parents/guardians offers practical guidance to help both groups understand and prepare for the transition process.

Both handbooks "Getting Ready for Transition" guides for parents/guardians and young people are available to download as a PDF document under resources on the MDDA website.

BH4 Testing for PKU Children

Anita Inwood – Metabolic Nurse Practitioner from Queensland and Kristen Fitzell – Dietitian from Victoria presented information on the testing process and criteria metabolic clinics use to determine the responsiveness of BH4 (sapropterin or Kuvan) in children with PKU. This was a highly informative session and provided an opportunity for discussions and questions. If you have any questions about BH4 testing for your child please contact your metabolic clinic. As of 1st May 2019, BH4 is listed on the Pharmaceutical Benefits Scheme for children and young people under 18 years old with Phenylketonuria. MDDA are committed to continue advocating for accessibility for adults.

Supporting Grandparents

This year we were lucky to have a group of grandparents join their family at the Retreat. While grandparents often provide an extended family support, they too can feel overwhelmed and concerned with their grandchild's diagnosis. A facilitated discussion session specifically for grandparents was held where experiences, concerns, tips and resources were shared.

"Thank you for the knowledge I have received in 3 days. I have met some great people, come away with great ideas. Thanks for including grandparents from a grateful grandfather".

Arthur - Grandfather to Luca, PKU, 2 years old

Tasmania Family Retreat

Zest “Boost Camp”

At this year's Retreat, we ran our very first Adult Vitality “Boost” Camp as we launched Zest, a program adapted from a wellbeing program that was run in 2017. On Sunday morning the IEM adults at the Retreat, got to enjoy various presentations that introduced them to the Zest program and boosted their personal zest.

These sessions included:

- A healthy LowPro sit down breakfast with a ‘Find your Sparkle’ presentation from motivational speaker Julie Cross. This presentation had the group laughing, crying and thinking about what gives their life “sparkle”. Sparkle is the motivation to keep on track with diet and wellbeing activities.
- An introduction to the new Zest program, a comprehensive and personalised program that covers mental, emotional, social and physical wellbeing and helps adults uncover and nurture their zest.
- Some great inspiration to manage healthy eating for optimal protein intake as well as including a range of delicious and fresh foods that make you feel good from Royal Melbourne Hospital dietitian Anne-Marie Desai.
- LowPro Inspo - Morning Tea on the Go live demonstration from Bianca & Ben, including some really interesting and varied smoothie ideas, bliss balls and some delicious dips ideas.
- And finally, an introduction to goal setting and using the new My Low Pro Pal App within the Zest program.

It was such a privilege to spend the morning with this motivated and inspiring group of adults who provide so much leadership to our community.

MDDA Member Advantage Program Launch

This year's Retreat was also jam packed with new and exciting programs and initiatives, and the MDDA were excited to launch the new Member Advantage Program on the Saturday. It was a great opportunity for the MDDA team to showcase what they have been working hard on since the last Retreat. The \$35 (annual) Member Advantage Program gives you access to many specifically designed programs, products and services created to help support families and individuals navigate the pathways of managing their IEM - throughout all of the life stages. Some of the highlights of the launch included:

- The launch of our new YouTube channel LowPro Inspo with a trailer.
- Introducing our LowPro Eats program and hearing from Pete from The Grand Hotel Warrandyte who currently runs this program.
- Showing the first beta version of the new MyLowProPal dietary management app.
- Introducing Zest, MDDA's adult vitality program.
- Presenting our Patient Pathways Program which included launching our PeeKabU Kids Club, our Newly Diagnosed Bags, that we were able to give to our new families, our Carer compendiums and our LowProTeens program.

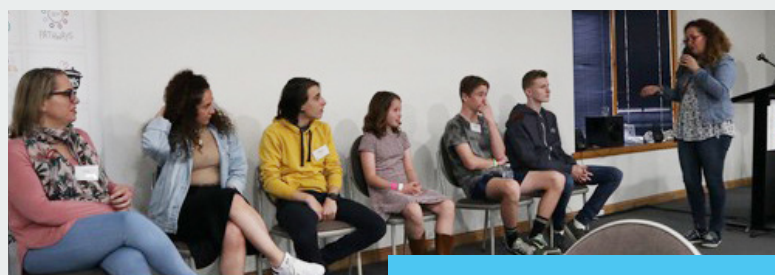
To read more about the initiatives in this program please go to pages 10-11.

Other IEM Streams

At this year's Retreat, we held an ‘Other IEM Stream’ that ran sessions that directly benefited the families of those who have a child with an IEM other than PKU. One of these sessions included “Emerging Treatments and Trials for IEMs other than PKU” run by Anita Inwood, a Metabolic Nurse Practitioner from Queensland Children's Hospital. This informative session gave other IEM parents (including IVA, Tyrosinaemia Type 1, GA1, MMA, and MSUD parents) an opportunity to learn and ask questions on clinical trials and emerging therapies. Anita explained the mechanism of gene therapy and how this treatment aims to treat the disease and involves introducing new genes that produce the missing enzyme. Some of the main takeaways from this session included:

- A clinical trial is a research study to answer specific questions about new therapies or new ways of using known treatments. Clinical trials are used to determine whether new drugs or treatments are both safe and effective. Carefully conducted clinical trials are the fastest and safest way to find treatments that work.
- All clinical trials are based on a set of rules called a protocol. A protocol describes what types of people may participate in the trial; the schedule of tests, procedures, medications, dosages and the length of the study.
- Due to the nature of rare diseases, requirements for testing with large numbers of patients is often not possible. Protocols are written to adjust for these smaller patient populations.
- The Government has strict guidelines and safeguards to protect people who choose to participate in clinical trials.
- Every clinical trial in Australia must be approved and monitored by an ethics committee to make sure the risks are as low as possible and are worth any potential benefits.
- All clinical trials have inclusion criteria for acceptance onto the program as well as exclusion criteria. Criteria are based on factors such as age, type of disease, medical history and current medical condition. Before you join a clinical trial, you must qualify for the study.
- You should know as much as possible about the research study before you join a clinical trial. It is important for you to feel very comfortable asking questions and satisfied with the answers received at a level you understand.

Further information on clinical trials currently underway in Australia and a Consumers Health Forum factsheet can be found at australianclinicaltrials.gov.au.



LowPro Food Review

A huge hit at this year's Retreat was the delicious low protein food! This year was fully catered by Pete and Chef Ben from The Grand Hotel Warrandyte. It was great to have LowPro food easy and available for all IEM people to enjoy regardless of their protein allowance.

Whilst breakfast and lunch provided a buffet full of tasty, delicious food, it was the Friday and Saturday night dinners that provided the real highlights.

Friday night's "Build-your-own (LowPro) Pizza Night", sponsored by Orpharma, was the perfect first night dinner, as people got to know one another and reconnect with old friends. Cooked in an authentic wood fire oven, we made our own favourite pizza with toppings and also enjoyed the yummy dessert pizzas that came after.

Night two also provided another wonderful selection of LowPro meals, this time with different food stations. This included: a Moroccan station with LowPro vegetable paella, a Mediterranean Station with pumpkin gnocchi, garlic focaccia and vegetable moussaka, and a Asian Fusion station with Asian noodle salad. Having this range of cuisines, showcased the diverse nature of what delicious and healthy LowPro food can be.

It gave everyone who attended the Retreat plenty of inspiration to take home to cook in their own kitchens. Kids and adults alike also loved the LowPro donuts and chocolate fountain for dessert on Saturday night, giving the perfect ending to a night of delicious food! Breakfast also included a wide range of options for our Low Pro adults and kids, with Saturday's breakfast proving to be an all-round favourite with a live waffle station, sponsored by Cortex Health.

There were a lot of fun options when it came to the Low Pro food, and everyone enjoyed having a wide range of different foods to choose from over the weekend. The kids also enjoyed being able to choose their own cupcake toppings when they decorated their own LowPro cupcakes, sponsored by Nutricia. A huge thank you again to Chef Ben and Pete for all the hard work that they did over the weekend, it wouldn't have been the same without them!



Thank you to Vitaflo for sponsoring The Grand Warrandyte team to be our LowPro caterers for this event.



Tasmania Family Retreat

Julie Cross - Special Guest Speaker "Find your Sparkle"

Julie shared her life experience, life challenges, grief, joy and how she made her dreams come true. We laughed a lot and cried a little, using her story to inspire us to live our best lives despite all of us having our own challenges. Julie encouraged us to; find our own Sparkle, find happiness with where we're at today and acknowledge to ourselves that we are okay just the way we are. Julie reminded us to:

- Avoid being judgemental and critical of ourselves, negative self-talk will dull our sparkle!
- Stop playing the never-ending exhaustive game of approval and comparison. Save our energy to do the things that really matter to us in our life.
- Do something that makes us feel great- meditate, exercise, sing, play music, read books. Catch our negative thoughts write them down and replace them with energy lifting empowering statements e.g. "I can't do that! becomes "I'll handle it!"
- View challenges in life as an emotional workout, develop the muscle of resilience.
- Focus on gratitude, start a journal, list the things you give and those which you receive.
- Ask yourself what it is you are really wishing for and what may be required to get it. Know your goals and think about what qualities you need to develop or strengthen to achieve them.

We all took some of Julie's sparkle (or spark for the grown men who were in the room!) with us in our hearts, inspiring us to feel great about who we are today and how we can be better tomorrow. You can find out more about Julie and her "Sparkle Chorus" on her website www.juliecross.com.au

Dr Minal Menezes

On Saturday, Dr Menezes presented the research work currently underway at the Children's Hospital Westmead in Sydney. Dr Menezes spoke about the 'Integration of genomics and high throughput drug screening for personalised treatment of PKU'. As the lead on the phenylketonuria research at the Kids Research and Children's Hospital Westmead, Dr Menezes provided an interesting and educational talk on this subject.

Dr. Menezes and her team are developing a PKU gene mutation library, collecting samples from Australian patients. This library will be used to identify the responsiveness of different mutations to existing drugs with a view to developing a truly personalised medicine approach for each mutation. This exciting and innovative approach has many potential benefits to our community – the same approach can be used for other protein IEMs and the use of existing drugs shortens the development process as they already have a demonstrated safety record.

Keep in touch with the MDDA to find out how you or your family member can participate in this research.



PeeKabU Kids Club Program

Over 50 kids & teens enjoyed a weekend full of activities! A Kids Club welcome session on Friday night encouraged kids to meet their peers, join in and break the ice, it didn't take long before new friendships formed!

We were extremely lucky with the weather for all the outdoor activities that were planned. The enormous jumping pillows, go-karts, mini golf, paddle boats and swimming sessions, kept the older teens entertained as well as being enjoyed by the younger ones. Giant Jenga and hopscotch were among some of the favourite activities with the younger ones as well as the mini arcade providing hours of entertainment.

We ran our first kids panel discussion session chaired by Bianca and Katy with IEM tweens/teens on the panel to an audience of all the kids at the retreat (parents were keen onlookers). This session was engaging, informative and entertaining, a great way for the kids to learn from each other and further build connections. It was wonderful to see the older teens take on a role and assist with the younger children during the weekend. The Sunday program finished off with cupcake decorating, a messy but delicious experience.





Creating life long Friendships

2016 NSW Retreat & 2019 TAS Retreat
Jordy & Riley

Jordy Blyth - PKU, 15 years old

Thank you for this [Retreat] weekend it was amazing! I had a way better experience this year as I got to hang out with younger kids, kick the footy, and help them make food. I met a lot of new adults with PKU and it was great to hear their stories! It would be great to have other events during this year that we can go to and extend the Retreats as I enjoyed it very much and I don't think I was the only one.

The retreat gives me a chance to meet a lot of new faces and learn a lot more and just get out of the house and have an awesome weekend. I would also love to be a leader of some sort in the future with the MDDA. Me and Riley had the best time and I hope this carries on for years to come, you are all like another family to me I love you all.



About Me

My name is Jordy Blyth, as some of you may know, I'm currently in grade 9 moving onto grade 10 next year at Newtown High School in Tasmania. I am a very passionate sportsman, I really enjoy my footy and running. I am a state runner holding up to 3 records for my school in track running and cross-country distance running and I play football (AFL) for Glenorchy Football Club and have done since I was 6.

My life as a child growing up hasn't been the best. I've been in and out of foster care all my life and am currently living with a carer named Alana, who I have been with for 4 years now and everything is great! She's a really good carer, that looks after my diet extremely well considering how many kids she has (10).

As for my mum and dad for various reasons I was moved away from them when I was 2 years old and my PKU care needed better management. Nowadays, I see my dad often and enjoy the weekends I get with him where I get a chance to share new things about my PKU and have a good bonding time with him. I don't see my mum very often though. My Nan Pauline which some of you may know is a massive difference in my life and has always helped me through things and cooked new meals for me and has been my number 1 support person through everything.

The reason I love the Retreats is because I get to share my experience with everyone and hear about theirs and get my head away from everything else and just have a great time. Thank you all for your support.

Stacey - Mother to Cailey, PKU, 14 years old

Both myself and my husband attended the Retreat with our daughter Cailey who is 14 and has classical PKU. We have been having a few struggles with her diet and she gets a bit of anxiety. We have noticed a few changes in Cailey where she keeps a lot of her PKU issues to herself and doesn't like to share too much of her PKU at school. She hides her PKU very well but we don't know if this is her age and being a teenager which comes with a lot of ups and downs.

Cailey was very unsure on attending the Retreat this time around as she was worried about meeting new people, but after attending we have walked away with a lot of tips and advice from the speakers and family's with PKU. This is so helpful for us as parents to be heard and relate to so many other parents that feel the same. It is such a nice feeling you get after attending these Retreats.

I really valued the section they did on teens for them to open up (*The MDDA ran a panel Sunday afternoon where IEM teens answered questions from the younger IEM kids*). Cailey was very worried about doing this but she managed to be talked around it. She loved it! The panel for teens to share their experiences and to be asked different questions from the younger kids with PKU and their parents and just to be heard how they see their PKU and experiences was lovely to see.

It was valuable to see her confidence come through and to see her open up and hear from all the other teens. She enjoyed it so much and I think for her this hit a turning point. After the Retreat Cailey has made lots of changes with her PKU wanting to take on more responsibilities with taking care of her diet, she is much happier and in a better place and she doesn't hide away as much and already we can see changes at school. This was Cailey's 3rd Retreat that we have attended and she is already talking about next year's Retreat.

Thank you to the MDDA for your support and to make these Retreats happen, we absolutely had a ball!



Tasmania Family Retreat



This was my first Retreat and I didn't know what to expect. After the first few hours I felt comfortable and accepted within the group. I have met some amazing people and some lifelong friends. I have gained so much knowledge that I will now have to contemplate and implement into my life. I hope to attend next year with my husband.

Therese-Alena - PKU, Adult

A brilliant weekend for not only my MSUD son, but for me and other family members. The food, talks and quality time spent was incredible.

Faith - Mother to Riley, MSUD, 15 years old

MDDA welcomed Dennis and Leigh as new MDDA members to the Retreat. Dennis attended as Leigh's carer, and was pleased to provide the following testimonial, which notes the differences in Leigh since he has been back on diet and highlights the importance of support.

For Leigh, he is saying new sentences, he has more understanding of what is being said, he is asking more questions and understanding the answers better. The improvement is very rewarding and can be very emotional at times. To see his life improve so much is so good. To meet other people that are dealing with PKU and talk to them is such a great help in understanding this condition. It is really invaluable and so important I have found, and if Retreats like this can continue things can only improve for the people we support. Thank you to the MDDA Team.

Dennis - Carer to Leigh, PKU, 64 years old



An absolute great combination of learning, laughter, and new experiences to share in a relaxed supportive atmosphere. Thank you.

Janeen - Mother to Rhiarna, GA1, 11 years old

The scope of what was covered over the [Retreat] weekend was beyond our expectations as newcomers to the IEM community. Meeting other families and such a dedicated group of volunteers and genuine caring people has been a truly life changing moment. We now feel we have so much more love and support as we continue on this journey together.

Shannon - Mother to Viktor, IVA, 4 months old



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The MDDA thank the Victorian metabolic clinics at the Royal Children's and the Royal Melbourne Hospitals for their support at this year's retreat, and also our many sponsors, in kind partners, speakers and volunteers that all played a key role over the weekend.

PeeKabU Newborn Starter Kit

Includes: Diaper backpack, newborn baby diary, muslin swaddle, facewashers, keyring, heel prick starter kit (incl. plasts, footwarmer, lancet sample pack) and welcome teddy.



Coming soon to all Australian clinics

Also available for sale at MDDA Marketplace (launching soon).

PeeKabU kids

Carers of missed or late diagnosed PKU adults

MDDA in collaboration with Royal Melbourne Hospital have created the PKU Carer Compendium for missed or late diagnosed PKU adults living in shared community housing facilities or nursing homes in Victoria. These high-quality visual handbooks and personal compendiums will assist in educating their carer on how PKU needs to be managed on a day to day basis.



The compendium features clinic contact details, treatment of PKU, PKU diet, meal plans, blood spot testing guide, resource list and other useful information.

Stage 2 will engage volunteers to assist with the roll out Australia wide 2020.

Thanks to RMH and the below sponsors for supporting this initiative.



MDDA Patient Pathways Program

The MDDA is proud to announce the launch of our Patient Pathways Program to meet the MDDA community's ever-growing need for information and support. Jo Campbell joins the association to lead this valuable new service for our community.

What is the Patient Pathways Program?

The Patient Pathways Program is a federally funded government initiative developed by the Centre For Community-Driven Research (CCDR) which aims to increase the capacity of patient organisations to help patients navigate the health system and access all services that are available to them, including clinical trials. The program has placed a specialist tele-health nurse in our organisation to provide a pathway for support for patients to access a coordinated comprehensive case management service, to talk about their experience and collect a repository of patient experience data that can inform future research, treatment, care, information and support across the health sector.



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.



The program provides support to the community in the following areas:

- △ Assistance with navigating the healthcare system, accessing services and clinical trials.
- △ Education and information provision.
- △ Guidance to develop your ability and confidence to proactively manage your condition.
- △ Social and emotional support for members and/or their families.
- △ Support of patient care with external healthcare organisations and facilities.
- △ Support for ongoing patient care with families and carers following hospital admission, discharge, and accident and/or emergency visits.
- △ Reconnecting adults to clinic and supporting their return to Diet For Life.

Meet 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



Retreat launch of our new Member Advantage Program



LowPro Inspo is our Low Protein YouTube channel that is designed to provide daily inspiration for people living with protein IEM's. The channel initially focuses on low protein cooking and recipes but will expand to also include other inspirational content from MDDA, our members and affiliated communities.

Whether you're a cooking fanatic, or a novice, there is something here for everyone. From cookies to noodle salad to bread, learn new recipes and new tips to cook something deliciously low pro!

LowPro Inspo is open to everyone, why not join up to our Member Advantage program and also become an inspirator, contributing to our inspiring and growing library of content.

Visit **LowPro Inspo** on YouTube and click subscribe.



All proceeds from the sale of items on the store go towards supporting further MDDA member programs and initiatives.

MDDA Advantage members also gain access to special member offers and discounts.

shop.mdda.org.au



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 of our many great products are available online to purchase – with all proceeds going to the MDDA to help us continue to support our Member Advantage Programs.

MDDA CONNECT

MDDA Connect delivers communication and support services across multiple platforms and channels. When you first join our community, MDDA Connect is the way that we connect you in with other members so you can learn new information, stay updated and make lifelong friends. Whether you are a subscriber or a part of our Member Advantage Program, you can benefit from the various features and benefits of Member Connect.

MDDA Connect features include:

- MDDA Community and Member Events
- Patient Community Facebook Forum
- Website & Social Channels
- MDDAs 1800 Number
- MDDA Newsletters



thegreatproteinchallenge.com.au

The Great Protein Challenge (now a global awareness campaign) is a public health educational awareness and fundraising initiative that helps support kids and adults living with IEMs. It enables people to walk in the shoes of a person living with an IEM for a day to understand the importance, complexity and difficulty of managing their condition.

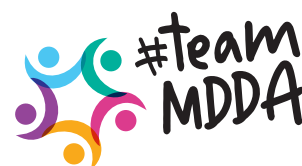
By being a part of The Great Protein Challenge, you will help raise awareness for all protein IEMs and provide an informative and fun way to engage in the conversation.

Funds raised through the challenge will go straight into continuing to support the community through building further programs and contributing to MDDA's Research foundation.

HOW **#LOWPRO**
CAN YOU GO?

Thank you
to our sponsor

B:OMARIN

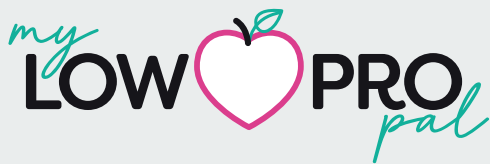


#teamMDDA is a way for you and your family and friends to raise funds in support of the MDDA. You can do so by selecting MDDA as your chosen charity as you participate in an activity of your choice and raise awareness and funds for MDDA whilst doing something you love.

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 doing a fun run, marathon or other outdoor challenge, **#teamMDDA** running singlets & T-shirts can be ordered (and personalised) via MDDA Marketplace.

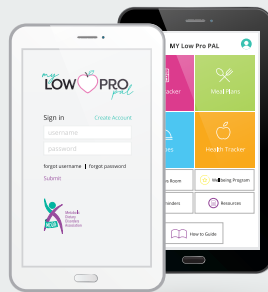
visit www.mdda.org.au/help/teammdda and join the team



To make life a little easier for those managing an IEM, whether it is assisting in protein counting, planning your next meal or helping you to create your next shopping list. **MyLowProPal** is here to help you and motivate you to stay on track and provide a little bit more organisation and wholistic healthiness into your life.

- Protein counting (per Australian IEM guidelines)
- Low protein recipes & meal plans (for all ages & protein allowances)
- Low protein product catalogue
- Shopping lists
- Daily food tracker
- Wellbeing goal setting & monitoring
- Blood spot monitoring
- Reminders

... Plus much more



Coming to the App Store early 2020 – Download MyLowProPal. Android version coming shortly thereafter.



ZONE • ENERGISE • SOAR • THRIVE

Zest is the MDDA IEM Adult Wellbeing and Vitality Program. Zest aims to improve the mental, emotional and physical health of Australian adults living with an IEM. Delivered via a combination of web-based seminars, teleconferences, online forums, weekly goal setting and one-on-one coaching. Zest makes habit-forming life changes in areas identified as limiting individuals from achieving optimal health and management of their IEM.

The initial program includes a 12-week coaching forum with 4 modules...

Zone	Energise	Soar	Thrive
Get into the Zone by focussing on healthy goals and habits.	Be Energised and ready to tackle challenges life throws at you.	Learn various tools and strategies that will help you to Soar.	Gain a support system and new habits to help you Thrive.

To find out more visit www.mdda.org.au/zest



Member Advantage

By joining MDDA's **Member Advantage Program**, you open the door to another level of support, with access to many specifically designed programs, products and services created to help support families and individuals navigate the pathways of managing their IEM – throughout all of the life stages.

Signing up to the MDDA Member Advantage Program is simple, and costs as little as \$35 per year* for a family subscription.

What's more, the first year is free for newly diagnosed families – as we understand more than anyone the importance of being a part of a caring and informed support network.

The MDDA **Patient Pathways Program** is an outreach support system that provides support, mentoring, educational programs and resources for individuals and families living with an IEM throughout every step of their journey. The Pathways Program includes different initiatives and programs that support those with an IEM through every stage of life - from first diagnosis to childhood to adulthood.

Parents of newly diagnosed babies, Food starters, Preschooler, School starters, Tweens, Transitioning adolescents, Adults, Maternal women and Carers of high needs (late diagnosed) PKU patients.

Within this program, MDDA provides a specialist tele-health nurse which provides patients with access to a coordinated comprehensive case management service, to talk about their experiences and collect a repository of patient experience data that can inform future research, treatment, care, information and support across the health sector.

If you would like to book a consultation with MDDA's Tele-health nurse, call 03 9723 0700 or email pathwaysnurse@mdda.org.au.

Visit www.mdda.org.au to find out more



Launching in 2020

Low Pro Eats is the MDDA foodies program. Designed to provide greater access and choices to people who Shop and Dine Low Pro.

Featuring:

LowPro Eats - Shoppers Guide

An guide that lists online and grocery outlets selling specialised low protein products and other suitable specialty items.

LowPro Eats -Venue Program

Enjoy hassle free and inclusive low protein dining out experiences by dining at a recognised Low Pro Eats establishment.



Fundraising



WA

Trivia Night

A huge thank you to this group of WA MDDA members for all the work they did to make the MDDA Quiz Night such a massive success. So much effort went into this. Well done on raising \$4700.



NSW

OH WHAT A YEAR!!!!



2019 has been a bumper year of giving by the PKU Association of NSW and we are extremely proud to announce that a total of \$304,304.00 has been donated to the three Australian PKU research projects currently active at the Westmead Children's Hospital (Kids Research) and the Murdoch Children's Research Institute (MCRI).

We would like to thank each and every donor who has generously supported and contributed to our Gala dinner and various events throughout the past 12 months.

We also cannot adequately express our ongoing gratitude to Dr Minal, Dr Michael Nafisinia, Professor Christodoulou, Xhing Zhang Tong and Dr Tchan for all of their hard work in helping us towards finding a cure.

Please contact info@pkunsw.org.au if you would like further information of Professor Christodoulou's "PKU Probiotic", Dr Minal Menezes "Personalised therapy for PKU", Dr Tchan's "MRI Brain Scan" research projects.

LOPROFIN® PRODUCT RANGE

A low-protein diet shouldn't mean less choice or enjoyment. The Loprofin® range offers quality low protein foods that help increase variety in your diet.

- Purchase online through **PKU Connect**
- Use with the vast range of low protein recipes provided by Nutricia online and in printed recipe books



Visit www.pkuconnect.com.au





Fun Run

On the 15th September, 30 plus #teamMDDA members & supporters in Adelaide completed the City to Bay Fun Run to raise money for the MDDA. Thank you to Leanna for organising and to Carmela and everyone who ran in support of the MDDA and Zara, aged 6 months who has PKU. We highly appreciate all the hard work with fundraising and raising over \$3000! The MDDA is thankful to Zara's family for choosing to raise money for our organisation, to help make a difference to all kids like Zara who live with PKU or another IEM. Their fundraising plans have not stopped with the run, with plans for a quiz night in 2020.

Thank you to everyone that ran in the City to Bay Fun Run!

If you would like to hold your own #teamMDDA fundraiser visit <https://www.mdda.org.au/help/teammda/> for more information.

Garage Sale

Thank you to the Hendricks family for donating the proceeds of their recent garage sale to the MDDA raising \$174.

Social Club Donation

Inspired by the Hendricks family's garage sale, the Brighton Primary School Dad's Social Club ran a gold coin donation night and raised \$100 for the MDDA. Thank you for your support!

Birthday Donation

What a lovely idea - Thank you to our member, Senada for setting up a Birthday fundraiser through facebook - raising \$1,740 for the MDDA



Contact us to find out more about V2U Low Protein Foods



Contact us

Freecall 1800 230 889

E enquiry@vitaflo.com.au

A VitaFlo Australia, Unit 3/119 Balliang St
South Geelong VIC 3220

Don't Forget!!

VitaFlo Christmas Advent Calendars

Complimentary & available through your clinic.

Important Information

Fate Flour, Vitabite Chocolate and Mini Crackers are food for special medical purposes and must be used under medical supervision. Not to be used as a sole source of nutrition. For oral use only.

[VitaFriendsPKUau](https://www.facebook.com/VitaFriendsPKUau)

[VitaFriendsPKUau](https://www.instagram.com/VitaFriendsPKUau)



Berry Coconut Sago

SERVINGS - 6

Ingredients:

100g Tapioca pearls
400ml Coconut cream
55g Caster sugar
50g Coconut flakes
100ml Maple syrup
375ml Water
1 tablespoon Lemongrass
1 punnet Raspberries
1 punnet Strawberries
1 punnet Blueberries
50g Passionfruit pulp

Method:

Place tapioca and coconut cream in a saucepan and soak for ~30mins

Add sugar and lemongrass to tapioca mixture and heat over medium heat until it reaches a simmer.
Simmer on low heat until tapioca pearls are transparent, and the mixture has thickened. Be sure to stir frequently so tapioca does not stick to the bottom of the pan.
Pour into cups and place into the refrigerator until completely cooled.
In a pan, toast coconut flakes. Serve cooled tapioca mix with fresh fruit/passionfruit puree and coconut flakes. Drizzle with maple syrup for added sweetness.



Veggie Nuggets

MAKES: 20 nuggets

Ingredients:

1 Zucchini
1 Carrot
200g Butternut pumpkin
200g Potato
50g Potato starch
50g Arrowroot flour
Parsley
1 cup Low protein flour
1 cup Soda water
1 cup Low protein bread crumbs
Salt
Pepper
Thyme

Method:

Oven roast pumpkin. Remove any excess water.
Boil potato and mash with fork.
Grate all other vegetables.
Mix potato, pumpkin, grated vegetables, potato starch and arrowroot flour together. Form into nugget shapes.
Mix low protein flour and soda water to form a runny batter.
Dip nuggets into mixture then cover in breadcrumbs.
Shallow fry in oil until golden brown.
Enjoy as a snack or serve with a salad and your favourite dipping sauce.

Grape, Halloumi & Cauliflower Salad

SERVINGS - 4 as a side dish

Ingredients:

300g Red seedless grapes
1 small head (800g) Cauliflower
1 small (100g) Red Onion, cut into eighths
2 1/2 tablespoons (50ml) Extra virgin olive oil
225g Biocheese (dairy free) Haloumi or Biocheese (dairy free) Fetta, cut into 8 pieces
1/4 cup Puffed rice
Sea salt and black pepper

Dressing

1/2 cup fresh Mint leaves
1 teaspoon Maple syrup or honey
1 teaspoon Apple cider vinegar
2 tablespoons Extra virgin olive oil

Method:

Heat oven to 180C and line a baking tray with grease proof paper.
Slice cauliflower on the round, about 1-2cm thick, lay on tray with red onion, drizzle with about 2 tablespoons extra virgin olive oil, toss gently to coat, then bake for 40 minutes.
Whilst veggies are cooking slice some of the Red Seedless Grapes in half and keep some whole, then set aside.
Make the dressing by blitzing the ingredients together in a blender.
Once cauliflower and onion are cooked, remove from oven and set aside, then heat a frypan on medium heat, add another 1-2 teaspoons extra virgin olive to coat and cook halloumi pieces 2 minutes each side, or until golden.
Arrange cauliflower, onion, Red Seedless Grapes, halloumi and puffed rice around a serving platter, drizzle with dressing, season with sea salt and black pepper and serve.



Products

Always check the nutritional panel on products



Forager fruits: Freeze-dried apple wedges infused with Blackcurrant

Protein per 100g:1.69g
Protein per serve:0.34g

Serving size:15g

Available from:

Health food stores

Online:The Forager Food Co.



Green Vie: Cheese slices

Protein per 100g:0.4g
Protein per serve:0.08g

Serving size:20g

Available from:

Online:Vegan Perfection



Well & Good: Slider buns

Protein per 100g:0.7g
Protein per serve:0.2g

Serving size:35g

Available from:Coles,
IGA & Health food stores



Orgran: Mini Outback Animals - vanilla cookies

Protein per 100g:4.2g
Protein per serve:0.9g

Serving size:22g

Available from:

Coles & Woolworths



Syndian: Cheezy Kale & Cashew Sausages

Protein per 100g:3.1g
Protein per serve:1.6g

Serving size:50g

Available from: Coles



Masterfood: Herb/Spices

As per guidelines.

Available from:

All good supermarkets



Sipahh: Flavoured straws

Protein per 100g:0.7g
Protein per serve:0g

Serving size:3.5g

Available from:Coles &
Woolworths



Sophie's Kitchen: Vegan smoked salmon

Protein per 100g:0.4g
Protein per serve:0.2g

Serving size:56g

Available from:Coles

Online:Vegan Perfection



Cocobella: Dairy free coconut yoghurt - natural

Protein per 100g:0.9g
Protein per serve:1.2g

Serving size:125g

Available from:Coles &
Woolworths

Special Medical Foods Suppliers



Cortex Health / Cambrooke

For orders to arrive pre-Christmas, get your
orders in **before** 19th December 2019

Limited dispatch from 20th December 2019 -
6th Jan 2020. Re-opens 6th Jan 2020

[www.cortexhealth.com.au/
products/low-protein-foods](http://www.cortexhealth.com.au/products/low-protein-foods)

Ph: 1800 367 758



Nutricia / Loprofin

Orders **MUST** be in before 11th December

Closed from 11am 24th December 2019

Re-opens 2nd January 2020

[www.pkuconnect.com.au/
product-category/low-protein-foods/](http://www.pkuconnect.com.au/product-category/low-protein-foods/)
[www.nutrition4me.com.au/
homeward-pharmacy](http://www.nutrition4me.com.au/homeward-pharmacy)

Ph: 1800 889 480



Orpharma / Mevalia

Orders **MUST** be place before midday 19th

December 2019. Closed 24th December 2019

Warehouse close 20th December

Re-opens 6th January 2020

[www.orpharma.com/products/
low-protein-food/](http://www.orpharma.com/products/low-protein-food/)

Ph: 03 9863 7267



Platypus Foods

www.platypusfoods.com.au



VitaFlo / Fate

Closed 23rd December 2019

Re-opens 2nd January 2020.

For emergency orders please call
03 5229 8222

[www.vitaFlo.com.au/products/
metabolic-disorders/apps/
vitaFlo-choices/fate/](http://www.vitaFlo.com.au/products/metabolic-disorders/apps/vitaFlo-choices/fate/)

www.vitaFlo.com.au/home-delivery
Ph: (03) 5229 8222

Queensland

2020 National Family Retreat

9-11 October 2020



Register your interest 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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