



MDDA NEWS

Newsletter of Metabolic Dietary Disorders Association

Issue 54
2014



Living with an IEM & navigating relationships

A fantastic weekend was had by all 65 individuals at our latest retreat. Located at the picturesque "Country Place" in Kalorama, Victoria, the venue was superb and the weather spectacular (that is of course until the skies opened right on cooking time!)

Attendees enjoyed informative and engaging sessions with invited Victorian health professionals and various other facilitators whom kindly gave up their precious weekend time to participate in the occasion. Kids had a ball in our kids program playing dress-ups, swimming and many traversing the daring trapeze and ropes course.

Everyone then enjoyed some great networking and team bonding time making movies in our **Superhero IEM Power Challenge** and getting their hands (and much more for some) dirty in our

"High Tea—Lo Pro" cooking challenge—where we witnessed and sampled some creative and delicious treats for all.

Many excellent discussions were had across the weekend both in our facilitated sessions and also more informally around the dining table, pool (or bar for some), and many friendships were forged.

To view our IEM Power Movies or to see the results of our cooking challenge, please [join MDDA's private Facebook group](#) or go to our website.

If you missed this retreat - don't despair as our next retreat is being held in Sydney in conjunction with the PKU/IEM Youth Camp in October.

Monique Cooper
MDDA President

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QLD Annual Christmas Party 2013

The Annual QLD Christmas Party supported by MDDA, RCH Metabolic Clinic and Vitaflo was held on Saturday 30th November at Taylor Range Country Club in Ashgrove. Families from the local area gathered to enjoy fabulous company and an array of lovely shared low protein food.

The day was once again a terrific success. The kids had a great time playing together and some even swam despite very rainy weather.

Santa arrived about the middle of the day with gifts for all the kids.

Finally the weather settled down in time for the annual water-bomb fight. Dr. Jim and Anita and their families had filled 1000 balloons - but they still seemed to disappear in a few short minutes!!! The lolly hunt was held inside this year and the kids certainly collected plenty of loot.

We wish to thank Vitaflo for their kind sponsorship of this event, it is a great opportunity for the kids to make connections with metabolic kids and for the families to share ideas, challenges and experiences.

Louise Healy

VIC Christmas Celebrations 2013



The MDDA Annual General Meeting and VIC Christmas celebrations were held on Saturday 30th November at The Grand Hotel in Warrandyte.

It was a great turnout for the AGM with members enjoying a relaxing drink and sampling some great low protein plates of goodies brought along by all to share while hearing of the MDDA's achievements for the year. (A complete report of the AGM can be found on page 4 of this newsletter).

Many families stayed on to celebrate with a delicious

dinner provided by the Hotel and tasty dishes of low protein lasagne whipped up by Monique. There was plenty of chance to engage in some great conversations and share experiences.

The kids enjoyed exploring the Hotel and bonded well in the kids chill out room next door to the dining area. They were all very excited to take home a little Christmas goody bag at the end of the night as well!

It was a great night and a fantastic chance to meet up with old friends and make new connections.





WA New Year Celebration 2014

On Sunday 23rd February Western Australia held a picnic at Kings Park to welcome in the new year. The day was a warm (or shall we say...hot!) one, but we managed to secure a large shady area under a huge tree who's resident kookaburra sat and watched us all day.

The event was attended by five families and was an afternoon filled with sharing of information, such as the latest low protein products out in the

supermarkets, recipes and of course, David's trip to the ESPKU Conference in Belgium.

The children kept busy all afternoon playing soccer and cricket. They also kept cool by running under the huge water spraying foundation by the lake and enjoying an icy pole.

Low protein pizza, vegetable jambalaya and hot chips were the go for PKU lunch and of course the day couldn't go by without David's famous

PKU donuts (which were enjoyed by everyone who taste tested, not just those with PKU!).

It was a very relaxing and fun afternoon and great to see the enthusiasm from WA members to get along to the event to meet and chat with others about anything and everything.

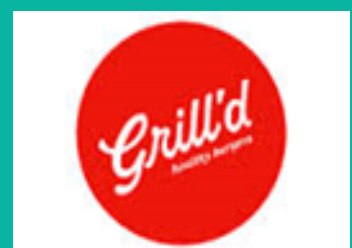
Maria Contera



Thank you to Grill'd Knox for your donation of \$100.00.

MDDA member Wendi Emmerson arranged for the MDDA to participate in Grill'd 'Local Matters program'. A terrific fundraiser which also raised awareness of the MDDA and IEMs.

Thanks Wendi for your continuous support in assisting the MDDA and our members.



Presidents Report 2012-2013

The 2012-13 financial year has been a year of development and advancement.

In November 2012 the previous year's AGM took place in Melbourne, and saw the continuation of the current Executive Committee, with all members maintaining their position. Susanne Hendricks stepped into a newly created role as our Wellness program director and Richard Drewitt stepped into the role of Vice President.

General committee members maintained their positions in the various states around the country.

Operational Priorities

With the deployment of our new 3-5 year operational plan, the MDDA took on a renewed direction at the beginning of this year.

With regular executive committee meetings, either face to face or via teleconference, we set about activating our new mission being;

The MDDA educates, connects and enables individuals and families living with an Inborn Error of Metabolism (IEM) – ensuring more informed choices and a better quality of life.

With this renewed focus and direction we are striving towards our longer term vision being that ;

All individuals living with an IEM are leading a life at full potential, not limited by choice or resource.

The MDDA take very seriously the role it plays in helping individuals to break down the emotional, social, political and sometimes physical barriers they are faced with in managing and coping with the many transitional challenges of living with an IEM.

We do this through providing families with a comprehensive list of resources, 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.

Outcomes

The following operational outcomes were achieved in 2013:

1. Organisational restructure of office resources
2. Deployment of a new member database
3. Continued IEM food grant advocacy and liaison

From a program marketing & events perspective we...

1. Implemented phase two of our new website and social media strategy including our very successful facebook group
2. Continued to produce regular Newsletters for print and email distribution (with three produced over the 12 month period).
3. Held many successful events around the country providing many members with face to face dialogue and experiences.
4. Developed further our wellness and teens mentoring programs gaining considerable momentum through various events and activities.

And financially we,

1. Continued Government Grant funding via the Department of Health under the Health Capacity Development Flexible Fund - securing a further three years of grant funding.
2. Obtained ongoing financial support from key partners Nutricia and Vitaflo
3. Conducted several fundraising activities across the country through the proactive and kind support of our members and other associates.

I would like to delve a little further into some of our achievements and key outcomes for the year.

Organisational Structure

Following the changes (and reduction) in office resourcing in 2012, and with the stepping down of Kerri Carboon, MDDA conducted a further review of organisational resourcing requirements to ensure alignment existed with its new priorities and focus.

This review determined that the executive committee had picked up a larger portion of office admin workload to what was sustainable (as a volunteer network), and several committed deliverables were put at risk or delayed.

It was therefore decided that an additional office administration was required to assist the efforts of executive officer Jenny Briant to ensure the MDDA could meet all demands of its key stakeholders whilst continuing to progress its set about charter.

As a result, we are pleased to welcome Karen Mills to the team as a part time office administrator and are grateful of her support and enthusiasm shown towards the MDDA thus far.

And of course we thank Jenny Briant for the patience and dedication she has shown in the midst of these changes and look forward to continue to support her with the ongoing work she does for the MDDA to enable us to achieve all that we do,

Events

MDDA held numerous social events around the country.

- 0-5 Get togethers were organised in Victorian and South Australia
- 2012 Xmas parties were held in Victoria, SA & QLD
- MDDA held two retreats for the year. The first in Feb 2013—VIC with over 60 participants was an enormous success by all that attended. The second was held in WA and hosted approx. 30 participants in a more intimate affair which provided for many string relationships to be formed.
- MDDA members participated in a number of cooking demonstrations around the country held by Nutricia
- MDDA once again participated in the Far North Queensland Clinic Run, with local member Kim Large and her son Ryan attending and representing this event as MDDA advocates, and generating some excellent awareness within the remote community on the role MDDA plays.

(Continued on page 5)

Presidents Report 2012-2013 cont

Special thanks go to MDDA committee members Cass Graue, Zoe Mitter, Louise Healy, Wendi Emmerson, Maria & David Contera, Kim & Ryan Large, Sonia Hellings and the entire executive committee for their support and coordination of these activities.

Awareness & Fundraising

Team MDDA activities continued throughout the year with members getting out and about in order to create awareness and fundraising for the MDDA.

Initiatives included :

- Run Melbourne fun run – July 2013 – many Melbourne members
- North Face 100 marathon - May 2013 – Dean Tulloch
- The WA Gala Ball - November 2012 – Mazzone's and Contera's
- Christmas in July Gold Coast – July 2012 - Zoe & Otto Mitter
- Bunnings BBQ Gold Coast - Sept 2012- Zoe & Otto Mitter

Special awareness days were supported around the country including Feb 28 Rare Disease Day "Rare Disorders without Borders" and also PKU Awareness Day. Member activities conducted in support of raising awareness for MDDA and IEM's included...

- QLD member Zoe Mitter organised a "walk" around the park to raise awareness for MDDA and IEMs
- Member Nat Hellings and friends from her Primary school set up a display in a Vic shopping centre to raise awareness of IEMs
- Susi Hendricks featured in an ABC Canberra Radio interview about the challenges of living with an IEMs
- 2 members Abby Delany, Justine Ingliss had their stories published in local newspapers to raise awareness and SA member Leo McDonald had a story air prime time in Adelaide on living with an IEM
- Justine also prepared and delivered a presentation to her local hospital colleagues bringing awareness and education on IEMs to the community.

MDDA thanks these members for their proactive support and assistance with raising awareness of IEMs in the

community and helping to raise funds for the MDDA.

In addition to these above member driven initiatives this fundraising result was also contributed to with,

- Sales of our Vitaflo sponsored Phe-Nominal Low pro cookbook (with final inserts completed in November 2012)
- Several generous voluntary member donations upon renewal of memberships
- And a fundraising campaign conducted by Adorable Photographs which took place online in June 2013 and we thank for their support.

Members

With the new database now in place and efforts focused now more on delivering member value, we hope to see our membership number increase and more of our subscribers continue to support MDDA financially through renewal of their annual membership.

Further efforts are also underway with local clinics around the country to better generate awareness and influence the desire to get involved of newly diagnosed patients.

Our Partners

MDDA appreciates the ongoing support provided by our key product partners. In particular Vitaflo and Nutricia for their very generous contributions to MDDA enabling us to continue to provide a variety of opportunities and events to our members

Nutricia is one of our major sponsors and financially supports MDDA each year enabling initiatives such as the MDDA Newsletter, access to cooking workshops, product donations & raffles for member events. In addition Nutricia kindly provided financial assistance for both the Melbourne and QLD retreats which went towards our teens mentoring and wellness programs and assisted many teenage and young adult members to be able to participate and assist with the challenges of compliancy.

Vitaflo is also an ongoing major sponsor and supporter of MDDA and provides valued support with key initiatives and projects taken on jointly

throughout each year. Completion of the PHE-Nominal LOW PROTEIN Celebration Cookbook final insert were made possible this year with their support. Vitaflo very generously contributed funding to MDDA to be able to provide the opportunity for two MDDA members to participate in the ESPKU conference which took place recently and will be covered in more detail in next years annual report. In addition Vitaflo also provided financial support for our Vic & QLD retreats enabling many maternal aged women amongst other be able to participate in the events.

Product donations from both Vitaflo and Nutricia along with other organisations such as Orgran, Basco, Cambrooke, The Vegg, Cheesly and PKU to you were received and appreciated. Continued donations of this kind are important to enable MDDA to be able to provide low protein option to all members at our events.

With Cambrooke's recent launch into the Australian market, we hope to forge a closer relationship with them in the coming year and as a result bring an even greater range of product options to our members at our events as low protein products become available.

External Liaisons

The IEM food grant provides many MDDA members with a regular source of financial support to assist with dietary management and compliance.

In February 2012, The Department of Health and Ageing announced a new procedure for all IEM Grant recipients to follow in order to continue to receive their grant.

MDDA played a proactive and constructive role in several issues that resulted from this announcement, and through numerous teleconferences and emails with the IEM Grant Department we were able to assist members with a greater understanding of the changes required by the department.

(Continued on page 6)

Presidents Report 2012-2013 cont

(Continued from page 5)

Clinics & Affiliates

MDDA continues to work closely with a number of external agencies, associations and health professionals, including members and representatives of...

- All state based clinics that care for both adults and children
- ASIEM - The Australasian Society for Inborn Errors of Metabolism
- HGSA – The Human Genetics Society of Australasia
- AGSA – The Association of Genetic Support of Australasia
- GSNV- The Genetic Support Network of Victoria
- APSU- The Australian Paediatric Surveillance Unit
- Rare Voices Australia
- PKU NSW

Relationships with these organisations are important to assist MDDA with advocating the needs of our members and providing the necessary and relevant resources and information to our community.

Thank you

I have thanked many people already throughout this report, I would also like to say an extra big thank you to a few key people this year that have been instrumental in helping us to achieve our objectives:

- Namely my fellow executive committee members, Vice President Richard Drewitt, Treasurer Paige Moore, Secretary Katy Drewitt and Wellness Program director, Susi Hendricks for your hard work and dedication once again this year.
- General Committee members Zoe Mitter, Louise Healy, Cass Graue, Maria Contera and Wendi



Emmerson for their continued coordination of local events and activities.

- Other general members of MDDA who have volunteered their time and support throughout the year including, those mentioned earlier whom actively helped to coordinate various events, awareness campaigns and fundraising opportunities.
- Our Advisory Council and LINK Network members for their continued involvement and support of the MDDA.
- Our Sponsors and product partners especially VitaFlo and Nutricia for their ongoing support
- The Department of Health and Ageing for their ongoing support and provision of funding to enable us to exist as an organisation and support group.
- And our ongoing partner and affiliate PKU NSW for their efforts in enabling us to work closer and closer together in support of our shared vision for the future and greater good for all Australians living with an Inborn Error of Metabolism.

In Conclusion

The financial year 2012/13 was a successful and very rewarding year for MDDA, and we as a committee of management take extreme pride in all that we have achieved this year. The MDDA community is becoming a very active and engaged community, and our hope is that by this time next year this will be even more so than now.

The pathway has been paved, and the effects are beginning to show through with a more connected, educated and enabled community of individuals and families.

I thank you for the continued opportunity to represent the MDDA as current president and I look forward to what this next year has in store.

Monique Cooper
MDDA President



PKU and IEM Awareness Day - 1st May 2014

We encourage you to raise awareness in your local community.

- Ask your childcare, kinder, school, university, work place if you can put up a display on their noticeboard.
- Ask your local library/gym, if you can put up a display.
- Call your local / national paper or TV and ask if they would like to write an article about a fantastic subject...YOU and what it is to live with an IEM.

Let's raise PKU & IEM awareness not just for a day but for a whole MONTH.

PKU & ME Gala Ball 2014

On the 1st February this year we had our very first PKU & Me Gala Ball. It started with an idea way back in May of last year to create awareness and also raise some much needed funds.

We were so fortunate to have so many generous companies donate to our ball – we had an accommodation package from Crown Towers, laps in a race car, tour of Collingwood Football Club and photos with premiership cup, Dishwasher, Roger Federer signed 2014 t-shirt, Village Roadshow VIP Passes to theme parks just to name a few!! We ended up with over 40 silent auction items and every company we approached asking for donations were so interested in our cause and asked loads of questions so we had already started creating awareness about metabolic disorders long before the ball which was fabulous!!

Our theme was 'Wear something blue for PKU' and it was fabulous to see everyone go to such a great effort. My girls Charlize and Matilda made blue rainbow loom bracelets for people who may have forgotten to wear a touch of blue which were on sale for \$1.00 and had sold out within the first hour (they were very proud when I told them this!)

Our ball was held in the Great Hall at the Ivanhoe Town Hall, Melbourne. We had over 200 people attend the evening. The Great Hall looked incredible with pale blue seats bows to set the theme.

We were lucky enough to have Denise Scott (actress and comedian) and Craig Willis (Voice of the AFL) agree to come and support our night. Craig was MC for the evening and was brilliant and Denise did a comedy spot which had everyone laughing out loud!

We started the ball with a short video my niece had made with my 9 year old daughter narrating. This gave an overview of living with PKU and what we



can do to help. My husband then gave a short speech explaining what diagnosis was like for us and living with a child with PKU.

The room was a buzz of excitement with people commenting on what great silent auction items were up for grabs. Craig Willis did a Q & A with Mick Lewis former Australian fast bowler and then Denise Scott entertained the room.

My husband is a Firefighter with the MFB and they were such a great support to us with 3 tables on the night and two very special friends who kindly donated their time to be auctioned – Win a date with a Female and Male Firefighter was a great success and just a bit of fun!!

We had an amazing band donate their time 'Who Said What' they had the crowd up dancing and having a great time.

It was great to share this special night with Tracey Scott who also has Harrison with PKU and Katy Drewitt who is an adult with PKU and who both helped organize and make this night the success it was. Monique and Paige represented the MDDA on the night and Monique gave a fabulous speech

regarding MDDA. She is a natural at public speaking!

The night absolutely flew and such a great time was had by all. People were extremely generous with raffle ticket purchases and auction bids.

When we had first thought to do a ball we had set our goal at \$10,000.00 and we would have been so happy with this amount. We ended up raising just over \$23,000.00 which still blows me away – such an incredible result! All of the hard work everyone put in certainly paid off in bucket-loads.

Organizing the ball was a very humbling experience, I just couldn't believe the generosity of people and businesses willing to support this great cause.

The feedback from the ball has been awesome everyone had such a great time and still mention it today. What a great memory!

There is a lot of work that goes into these nights and I would love to think about organizing another one in a few years time.

Tiffany Dean



VIC Family Retreat 2014 — Member Stories



My name is Bianca (I'm on the right), I'm 24 years old and I have classical PKU. I had the privilege of attending the most recent MDDA retreat held in Victoria. We were surrounded by great scenery, beautiful food and many interesting stories told by many wonderful people who attended.

Throughout the retreat I attended two main breakout sessions which were very helpful in targeting the trouble areas we encounter as people dealing with IEMs.

The first session I attended was headed by Kate Freeman, which discussed "IEM management – Teens to Adult Transitioning". We all know moving towards adulthood is a major transition in itself. It can mean taking on new challenges and having greater responsibility in life. However, it is also at this time that a person with an IEM must grab the reigns and assume direction with their diet. What we discovered during our session was that this coupling of two major milestones can make it tough. To combat this, we all agreed that taking on chunks of responsibility in the lead

up to the teen/adult transition time would help take the pressure off us. Slowly transferring responsibility during teen years for example taking your own blood tests, counting your own units or cooking a new low protein meal each week can help to reduce the shock of doing it alone once you're an adult.

The major message I took home from this talk was the earlier you can establish solid foundations of our dietary management as a child, the more normal and routine it will become later in life. So when the time comes to transition to adulthood and assume more responsibility, handling of the diet will be second nature, so it'll just be the usual problems of boys to worry about.

The second session I attended discussed "IEM management Motherhood - Healthy living, IEM management", also lead by Kate. This talk was extremely interesting to me. Since I'm closing in on maternal age, I am now at the stage of thinking about what lies ahead in terms of managing my PKU for motherhood. The group had many in the same position as me but also women who have had children, Katy who was busily brewing hers inside and a very

supportive husband. Kate was full of wisdom with her experiences managing women throughout their journey. How often to take blood draws, best ways to keep your levels stable, breastfeeding queries and predictions of how our Phe tolerance would change are all things she was able to shed some light on.

Being around women and healthcare experts who are able to introduce you into the world of motherhood with IEMs was great. Knowing women have gone through this before and having formed bonds with these ladies, I know that when the time comes I have people I can go to for advice.

Even though we were all of different ages, different backgrounds and from different walks of life, a defining factor of all those at the MDDA retreat was our drive to better the life of a loved one with an IEM. Everyone's personal story acted like a puzzle piece to inspire, support, teach and learn from, to come closer to discovering the best way of living with an IEM. Thank you so much to the committee for putting on such a great event.

Bianca Albanese



VIC Family Retreat 2014 Member Stories cont

I cannot remember the last time I experienced a weekend away so jam packed with informative, fun, happy & welcoming experiences. Not only was it a whole new world for me, the amazing inclusive Low Protein Buffet Meals & Protein Buffet options that the Chefs prepared were the icing on the cake. Needless to say, I wanted to steal the left over's when our weekend away came to its final hours.

The friendships that we made over that weekend would be a friendship not easily forgotten because the Retreat was more like an extended family get-together. Everyone was so friendly, polite, helpful, understanding & inspiring. We all swapped stories over a meal, a quiet drink or the social hours of the day. We talked about the high's & low's of everything that we have experienced to-date in between group sessions & during group sessions.

Between the eating, drinking & supplementing ourselves, we had an amazing Timetable of group sessions, speakers and activities. Initially I thought "OMG, how on earth are they going to fit all that in"? The answer, an incredible Team of Volunteers who put their heart & soul into everyone & everything.

Saturday Morning was the first group get-together that I was involved in. Louise Healy discussed "Mindful thinking for you and your relationships" with Adults.

This session was based around the thoughts & structure of your relationships & how to help yourself with not only positive thinking, but with positive action as well. Everyone had the opportunity to address issues with relationships & we discussed implementing change of thinking & action process to a positive one. This session was not only a helpful session, but it was also an uplifting session because Louise helped us discuss our current situations, battles & how to move forward. The confirmation of moving towards the next stage when you are feeling good & in a positive state of mind is so much easier to push through a challenge than during difficult times.

On the afternoon of Saturday, everyone was broken into Groups so that we could create a movie for IEM's. From a perspective of someone who was not involved in the movie making (due to retiring to my hotel room), the mini movies were not only creative, eye catching & story lined, but they involved everyone.

After the movie making session, there was a Big Cooking Fest. I don't think I have ever seen so many treats & potential Master Chefs in the making. Needless to say, I needed a much bigger stomach to finish eating all the treats, luckily sampling was an option.

The concept of a Cooking Book from the Cooking Session is a fantastic idea, I can't wait to cook everything & try them on my nieces & nephews (who are on a regular protein diet). Low Pro? you couldn't tell the difference. Bring on the Master Chefs of MDDA & their cooking inspiration.

Prior to our get togethers on Sunday morning, we introduced ourselves, saying our Name, our IEM, and the details pertaining to the IEM we have & where we currently are. I thought that this was a great idea & felt that the initial first day introduction would have been great.

On Sunday, we had a "Designing empowering programs promoting IEM Wellness" Group Discussion. We split into groups again & discussed what main things we as a group thought needed work, is working, what we couldn't live without, what we needed & the 3 most important things to us. I felt the Brain Storming Discussions were very helpful because they involved everyone and their suggestions.

The Adults group 25+ consisted of Nicole Moore, Alison Moules, and Susi.

What was working for us

Facebook page for MDDA - the internet is a standard part of everyone's day. We felt that when help was needed, support, time-out from the daily grind, a recipe idea or help with a problem we could type in a

message into MDDA's Facebook page & quite a few people would reply. If no immediate reply, a comment is made not long after & the information was reliable. If anyone that had doubts about the information, they would advise to check with their respective/dietician, packaging or the other option the Calorie King Website that has the protein breakdown per serving —www.calorieking.com.au

Metabolic Unit @ RWH is flawless. The unit is exceptionally run by Kate Freeman who is amazing. Guthrie readings are promptly reported back to respective people, follow up phone calls & e-mails are promptly returned, they are informative, helpful, supportive & naturally greatly appreciated. When Kate is not available, one of the other young ladies always contacts us & this service is just as exceptional.

What is not working for us

Link to MDDA to other websites for updates on information including product sourcing or new & current products, changes in products, availability, overseas suppliers (this has been actioned)

What we would like

Establish a wallet size/bag size Fact Sheet pertaining to the Individual IEM advising of dietary & supplemental nutrition in an emergency.

Conclusively, my 1st experience at an MDDA Retreat was amazing. The amount of time, effort, structure, personal care, support, experiences, lovely surrounding, amazing chefs, food availability, presentations, fun, cook up, personal time, child minding, bar facilities (for us who enjoy a drink), informative presentations, Group Sessions, room facilities, consistently available on/off time volunteers was phenomenal.

I enjoyed my first experience immensely.

*Alison Moules
(Pictured middle)*





VIC Family Retreat 2014





VIC Family Retreat 2014 — Member Stories cont



The MDDA retreat, held in February of this year, was beneficial for me on so many levels.

I expected the retreat to be informative, fun, and interesting - which it was, but I didn't expect to have the feeling of a weight lifted off my shoulders connecting to so many amazing people who understood my journey so well.

All of us know intimately what it is like to be touched by an IEM and all of the effects, repercussions, struggles and efforts that are involved. My daughter Frankie is 19 months old and suffers from PKU. I find it an isolating experience often, because almost everyone I talk to about it can't help but fail to understand what it's like to live with a child having an IEM on a daily basis, and most have never even heard of it.

Explaining her condition to new people can get exhausting. Simply to be amongst people with whom you don't have to validate why it's necessary that your child eats chips with their meals, or why they must have a special formula three times a day was so

freeing - chips were provided with the meal, as were scales, and those drinking formulas outnumbered those who didn't! Everyone you meet totally understands what the IEM side of your life is like without you having to say a word.

It was heartening to meet healthy, happy young adults who are on the same amount of protein per day as my one year old. It was fascinating to hear from intelligent and articulate adults what it feels like when you go off diet and to hear from teens how they find their hospital visits and how they define themselves with and beyond, their condition. I didn't just learn new recipes, I got competitive about taste and texture of low protein meals in our cooking competition!

Flora Pearce from Melbourne's Royal Children's Hospitals, spoke to us about managing family dynamics, how to deal with family members who may accidentally hinder rather than help.

I particularly enjoyed Louise Healy's talk, "Mindfull thinking for you and your

family" which taught me how mindsets as carers can and will affect the mindset of those we care for. This got me thinking about questions like - 'What can I do from now to encourage Frankie to be compliant with her diet, particularly when she grows into a teenager and 'How do I still be the parent I would want to be if my child didn't have PKU?' For example, how do I make sure Frankie gets her protein if she refuses what I have prepared for her without pandering or engaging in a power struggle?

I came away really inspired to be strong on my PKU journey with Frankie. I also felt more relaxed than I had in a while, having all meals provided for her for three days was such a great treat. I was delighted to know that the kids she met on that retreat would be the same teens she would later go on camp with. It was lovely to meet people I had only known on Facebook previously and I am so grateful to the MDDA and the wonderful work that they do. I can't wait for the next one!

Nicky Batrick-Nolan

VIC Family Retreat 2014 — Member Feedback

Such a well organised but relaxed easy going atmosphere. The Q & A session were great. Even if you didn't have something to share, you got so much out of the session just by listening to everyone's experiences. The cooking session was fabulous. Initially I thought I wouldn't be any good thinking up a recipe but joined a group, got involved and what a huge success. Food and facilities were all really good. Would recommend future retreats to IEM families."

Robyn

"The weekend was fantastic meeting all the families and the MDDA committee again. It has given me the incentive to go home and be organised to get my diet back on track. It's given me new ideas for meals and snacks. Meeting new people I've never met before has also helped a lot. The whole weekend was great. Thanks to all who had a part in organising the retreat."

Nicole

"The retreat came along at just at the right time for Chloe and I. It has given us the opportunity to re-connect with other IEM families, share ideas, have a laugh and relax in a beautiful setting. Watching Chloe drink her formula with the other kids was 'priceless'."

Fiona

"This retreat provided me with invaluable connections to the PKU community, was a great source of education and for Frankie (18mths) to forge relationships with people who will become her support network as she grows up."

Nicky

"Loved the retreat location! Retreat inclusive information, sessions, cookups, presentations, family inclusive, all generation inclusive. Has been a great motivator and incentive to proceed with diet, achieve my goals and look after myself."

Alison

"The MDDA IEM retreat was a great experience for all involved. Being able to meet new people in similar positions to you regarding your IEM and to be able to share personal experiences is very fulfilling. The presence of health professionals provided great information. The MDDA did a great job facilitating the event and should be proud of all their efforts for putting on such a successful event. It has given many the motivation to be more involved to push MDDA to bigger and better places."

Bianca







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Whether it's the school holidays, an afternoon play date or back to school time, you can get your kids through those mid-afternoon munchies and through to dinner with a wholesome and nutritious glass of milk and a Sipahh straw.

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THANK YOU!

To all who helped make the VIC Family Retreat 2014 such an amazing success

A massive thankyou goes to everyone that helped support the MDDA VIC Family Retreat including Jenny and Karen in the office, the MDDA Executive Committee and other volunteers.

Special thanks to Maureen Humphrey and Flora Pearce from the Royal Children's Hospital along with Kate Freeman from the Royal Melbourne Hospital for their invaluable support as presenters on the Saturday.

Also to our product supporters VitaFlo, Nutricia, Vegan Perfection and Sipahh who helped to ensure that a great availability of low protein products and ingredients were available throughout the event. The Chefs at The Country Place created some sensational meals for our members and the 'High Tea' cooking challenge was a huge hit and loads of fun for all.



Vegan Perfection

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The MDDA thanks the Department of Social Service Disability Conference Funding (formerly FaHCSIA). The support of the Department of Social Services by way of provision of funding is greatly appreciated and acknowledged.

This funding allowed individuals and their carers living with an inborn error of metabolism to attend the conference who may have been unable to attend.

ESPKU 2013 Conference

I arrived in Antwerp at the Radisson Blu Astrid at about 3pm with hubby and Toddler in tow. After a long flight I was feeling very tired but buzzing with excitement.

Friday morning began with a communal breakfast in the main restaurant of the hotel with a great array of low protein foods including cereal, fruit platter, bread, hot breakfast of tomatoes, hash browns and mushrooms. Breakfast was shared with David Contera and Eric Lange, the President of ESPKU whom has two children himself with PKU.

As you can imagine the conversations were exchangeable with common interest and life experience in regards to living with and managing PKU.

Our very first session for the day commenced at 8:30am where we were introduced to the BOKS (Belgian Association for Children and Adults suffering from a metabolic disease) representatives, Lut De Baere and Nadia Connnoosji, who were responsible for the organisation of the conference and did such fantastic work. We also heard short messages from the president of ESPKU, the President of the European Council and the Minister of Health and Social Affairs.

We were accompanied that morning by the Prince of Belgium, Prince Laurent whom I had a brief discussion with as he found interest in my experience of having PKU and also a healthy, happy toddler. I was super nervous talking to a prince so much so that I didn't even realise a team of media experts in his face filming the whole lot and it was only brought to my attention when David mentioned it to me. Who knows I could have been famous that day in Belgium.

Dr Van Spronsen spoke about the plans that were almost completed for the European Guidelines for Treatment of PKU. The plan was developed by a board of medical and health experts regarding PKU in Europe. They aimed to have the plan completed by the end of 2013 and it aims to have a consistent strategy to ensure all patients will be provided with high quality care. How nice would it be for Australia to have National Guidelines on treating PKU?

The next presentation I attended was "Maternal PKU" presented by Professor Treves, a retired health professional in the PKU world. Having been through the pre-conception diet and welcoming our healthy daughter into our lives 19 months ago now, Maternal PKU resides as a very strong passion of interest to me

The findings were that an effective diet by the maternal PKU patient before pregnancy is crucial. Untreated maternal patients or poorly treated patients run the risk of the offspring developing many preventable fatal disorders, including a high rate of mental retardation, birth

defects that are life threatening including heart defects, brain foetal growth and body foetal growth. There was also a high percentage rate in the offspring developing a wide nasal bridge and offspring's with small head circumferences.

The findings also proved that a high percentage of untreated mothers carried foetuses that were small for their gestational age. This can be caused by Phenylalanine exchanges being too low during the pregnancy that then are at risk of developing diabetes later on and other metabolic syndromes.

During this presentation, of course I was running through my head, as the paranoid mother that I am of what I did and didn't do during my pregnancy that may have produced a healthier child and then I realised not a lot at all. My clinic suggests between 120 and 300 micro mls and the European guidelines suggest a slightly higher maximum reading of 360 micro mls.



MDDA would like to thank VitaFlo for their very generous sponsorship to enable Carmen Esparon (QLD) & David Contera (WA) to participate in the ESPKU 2013 conference held in Antwerp Belgium.

I guess now I can say that my trust in the health professionals within the metabolic clinic I visit is supported.

The morning sessions were followed by Genetics and metabolic, New Born Screening, The role of prenatal diagnostics, maternal PKU testimony, and personal experiences testimonies.

New born screening occurs in and is done by the heel prick and tested by blue print but different countries have their own regulations. In some countries, the new born screening is not an obligation. The European council is in discussion of including nationally regulated mandatory new born screening that are consistent throughout all European countries in the European Guidelines for treating PKU.

The Maternal PKU presented content around what to do to prepare yourself for pregnancy and how to manage the diet and pregnancy. It was explained that a female with PKU and a partner as a carrier has a 50% chance of having a child with PKU and a 50% chance of having a child that carries the gene for PKU. If your partner has PKU it is evident that your children too will have PKU.

The practice explained was very similar in the way we (Brisbane adult clinic) manage maternal PKU; in fact, I don't think I can find much difference at all. The pre-conception diet consists of a prescribed amount of natural protein of 2-g per day, later on as the foetus grows; the maternal patient is introduced to more protein gradually. In the placenta the blood levels are 2-3 times higher than a PKU mother so it is very important to manage the levels, in particular because of chances of the foetus having PKU.

The blood Phe levels are monitored twice a week in some cases but at least once a week by a blood test taken before breakfast with a target level of below 300micro mls. The recommended time to remain on a pre-conception diet is 3 months before trying with consistent Phe levels below 300 micromg, however longer is preferred to ensure you can control Phe levels.

If you fall pregnant while off diet, the first 12 weeks are most critical. It is when the foetal organs are forming. Go on diet, try and get Phe levels below 300 micromg as soon as possible. It can reduce the risk of further damage to the foetus.

It was time then to relieve the brain of excessive information and to feed the stomach instead. During this time I also took the time to venture through the product and information stalls and spend some time getting to know the rest of the VitaFlo family from this side of the world whom too were so lovely and welcoming.

In Belgium children begin school at 2.5 years of age. The "PKU & School" session touched on the importance of trying to allow the PKU child to feel included and not different, having the family provide similar foods to those being served to other children for the child with PKU.

Mevr. M. Vandriessche explained the a child's developmental stage of realising that they eat different foods to others around them sets in at around the age of 4-5 years of age so this practice being extremely important to implement prior to this realisation in order to prepare them for a certain degree of understanding and inclusiveness.

In Belgium they have a not for profit organisation that plans PKU camps since 1986 for children aged 6-18 years to attend, and for children with other IEM's. The idea is to educate patients as a play

(Continued on page 15)

ESPKU 2013 Conference cont

(Continued from page 14)

based program regarding the disorder and strategies on how to comply with the diet, form relationships and share experiences with others alike and provide somewhat of an easier transition into the those tough years from childhood to adolescents.

The team at the camp include metabolic dietician, social workers, volunteer supervisors and educators, a cooking team including a qualified cook. The plan is to provide meals that are nutritionally balanced, can accommodate for children's tolerances that vary between 250micro mg and 1000 micro mgs per day and provide adequate calorie substance. All dietary information is provided for each meal and serves as the camp cookery book also. The idea in order to allow children/patients to learn the skills to manage their diet is provide tokens that reflect their Phe tolerance for the day with each meal provided allocated a "cost" in Phe so therefore children get to spend their tokens on the food without exceeding their Phe tolerance and at the same time provided with opportunities to manage their diet successfully. I personally love this idea. The children would also learn the importance of responsibility and being accountable for their food choices and provided with opportunities to do so safely with the guidance of a dietician. As a part of the program blood Phe levels are taken or each child and recorded on the first and last day of the camp.

For the adolescents group meetings and information sessions include how to manage a diet at school, during time with friends and parties, learning to read content of food on labels and calculate from protein to phenylalanine content.

I am a huge advocate for education in childhood in particular and believe education provides knowledge. My number one motto, that resides with me relating to the management of PKU in particular is when you know more you can do more, or in this case manage and comply more successfully. It is because of my strong passion in childhood education and that of PKU compliancy that I would love to see something of a very similar program in Australia. It is important for children living with PKU are provided with the tools and opportunities to grow and manage the condition and I would love to be a part of such a program.

Then it was time to visit more stalls in which I found an awesome product store that was fairly new to the market, Mevalia. They claim to provide high quality low-protein foods that not only look appetising but are nutritious and full of flavour too. Well, I can tell you, from what I tasted, breads and cookies, and waffles from the all purpose flour they are remaining true to their word. Now the battle begins for them to import to Australia so that our variety in food options can slowly expand.

Saturday morning I was excited to attend a favourite presentation — "What is the value of questionnaires for Quality of Life in day to day care"

It is important to realise that quality of life is the ultimate outcome of treatment. The goal is not only to monitor Phe levels and diet. It is a means to an end and ultimately the clinic's goal and what should be what each patient strives for the best possible of quality of life. The best way to measure is to do so is through a questionnaire relating to the patient's well being, and measure the difference between the patients and the general population and look for answers that are consistent throughout and then which may outline improvements required to help reach their ultimate quality of life. The responses provided are how the metabolic team identifies any gaps in their practices and strategies to implement when treating patients.

Now, for my favourite session of the conference, "Possible deficiencies of micro and macronutrients". This was presented by Associate Professor Gizewska. The golden treatment of PKU is a low Phenylalanine diet introduced as early as possible and continued on in most cases for a life time. Our body has the amazing ability to take what food we eat and turn it into us so the quality of the food we put into our body has a huge impact on our health and nobody knows it better than patients with PKU.

Professor goes on to talk about the importance of micro and macronutrients. Macronutrients are substances that we are all familiar with. They are the foods that typically a person with PKU cannot tolerate. They are the foods that contain fats, proteins and carbohydrates and usually are all accompanied with elements of phenylalanine. Micronutrients on the other hand are the vitamins, minerals in trace amounts and antioxidants that are essential for overall good health and normal growth and development of living organisms. There are number of risks that can lead to the risk of nutrition deficiencies but there may also risk of overdosing on differing substances. So that means that the problem may lie with the complexity of the specialised diet. Nowadays there are more than 30 different deficiencies. Patients that are not compliant with their PKU diet are at higher risk of nutrition deficiencies and imbalances than those who are compliant.

When focusing on PKU there are 3 main principles of diet. Natural source of protein that is measured and differing to each individuals Phe tolerance and of course with just this amount of food the recommended daily amount of protein cannot be reached and is why patients require the amino acid, Phe free substitute. But these 2 things are not sufficient to complete the energy requirement which is why it is important to include the low

protein foods in the diet.

Evaluating a nutritional status in a PKU patient can be quite difficult, first of all the patients need to be identified as achieving a normal clinical status, from the psychological development point of view, look at the growth and weight, BMI but remembering that every patient is unique and each patient has their own degree of PKU and the protein allowance. Most patients receive 85% of the required protein intake from their amino acid substitute in which contains calories or otherwise known as energy. Professor suggests that it is important to give energy with the amino acid supplement as low calories can also contribute to unstable Phe levels. The question remains on how much energy should be given and the Professor states clearly that they don't know and that they are looking for guidelines.

We formed great friendships immediately and are already planning visits within the next few years and are in regular contact via social media and email.

What an eventful few days that I experienced with David and my family. One that will never ever be forgotten and one in which without sounding Cliché, was life changing. My time had its ups and downs but I would not change a thing as they all added to the experience and allow stories to be told. In saying that it was the time of my life and also allowed my family to have their first family holiday afterwards, very much deserved and pretty special to have our first in Europe.

I owe all of this experience to the lovely Robyn from VitaFlo and the MDDA. Such a huge thank you in allowing me to venture into a new world of PKU and share more information with all that I can reach. It is the management of PKU that I live with that will benefit. After all, when you know more you can do more.

Carmen Esparon

The full story can be found at

www.mdda.org.au/discover/sharing-experiences



PKU Research at Children's Hospital, Westmead Update—January 2014

Our small but enthusiastic research team continues to work on new approaches to therapy of PKU.

Taking the nonsense out of PKU

In my last report I introduced the concept of stop (also called nonsense) mutations, which are found in around 10% of people with PKU. These mutations lead to a shortened PKU enzyme which either is non functional, or is so unstable that it falls apart altogether. There are drugs available that can trick the cell's genetic machinery to read through the stop mutation and so potentially produce a functional PKU enzyme. This approach to therapy is currently being used in clinical trials for cystic fibrosis (CF) and Duchenne muscular dystrophy (DMD). Last time I reported that Gladys Ho (now Dr Ho!) had developed a system to test these potential read-through agents. This work was recently published (see below).

In November I was invited to a workshop in the US hosted by the company that has specialized in generating the read-through agents being used for the CF and DMD trials, and had discussions with them about considering PKU for a clinical trial. I await further word from them.

In the meantime, we have become aware of another drug that is believed to have similar properties to established read-through agents, and Gladys is currently preparing a series of test tube experiments to evaluate this new potential therapy.

In another stream of our PKU research, we have been screening the PKU

gene in children being treated at our Children's Hospital at Westmead (CHW) for a number of years, identifying those who we believe are likely to be responsive to Kuvan, in anticipation of Kuvan being available one day. This work was also recently published.

We have also recently written a research paper giving an overview of PKU, describing future therapeutic options.

Progress with our GM PKU Probiotic

In my last update I reported that we had begun testing our genetically modified probiotic in our PKU mouse, work being led by PhD student Naz Al-Hafid. Our initial set of experiments yielded very encouraging results. When we fed our mice with the probiotic and phenylalanine in solution, we were able to show that the probiotic prevented the phenylalanine from getting into the bloodstream, indicating that the phenylalanine was being broken down by the probiotic before it could be absorbed.

The next experiment was to see whether the probiotic could have the same effect on phenylalanine captured within protein. Unfortunately, we could not demonstrate that our current probiotic was able to breakdown this protein-bound phenylalanine. We are currently evaluating possible mechanisms for this, including the possibility that the probiotic we have been using (*Lactococcus*) is not surviving long enough in the mouse gut to tackle the extra challenge of having to breakdown phenylalanine within protein. Possible strategies for

overcoming this issue include modifying the *Lactococcus* to make it more resistant in the gut, or possibly moving our system into another probiotic like *Lactobacillus*, which is trickier to genetically manipulate but which has better survival in the gut.

So, as is often the case in research, we have had made some encouraging progress, but also had some setbacks. The team remains enthusiastic about our PKU research, and hopefully our next report will have even more encouraging progress.

Recent publications from the CHW Team

Ho G, Reichardt J, Christodoulou J. *In vitro* read-through of PAH nonsense mutations using aminoglycosides: a potential therapy for phenylketonuria. *Journal of Inherited Metabolic Disease*. 2013; 36 (2); 955-959.

Gladys Ho G, Alexander I, Bhattacharya K, Dennison B, Ellaway CJ, Thompson S, Wilcken B, Christodoulou J. The molecular basis of phenylketonuria (PKU) in New South Wales, Australia: Mutation profile and correlation with tetrahydrobiopterin (BH₄) responsiveness. *Journal of Inherited Metabolic Disease*. (accepted 22nd November 2013)

Ho G, Christodoulou J. Phenylketonuria: translating research into novel therapies. *Translational Pediatrics* accepted 8th January 2014

Professor John Christodoulou AM,
Head, PKU Clinic



Innovation in Nutrition

THANK YOU!

The VIC MDDA retreat held in February at the scenic Country Place, Kalorama was a huge success with 65 participants able to benefit by sharing experiences and better learning how to manage their IEMs.

We would like to thank our generous sponsor VitaFlo not only for the products supplied for the weekend but for their substantial financial support which allowed many of our members the chance to attend the retreat where otherwise it would have been financially unviable. We have been able to reach out to and connect so many more families with this much needed support.

www.vitaflo.com.au



PKU NSW & MDDA join together to host...

“IEM POWER DOWNUNDER”

National PKU / IEM Youth Camp

29th September — 3rd October 2014



Calling all Youth's and Teen's between 8-17 years with an IEM!

This is a camp for you to meet other kids with IEMs, share stories, learn skills, enjoy a bunch of awesome activities and challenges, and best of all have a week away from mum & dad...oh and did we mention HAVE FUN! Narrabeen Sport and Recreation facility on Sydney's Northern beaches is where we'll be for five fun filled days during the September school holiday break. From years of successful management by PKU NSW, this camp has been extended to now provide the opportunity for all IEM kids (not just PKU), to participate. Adult supervision, IEM mentoring and special dietary catering are all key components of the camp, and we are also excited this year to have PKU adult and international adult Kevin Alexander join us for some story sharing and movie making workshops.

NSW FAMILY RETREAT

3rd — 5th October 2014

This family retreat will be held immediately following the NSW Youth Camp. Pick up your kids from camp at a nearby venue have some FUN of your own. The retreat will provide an invaluable opportunity for people with IEM's and their families to meet in a social environment and build positive relationships with other members of the MDDA and PKUNSW community. Youth's will continue to develop friendships they have made on camp and also meet others that did not attend camp. The retreat program will emphasis community support, interaction and sharing. Enjoy a relaxed and informal environment where you will make new friends, learn new ways of coping, learn new food ideas and leave with a sense of wellbeing and empowerment to harness your IEM Power.

Proudly brought to you by



- Social Activities, Fun Team Activities
- Speakers of Interest, Ask the Panel
- Cooking Challenge – all involved
- Specialist breakout groups by transitional stage inc. kids/teens, adults, maternal, parents/families
- Special “Other/Rare IEMs Program”
- Clinic updates, Latest research insights.



Working together as one

For more information visit www.mdda.org.au/iempower or office@mdda.org.au
Freecall: 1800 288 460 or (03) 9723 0600

Member Story—Summer Henthorn



Summer Henthorn has just turned 11 and has PKU. Summer has always adhered strictly to her PKU diet. As a baby her starting level was 2000. She is currently on 27 units.

She has had a great year in 2013. She has done very well at school and has been involved in so much this past year from solos in her choir, to being elected as one of the mini vinies leaders, getting one of the main roles in the school play, getting to regionals for public speaking and outside of school winning a trophy for most improved senior in her performing arts school and graduating from two modelling courses.

Summer loves life and is funny and bubbly and clever, loving and mature. She just had a birthday party last week and just had her two besties for a sleepover. They had an awesome time going to Frozen and to a kids dance/pilates class

afterwards, followed by water bombing and other games. She had rice paper rolls filled with vegies and dipping sauce but her favourite thing was the lolly bar (an idea she requested) with suitable lollies of course.

It was a hit with her friends too. Here are some 11th birthday pictures of Summer and the lolly bar.

PKU never stops her having a good time.

Anne-Marie Henthorn



Sonia Hellings Open House

On Tuesday 18th March Sonia Hellings kindly opened her home to any members in the Melbourne area wishing to catchup for a very informal meet and greet.

We had six ladies arrive for a lovely coffee/tea and a sample of some freshly home baked goodies. The Low Protein bread, Hot Cross buns and mini apple pies were delicious.

The conversations were very lively and it was a great opportunity to share stories and tips concerning the issues faced in raising youngsters with IEM's and creating greater awareness in the general community.

A big thank you to Sonia for organizing this event and making everyone feel so welcome in her home.



NEW ARRIVALS

Beautiful twin baby girls Congratulations!

Congratulations to Julie and Andrew McDonald on the early arrival of their adorable twins Amelia and Olivia, sister to big brother James, on the 19th of February. Doubly the joy and double the happiness for you all!

WA Luncheon 2014

On Sunday 9th March, a group of 14 MDDA members got together for lunch and a very intimate catch up (squishing into our own private dining room for 10 was fun and made for some great discussion!).

Also joining us was Adult Dietitian Catherine Manolikos whom works at Royal Perth Hospital and has been an active supporter of MDDA and our Western Australian IEM Adults for a number of years.

At the lunch, I had the opportunity to provide the group with an update on current activities and happenings at MDDA, and plenty of enthusiasm and discussion took place around possible further events and activities in Perth and its surrounds.

As an outcome from this luncheon, MDDA will be establishing a WA Facebook group for anyone in the region that wishes to connect more directly with locals and be involved and have a say in the planning and discussion of any such initiatives. This will be a great way for all WA folk to stay connected and work together to ensure plenty of activity and local support

is available to everyone across the state... and we are on a mission to get more WA IEM people connected – as there are many more out there!

A taste of what's on the horizon in WA....

- A WA "low pro" cooking day (member driven – MDDA supported). Cook up a storm with fellow members and take home a freezer load of food.
- More WA social events and fundraisers (possible trivia night, labcoat walk etc)
- Another WA weekend retreat (date and location to be decided in coming months but likely to be Mar-May 2015 and within 60-90 mins of Perth)

In addition to these events, the MDDA is keen to help support any WA members that might be considering travelling to Sydney to participate in the NSW teens camp (Sept 29 to Oct 3) and/or family retreat (Oct 3 – 5) later this year.

WA members are encouraged to complete the expression of interest form enclosed with this newsletter (and also found on the MDDA website), and we will

be in touch to discuss options and possible funding assistance shortly thereafter.

Special preference will be given to teens attending the camp, and adults that have not participated in a retreat before. We are also eager to encourage a large network of "Other IEM's" at this event in addition to our more common PKU followers, and would love to hear from you if you are an adult or parent of a child that fits this category and is wanting to connect with similar IEM families.

All in all it was a fantastic catch up for all, and I thoroughly enjoyed the opportunity to reconnect with those families I had previously met at various events and our last WA retreat. I also had the pleasure of meeting some new (and very inspiring) adults with amazing stories that I can't wait to hear more about and see how MDDA can further support them on their journey's.

To get involved in the exclusive WA Facebook group, please email office@mdda.org.au

*Monique Cooper
MDDA President*

facebook

Calling all UCD, GA1/GA2, MSUD, MMA, MA, OTC & all other IEMs

Join the discussions on our Facebook group!
www.facebook.com/groups/metabolicdietarydisordersassociation
and request an add to the group

IEM Labcoat Walk Do It yourself

We are keen to hear from anyone willing to join a local team of volunteers and get involved in organising an IEM LABCOAT WALK in their region/state this May - extending on the PKU NSW tradition and helping drive awareness for PKU and all IEMS.

If you are interested in holding a Labcoat Walk in your area, please contact the MDDA to receive your DIY Starter Pack.

Ten simple DIY Steps to running a successful Labcoat Walk:

- Establish a local organising team (we can assist)
- Pick a location / track (busy location, central to all and family/pet friendly)
- Set a date
- Create your invites (we will help)
- Invite "Walkers"
- Distribute participant kit (and optional Labcoat fundraiser kit)
- Order your Labcoats (we will supply)
- Host the day – have fun!
- Conclude with an optional BYO picnic for all
- Send your pictures and stories into MDDA to showcase in our next newsletter.



Contact the office and we can support you with materials and information to assist you.
office@mdda.org.au Freecall: 1800 288 460 Ph: (03) 9723 0600

Hot Cross Buns

Makes 6 – 8

Ingredients for the buns

40g brown sugar
180ml low protein/free milk substitute
250g Low Protein Baking Mix
½ tsp salt
50g hard margarine or butter
2 tsp yeast (from sachet enclosed with low protein baking mix)
1 tsp ground mixed spice
1 tsp cinnamon
100g sultanas soaked in orange juice*
25g mixed peel (optional)



To make the cross

35g Low Protein Baking Mix
50ml water
1½ tsp oil
Vanilla Essence

For a sugar glaze

50g caster sugar
50mls water

Method

1. Pre-heat the oven to 220°C
2. In a small bowl or jug add the brown sugar to the low protein/ free milk substitute and stir to dissolve.
3. Place the low protein baking mix and salt in a mixing bowl. Stir. Rub in the margarine or butter until the mixture resembles bread crumbs. Stir in the yeast, spice, cinnamon and fruit. Make a well in the center and add a little of the low protein free milk substitute and sugar mixture. Stir gently using a large metal spoon. Gradually add the rest of the low protein free milk substitute and sugar mixture a little at a time, stirring well between each addition.
4. Mix well until it forms a thick smooth batter. Do not worry. Leave it to rest for 4 to 5 minutes. Meanwhile, grease a large baking tray.
5. Divide into 6 or 8 and form into rolls and place on greased tray. Leave in a warm place to double in size.
6. Make the cross mixture and pipe a cross on each bun.
7. Place in a hot oven for about 20 minutes until the buns are brown.
8. Make a sugar glaze by putting the sugar and water into a small saucepan and bring it to the boil. Simmer for 5 minutes. It will thicken slightly.
9. As soon as you take the buns from the oven, brush their tops with the hot glaze.

These buns freeze very well.

*Calculate as guided by your dietitian

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Bunny Cookies

Ingredients

1 cup butter
2/3 cup sugar
2 tsp egg replacer
10ml water
1 tsp vanilla essence
½ tsp salt
2 ½ cups Low Protein Baking Mix



Method

1. Preheat oven to 180°C.
2. Cream together butter and sugar.
3. Mix together egg replacer and water, beat into mixture
4. Add vanilla, salt, and Low Protein Baking Mix.
5. Mix until all ingredients are well blended.
5. Chill dough for 3-4 hours prior to rolling.
6. Roll out and cut into shapes using a bunny shape cutter.
8. Bake for 8-10 minutes.

Variation: Dip in melted VitaBite and refrigerate until set.

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: office@mdda.org.au

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

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