



MDDA NEWS

Newsletter of Metabolic Dietary Disorders Association

Issue 52
2013



Vic Family Weekend Retreat

22nd – 24th February 2013
Yarra Valley Conference Centre

Our ongoing Journey

At times the journey of life throws us challenges. Some are easily to adjust to whilst others take us time to accept. A person with an IEM goes through the same challenges as those without. Their challenges are even more difficult than ours. Some struggle to accept the constraints the diet has on their lives whilst others struggle with just adhering to the diet. However what is important is the discovery phase. This is where people with an IEM, their families and friends start to discover what living the life of an IEM person really is.

was about **Health and Wellbeing**, The challenge for individuals is start looking within. A journey of self discovery allows us to escape our busy lives. Louise Healy reminds us that there is a need for a *disciplined and focused mind*.

I hope those who attended the recent Vic Retreat have gone away and refocused on the things that matter. It is not always about the constraints or the adherence to the diet. It is all about the discovery of life and the journey that it takes us.

The focus of the recent **Vic Family Retreat**

Richard Drewitt

this issue

MDDA Committee 2012-2013	P.2
Changes to IEM Grant	P.3
Vic Family Weekend Retreat	P.4
Developing a Wellness Program	P.5
Update from Nutricia	P.6
Christmas in Vic / Brisbane 2012	P.7
The Children's Hospital Westmead	P.7
Product Updates	P.8

**Donations over \$2.00
are Tax Deductable**

You are invited to take on a challenge that might consist of a fun run, walkathon, triathlon, city to sea, golfing/tennis tournament or any other activity that requires a bit of stamina and endurance to complete (not necessarily limited to sporting events either). Whatever it might be, we are happy to get behind you and support you - no feat will be considered too small for Team MDDA.

Our next TeamMDDA Challenge. . .

THE AGE
RUNMELBOURNE

July 21, 2013 FEDERATION SQUARE

Register your interest by contacting the MDDA office.



If you want more information on Team MDDA or are interested in signing up for your own challenge, please contact teammdda@mdda.org.au or visit www.mdda.org.au and we can get you on board straight away with your very own Team MDDA Welcome Kit to get you started.



MDDA Committee 2012-2013

LR: Wendi Emmerson (Vic), Susi Hendricks (Vic-Wellness), Paige Moore (Vic—Treasurer), Monique Cooper (Vic—President), Richard Drewitt (Vic—Vice President), Katy Drewitt (Vic—Secretary), Jenny Briant (Vic—Executive Officer), Cassie Graue (SA), Zoe Mitter (QLD) & Maria Contera (WA).

About the MDDA



www.mdda.org.au

The Metabolic Dietary Disorders Association is a national self-help group supporting people affected by genetic (inborn) errors of metabolism. Our aim is to offer families a comprehensive resource of information and support. We provide members and their family's forums to share experiences and information, to educate themselves and the general community about living with an inborn metabolic dietary disorder. The MDDA fosters co-operative relationships between members, healthcare professionals, government departments and other agencies to promote the health and well-being of members. MDDA objectives are pursued by the Committee of Management.

Changes to IEM Grant

The Department of Health and Ageing is notifying all grantees about changes to the Inborn Errors of Metabolism (IEM) grant from February 2013.

IEM patients who receive financial assistance to purchase special dietary foods for their IEM condition, will be required to re-apply for the IEM grant every 12 months.

To maintain eligibility to receive the IEM grant the patient is required to schedule an appointment for a review by the metabolic specialist, and provide the Department with a new application. Failure to do this by your advised date will result in immediate cessation of the IEM grant payments.

If the IEM grant payment ceases due to non-compliance with the

revised requirements no retrospective IEM grant payments will be made if a new application needs to be submitted.

To maintain eligibility the patient needs to be re-assessed regularly by their metabolic specialist which advises the Department that the patient continues to have special dietary requirements.

It is the responsibility of all patients to schedule review appointments, as required by their treating metabolic specialist and to ensure that re-applications are provided to the Department.

Metabolic specialists will be required to notify the Department of patients who fail to comply with the conditions of the IEM program. Following this advice, and if the situation is not adequately

addressed the IEM grant may be withdrawn.

If you have any questions please contact the Department directly.

IEM Program Officer
Pharmaceutical Benefits Division
Department of Health and Ageing
MDP 901, GPO Box 9848
Canberra ACT 2601

Ph: (02) 6289 8980
Fax: (02) 6289 8537
Email:
iemprogramofficer@health.gov.au

The MDDA is aware that potential confusion may exist with this new renewal process for the IEM grant however it is our understanding the Department is attempting to ensure only patients who are Dietary compliant and who attend clinics remain eligible for the IEM grant.

The MDDA would like to thank the following sponsors and suppliers of the Victorian Family Retreat 2013



www.vitaflo.com.au

Thanks VitaFlo for your continued support.



www.nutricia.com.au

Thanks Nutricia for your continued support.



www.cobspopcorn.com.au

Thanks to cobs popcorn who supplied snack size bags of popcorn enjoyed throughout the weekend and in the showbags.



www.veganperfection.com.au

Thanks to Jeremy a long time supporter of the MDDA. The Redwood Cheezly cheese, Vegusto cheese and Bonvita chocolate were delicious!



www.sweetwilliam.com.au

Thanks to Sweet William, kids and adults enjoyed yummy treats of Scoobie-Doo chocolates.

Vic Family Weekend Retreat—Feb 2013



The first of many Family Weekend Retreats was held in the beautiful Yarra Valley in Victoria at the end of February 2013.

We gathered together on the Friday evening for Pizza and for introductions. Many came from far and wide. From Perth, Adelaide, Sydney, Brisbane & Far North Queensland (Mackay). Not bad for a Victorian weekend!

The Saturday started with a session of Yoga followed breakfast in the main dining room. We then moved into the conference room for the welcome and other formalities. We heard from the owners about how the Retreat area was saved from the Black Saturday's Bushfires in 2009. We then moved into the formal sessions.

The first formal sessions were aimed at the Parents & Adults. Susi Hendricks led a session on *Making the right choices to a healthy and successful existence*. Followed by Louise Healy's session on *Developing the skills to help you or your child optimise self management*. Both these sessions were very informative and received great feedback from attendees.

Mark Boyce spoke with the 10-17 year olds about *Developing Independence—preparing for and coping with adolescence*. The young people tell us this was a great session.

After lunch Mark Boyce continued with all groups (Parents, Adults & Teens) discussing the topic *Transitions—Preparing for and coping with the transitional live phases of our children or as an IEM adult*. It was great to hear the comparisons made from a Young Persons perspective to that of an Adult. A great workshop which allowed both sides to voice their thoughts in coping with IEM during the transitional phases.

We heard about the Nutrica new PKU Connect website along with a preview of the new MDDA website and a quick look at recent postings in our MDDA member Facebook page.

The afternoon focus groups covered topics such as *It's all about food* (Zoe Mitter) and the *Teens Mentoring Program*.

Fiona Wedding from Nutricia hosted a *cooking demonstration* experimenting with Low Protein pre-dinner treats, mocktails etc.

The day concluded with a group photo, Dinner in the dining room, movies for the kids and social gatherings. Some went into the early mornings — Good times / Good conversations.

Sunday began with an early room checkout followed by breakfast in the dining room.

We then moved to the Tennis court for some *Team Bonding activities*. From moving your team whilst standing on newspaper, turning a blanket over without getting off the blanket and jumping on all 30 boards in order to save the planet! They were all great bonding activities. Thanks Mark for the fun!

As the weekend was coming to a close we were challenged by the *Value Auction*. This involved bidding for things such as Good Health, everlasting beauty, etc along with a Great Sense of Humor (we brought that one!). Great to work as a team to decide which ones to bid for.

We concluded our weekend with a slideshow full of great photos and great memories. It was an amazing weekend. We finally were able to put a face to those we chat/message with on Facebook.

MDDA would like to acknowledge the generosity and substantial contribution Vitaflo made for subsidising flights for those interstate, the registration for IEM teens & maternal women and the showbags.

Perth is next...in March 2013.

Richard Drewitt



Group photo for those with an IEM.

Developing a Wellness Program

I was lucky enough to attend the Victorian MDDA retreat as I am involved in setting up a health and wellness program for teens and prospective mothers with an IEM. I gave a short presentation on factors I believe are important to consider in developing a wellness program. This is a summary of some of the things we discussed.

Research on factors that influence compliance with a long term health regimen has found multiple and complex reasons for compliance or non-compliance with a long term health plan. Some of the factors that seemed relevant to the IEM population included:

- having a negative attitude towards the illness predicted low compliance
- believing the condition could have severe consequences for health and wellbeing predicted compliance
- believing that the therapy will have benefits predicted compliance
- a good relationship with the prescriber predicted compliance

I think these factors jumped out at me because they are factors that are in our control. If you have a disciplined and focused mind then you can choose to see and react to things in ways that are most useful to you. But how do you get a focused and disciplined mind?

A focused and disciplined mind comes from doing three things:

Becoming aware of the ruts, patterns and thinking that habitually control our minds. For example you may spend

time dwelling on 'what ifs' - What if my child rebels against the diet when he/she is older? What if other children are mean to my child because they have an IEM? What if I can't get my levels controlled before pregnancy? What if I had never gone off the diet? Becoming aware of these habits will help you to realize that most of this thinking is not helpful and will give you the opportunity to focus on more useful thoughts.

Focusing attention on thoughts, habits and practices that are helpful. For example when you notice a worry ask yourself "what can I do about this right now?" If you cannot, focus on something else; the best thing is whatever you are doing at that moment.

Repeating this process regularly. Brain science tells us "what fires together wires together", meaning the more you think something the stronger the habit of thinking it becomes but the opposite is also true, when you choose to repeat healthy and useful habits those are the habits that wire together and become "hard wired" in your brain.

The good news is, if you realize that you have some habits of mind that are not helping you deal with your or your child's condition in the best way you can change them starting right now. Not only will you be dealing with the condition better but you will be cultivating a happier, healthier and more resilient mind.

If you have any ideas or input for a IEM teen or maternal wellness program please feel free to be in touch with me (louise@reinvention.com.au)

Louise Healy

FEEDBACK WANTED!

Did you attend the Retreat? What are your thoughts? Did you like the venue? Was the session suitable? What was missing? Are you keen to attend the next Retreat?

Let us know your thoughts. Email us at office@mdda.org.au with your feedback.



An update from Nutricia

The Nutricia Metabolic team are proud to announce the launch of our new Loprofin Flakes*! This great new breakfast or snack food is available in a strawberry or apple flavour and can be ordered through our Nutricia Customer Service team by calling **1800 889 480** or online www.nutrition4me.com.au.



But wait there's more! In April 2013, we will be launching our new **PKU Connect website**. This new website will allow you to connect, learn and share with other individuals in the PKU community! The new PKU Connect website will also allow members to order low protein foods, such as our new Loprofin Flakes.

Our **PKU Connect Australia Facebook** page has gone live. Make sure you login to Facebook and 'like' our page to access new recipes, photos from events and join in on the discussions about PKU.

Risotto Filled Capsicum Recipe

Ingredients:

- 1 capsicum
- 1 tblspn olive oil
- 1 clove garlic
- ¼ onion, finely chopped
- ½ cup Loprofin Rice
- ½ leek, sliced
- ½ cup mushrooms, sliced
- 350ml boiling water
- Salt and pepper to taste

Method:

1. Heat the oil in the fry pan.
2. Cook the garlic and onion for 2-3 minutes.
3. Add the Loprofin Rice, leek and mushrooms and mix through. Add the water and stir again.
4. Bring the rice mixture to the boil and simmer for 10 –12 minutes checking regularly. Adding more boiling water as required.
5. Season with salt and pepper to taste.
6. Slice the top of the capsicum off and discard. Trim the inside removing seeds and white core.
7. Cook capsicum in frying pan until slightly softened.
8. Place rice (now risotto) into the capsicum and serve.

The filled capsicum could be baked in the oven at 180°C for 15 mins to ensure the capsicum is cooked.

This recipe was made by a MDDA member at Nutricia's Masterchef Challenge, 2011 - It has been tweaked slightly to ensure it provides you with the lowest protein and the best taste. Enjoy!

Note: Everybody's low protein diet is different. If you're unsure about suitability of particular ingredients for your diet please check with your dietitian.

If you would like further information, please feel free to call our Clinical Care Line on 1800 060 051.

*A food for special medical purposes for the dietary management of inherited metabolic disorders requiring a low protein diet. Always consult your healthcare professional before use.





Christmas in Victoria 2012

The 2012 Christmas gathering was held at Jells Park in Melbourne's Outer Eastern Suburbs. It was great to see new faces as we caught up with existing friends and families. With everyone bringing a plate to share there were plenty of low protein options available to taste and for those to share recipe ideas.



The kids enjoyed the playgrounds whilst the adults engaged in conversations about all types of topics including dealing with their kids and their dietary challenges. It was great to be part of these discussions.

All in all we had a great day, with great weather and had a chance to relax as we entered into the festive season!

Richard Drewitt



Christmas in Brisbane 2012

Families from the Brisbane and surrounds gathered at Taylor Range Country Club on December 2 2012 for our annual Christmas party. Swimming, playing and sharing ideas and experiences were the order of the day. We had two brand new (and totally gorgeous) PKU babies attend with their families, we hope they felt welcome to our little group.

We enjoyed sharing our favorite low protein treats with each other and had a special guest – Santa – drop in with gifts for all the kids. Santa wanted to know if everyone had been good – next time you see Dr. Jim ask him whether everyone at the party thought he had been good!! Dr. Jim and Anita organised the traditional lolly hunt and water bomb fight - plenty of laughing and screaming kids had a ball.

Thank you to Nutricia for their sponsorship of this wonderful event and to Anita for all her help in organizing it and sending out invitations. My family had a great time and I always love the opportunity for Eva to hang out with other kids like her and to eat freely from the party table. Hope to see you all at this year's party – I have already started planning it.

Louise Healy

The Children's Hospital Westmead Update

Farewell to Siobhan Brown

We are sad to tell you that Siobhan Brown is leaving the team in early March for adventures overseas. Siobhan was employed as our very first Nutrition Education Assistant with initial funding from monies the PKU clinic had raised back in Camperdown days, extended by a Telstra Grant applied for by the NSW PKU Association and since early 2011, funded by Vitaflo Australia.

As many of you will know Siobhan has been a source of great practical help to families and the children, helping guide appropriate food choices and helping with the practicalities of preparing low protein foods and meals -in clinic, in education sessions, by phone and at the PKU Camp.

In the background she has done much to improve the menu for our patients when admitted to hospital and has worked on the written and pictorial resources available. We are very sad to see her go but wish her a wonderful time travelling.

We are very pleased and grateful that we have ongoing support from Vitaflo Australia to replace Siobhan in this 2 Y2 day per week role and will hopefully be advertising soon.

Dietitians at the clinic

The team would also like to acknowledge the attentive and supportive contribution of Prue

Watson, Dietitian in the management of the babies and children with PKU over the last 5 years. During this time, Prue has also been in charge of the Department of Nutrition and Dietetics and this considerable managerial task and recent re-allocation of workloads within the Department has resulted in a handover of the "PKU baton" to Christie Graham since November 2012. Clinic cover and phone calls will now be covered by Sue, Barbara and Christie. Please ring 9845 2225 if you have any queries or email all of us.

Low protein foods from the USA

Several families purchase low protein foods from the USA online or when they are travelling. The nutrition labelling is different to Australia providing protein content only per serve. It has come to our notice that some of these serve sizes are quite small and without the protein content per 100g it is difficult to know how much protein there is in larger quantities.

Many do however provide the amino acid content and you can use this as your guide:

- 50mg phenylalanine is equivalent to 1g protein
- 15mg phenylalanine is equivalent to 1 phe unit

If you restrict other amino acids please discuss with your Dietitian.

Product Updates



3.7g Protein per 100g



0g Protein per 100g



0.5g Protein per 100g

CONTACT US

Address Shop 4
6 Thomas Brew Lane
Croydon VIC 3136

Postal PO Box 33
Montrose VIC 3765

Phone 03 9723 0600

Fax 03 9723 0700

Freecall 1800 288 460

Executive Officer
Jenny Briant

Email office@mdda.org.au

COMMITTEE OF MANAGEMENT 2012—2013

President

Monique Cooper (0414 734 061)
(PKU Parent VIC)
President@mdda.org.au

Vice-President / Public Officer

Richard Drewitt (0429 075 131)
(PKU Spouse VIC)
VicePresident@mdda.org.au

Treasurer

Paige Moore (0437 491 115)
(PKU Parent VIC)
Treasurer@mdda.org.au

Secretary

Katy Drewitt (0488 777 241)
(PKU Adult VIC)
Secretary@mdda.org.au

Health & Wellbeing

Susi Hendricks (03 9592 8926)
(PKU Parent VIC)
Wellness@mdda.org.au

Check out Vitaflo Australia's new website

www.vitaflo.com.au

Features include:

- Downloadable Fate & Vitabite Order Form
- V2U Home Delivery information and downloadable Application Form
- Place an order online
- Access to all product brochures including the popular ProZero Recipe Books
- Latest News and Events
- And much, much more!
- Have your say, email us and tell us what you think



Our PHE-nominal Low Protein Celebration Cook Book



Includes sections covering Birthday Parties,
Dinner Parties, Finger Food, Easter & Christmas.

MDDA Member Price **\$33**
Includes postage

You can order Cookbook from the Office.

Members who have already paid for the first instalment will have
the last sections sent to them shortly.

MDDA News

This newsletter will only grow and get better with your input. Please share your stories, ideas and tips, birthday celebrations and functions with us.

Email to: news@mdda.org.au

Photographs or hardcopies:
PO Box 33 Montrose, Vic. 3765

All photographs will be returned.

Copyright

Individuals are free to reproduce material with the expressed written permission from MDDA. Please contact the Office for approval.



Australian Government
Department of Health and Ageing

The MDDA acknowledges funding assistance received from the Commonwealth Department of Health and Ageing and Nutricia which makes this publication possible.

