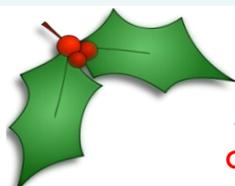




# MDDA NEWS

Newsletter of Metabolic Dietary Disorders Association

Issue 56



*Merry Christmas and a Happy New Year!*

**Our office will close on Friday 19th Dec 2014 and reopen on Monday 12th January 2015.**



## Reflecting on 2014

In our last issue for 2014 we share with you inspiring stories and pictures of the **NSW Family Retreat** held on 3<sup>rd</sup> to 5<sup>th</sup> October at the Sydney Conference and Training Centre, Ingleside. Lots of familiar faces joined us again which was great to see, and in addition we had many new families and individuals come along for the first time. PKU, HT1, GA1 and MSUD families all had a chance to interact together and share and learn important information about their conditions.

The MDDA AGM announced 2013/14 results and some exciting new initiatives that we have planned for the coming year all of which can be found in the **Presidents Report 2013-14**

We provide you with answers to some of the most commonly asked questions concerning the **IEM Grant**, latest information on **ASIEM Standard National Treatment Frameworks** and research into **PKU and Oral Health**.

In addition you will find an update on the **NPKU Conference 2014** held in Salt Lake City, as well as social events and fundraising initiatives by members across the various states and some tasty Christmas Recipes to get you into the festive spirit.

*We would like to wish everyone a very Merry Christmas and a happy, safe and prosperous 2015.*

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

# NSW Family Retreat 2014



There is plenty of research to show the numerous benefits of positive social relationships on our wellbeing. The feeling that we're respected, cared for and listened to has shown to enhance our mental health, our health behaviours, and our physical health. Our MDDA retreats I think, demonstrate a living example of this in action.

The retreats provide the opportunity for all members of our IEM community living and managing their treatment to come together. We share stories, experiences and ideas to help us navigate our journeys. The retreats can also remind us that we don't have to do it alone and that resources and support are available.

As a Facilitator at the NSW Retreat, I had the privilege of meeting the wonderful families living with the IEM: Tyrosinaemia, Type 1 (HT1). Thanks to the funding provided by Menarini, we were able to bring together eight families, living throughout Australia who had not had the opportunity to meet previously. There are many types of IEMs, some more rare than others, and with complexities that affect diagnosis and treatment. The consequences of not diagnosing and treating in time can be fatal for some. As a parent of a child with PKU, I had never had cause to give this much thought until my first session with the HT1 families.

Coming together as a group for the first time, the families had the opportunity to share their stories and experiences, and the benefits of this I think were truly inspiring. They had the opportunity to share their stories with others who really understood their challenges, families who had had similar experiences, and knew all too well the fears and doubts and joys of living with this metabolic condition. Tears were shed and

laughter was had, and I have no doubt that after forming connections at the retreat, they will be able to provide ongoing social support to each other.

Coming together as a group meant we were able to establish their own 'sub group', and set up a Facebook page whereby they can communicate easily. As a group we were also able to submit an online submission to the Pharmaceutical Benefits Advisory Committee who are considering subsidisation of the medication needed to prevent serious health complications for those diagnosed with HT1. Had we not had the opportunity to come together, they would not have known about the submission, and their voices would not have been heard.

We also had families with other IEM's at the retreat: MSUD and GA1. Although much smaller in numbers, they also found it helpful to learn about the similar challenges they may share. At our sessions, we all agreed that regardless of which IEM we live with, we do have our commonalities, however within this small community, there are even 'smaller' groups amongst us, with unique challenges who require at times a different type of support. So we at the MDDA are very keen to hear from anyone who is living with and/or managing an IEM – and all were encouraged to 'spread the word' so that we can keep increasing our community.

In addition to social connection, another aim of the retreats is to provide Education, and the health professionals from our IEM community, generously shared their time and knowledge over the course of the weekend. At this retreat, Dr Jim McGill (Metabolic Specialist – QLD), Dr John Christodoulou (Metabolic Specialist – NSW) and Sue Thompson (Dietician – NSW) provided

presentations on the latest research and answered numerous questions.

Our Q & A panel raised issues such as making healthy food choices, balancing treatment regimes and other important responsibilities, and what we may be able to look forward to in research regarding the IEMs.

Dr Jim McGill provided an interesting session on Transitions and the challenges associated with moving from the paediatric clinic to the adult one now that the benefits of "diet for life" are known and encouraged. I know as a parent of a teenager with an IEM, that the day will come when I will no longer be the 'keeper' of my son's treatment and to minimise stress on all family members involved, successful transition becomes very important. Research in this area is very active at present, so stand by for more information.

All in all, based on the interactions I was a part of and observed, and the feedback generously provided, I would say it was a very successful weekend. We all had plenty of food choices, the kids (of all ages) hung out together and had fun, and the adults talked, listened, and learnt. The MDDA is very fortunate to receive funding to help families attend these retreats and we hope this will continue.

A big heartfelt thank you to all who attended and contributed in all the different ways and made it the special event that it was! I look forward to having the opportunity of meeting more of you and seeing some of you again at one of our other retreats!

Susi Hendricks  
Psychologist & mother of 3 (1 with PKU)  
Wellbeing Co-ordinator  
MDDA

# NSW Family Retreat 2014 - Tyrosinaemia Type 1

In October our family attended the MDDA retreat in Sydney. This was our first time attending a retreat and also the first time we met other families affected by Tyrosinaemia Type 1 (HT1).

We found everyone at the retreat very welcoming, which soon put any nerves we had at ease. The retreat itself was extremely well organised with great information sessions and fun activities. We really appreciate the effort that went into the organisation and running of the retreat.

For myself, as a parent of a child with an IEM it was wonderful to meet other parents who know what it is to have a child with an IEM, to be able to talk with others who understand about the daily struggles of meal planning, and tricks to get kids to drink their formula. I also found it really helpful to be able to talk to the PKU parents who have children older than Jayden (13), to get ideas on the best approach for the teenage years and how to encourage Jayden to become responsible and independent with his diet and medication, without overwhelming him.

I found the information sessions to be extremely helpful with day to day management tips and also the latest insights in the medical field. It is good to know that the medications our children are on seem to be quite safe

but at the same time research is still being carried out with the hope of finding an even safer solution for HT1 patients.

For me, meeting the other families with HT1 was a really powerful experience. Most of our children with HT1 had really hard starts to life, and had been close to being lost through liver failure. It is the first time I have been able to share our story with people who understood where we had come from, from having a very sick child to initial diagnoses and through the journey of NTBC medication, wondering if the medication would work, up to where we are today, that in itself was an uplifting experience.

One of the best outcomes of the retreat is that we now have a group of families who have been brought together as a community, who each understands the other's journey and a group that now can help each other out. Having the eldest HT1 child present at the retreat made me aware of the help I could be to those who have younger children and are still yet to go through the transitions of day care, to pre-school, primary school etc. and also just the general changes in attitude, mood, even eating habits that comes with the different age groups. I also now have a group of friends and parents whose experience has been a little different from ours that I can learn from and get tips from.

It was rather heart-warming watching all the kids together, all drinking some type of formula or swallowing tablets or eating low protein foods as though it was completely normal and they weren't any different to anyone else. On our bus trip back to the airport Jayden was sitting with another HT1 child and they were comparing what foods they liked and then they started to talk about how many grams of protein was in different foods and it dawned on me that this was the first time that Jayden had been able to have a conversation like this with another child. Nowhere else would he have been able to have this conversation and it really bought home to me just how important these retreats are for our children. It is just as important for our children to form friendships with other IEM children as it is for us as parents to have support by people who understand.

It was really wonderful knowing that the low protein diet was well catered for and the kids could pretty much have free choice at the buffet. I'm sure anyone who has a child on a low protein diet would understand, even a holiday is not a true holiday! There is still the cooking of low protein meals, the packing of breads, cereals, pasta's, snacks etc. Well the MDDA retreat for me was the first "real" holiday that I have had since Jayden was diagnosed with HT1. The only place I have been able to go to and totally relax without a care in the world as to what ingredients I needed to find or make for the next meal. It was the first time I could pack light, without having to bring the pantry along. I went home from the retreat feeling rather revived.

I would like to give a huge thank you to Menarini for making it possible through their funding for the HT1 families to be able to meet for the first time and I would also like to thank the MDDA for all of the effort put in in helping us all get to the retreat.

Shanna Driussi



I really enjoyed going to the MDDA retreat. I found it was good that the PKU & HT1 and the other IEMs could learn about each other's conditions and how they were managed.

At the retreat I got to meet other kids with Tyrosinaemia for the first time. It was really good to meet the other kids

and to be able to talk about Tyrosinaemia with kids who actually understood.

I really liked how the buffet included low protein foods and I could go and help myself and choose the things I liked. It was also good to be eating the same food as a lot of other people. I also liked how there was new foods like

the Vitaflo crackers and the bio-cheese to try.

The best part of the retreat was that we got to have heaps of fun doing activities and I didn't feel different from anybody else.

Jayden Driussi

# NSW Family Retreat 2014 - Member Feedback

"Thankyou to MDDA for organising such a great event. It is invaluable to our family to meet other families experiencing similar challenges. It was fantastic to meet brilliant role models such as Kevin Alexander and also hear about latest research from medical professionals"

Micaela  
PKU Parent NSW

"This was our first involvement with MDDA even though our IEM daughter is now 5. Boy are we glad we took the plunge! It was amazing to meet other families who have been through very similar experiences and great for the kids to meet others who have to deal with the same daily dietary challenges. We've made some special new friends and look forward to doing it all again in coming years!!"

Tom & Natalie  
Tyrosinaemia Parents SA



"My main aim for attending the retreat is for Connor to feel part of a family. To experience that there are so many other kids the same as him. This has been achieved as I have watched the smile on his face over the last 2 days.

I can't thank the MDDA enough for all their efforts and financial help to enable not only Connor and I but my two other kids as well. Not only that, I have made new friends, I'm up to date with current research and taking home new tips and ideas to help me be the best support I can for Connor. Thankyou MDDA"

Robyn  
PKU Parent VIC

"MDDA provided an escape from our routines for a few days but mostly it has helped us connect with other HT1 families – my children have made great friends. The information provided and connections made are life changing. Thankyou for the opportunity and for taking us out of the dark and connecting us to information"

Faye  
Tyrosinaemia Parent VIC

"The Family retreat was a wonderful family experience for Nat and Brooke.

Nat and Brooke were very excited to try some new free food recipes and meet some new people and catch up with some friends.

Attending a MDDA family retreat is one of the things Pete and I look forward to. It's about meeting new people, listening to stories and life challenges and gaining new information.

We walked away from the family retreat feeling re-energised, not alone and very proud of being part of the MDDA who are making such a difference to our families life and journeys in bringing people together. Thankyou so much"

Sonia & Pete  
PKU Parents VIC



## Major Sponsor for the NSW Family Retreat & National PKU/IEM Youth Camp

The MDDA gratefully acknowledge our major sponsor VitaFlo for their generous financial and product support for the NSW Family Retreat and National PKU/IEM Youth Camp



## Thank You!

The MDDA is also grateful to Menarini for their grant enabling individuals and their families with hereditary Tyrosinaemia Type 1 to attend the NSW Family Retreat

## Product Sponsors for the NSW Family Retreat

A huge thankyou must go out to all our product sponsors of the NSW Family Retreat who kindly donated their products for our showbags, cooking challenge and Low Protein menu.

Thankyou to the following companies:



# National PKU/IEM Youth Camp 2014

The National PKU/IEM Youth Camp was held from 29<sup>th</sup> September to 3<sup>rd</sup> October at Point Wolstoncroft Centre, Gwandalan NSW. Five fun-filled days were had and gave the IEM teens the chance to come together, meet other teens with IEM's, share stories, learn skills and enjoy a bunch of fantastic activities and challenges.

The campers challenged themselves to the swinging ropes as well as participating in rock climbing activities. They also had a unique opportunity to inspect up close and personal a highway Police patrol car whereby they dabbled in breathalysing, handcuffing, trying on bullet proof vests in addition to turning on the sirens and playing with the cool gadgets inside the car.

There were plenty of water activities to keep cool and also the awesome "Wombat Hole" maze where the kids got to challenge their nerve.

Westmead Children's Hospital Dieticians Alex & Ashley facilitated an education workshop introducing strategies for diet management along with PKU Nurse Rosie Junek who was on hand to provide her expertise. The children were treated to a presentation and film workshop session by world renowned International PKU advocate Kevin Alexander who provided the kids with an insight into his own experience & struggles growing up with PKU.

A series of 5 award winning videos were put together by the campers and judged by Kevin Alexander himself. Congratulations to all the campers involved in the videos for your wonderful efforts.

A big thank you to Nutricia for sponsoring Kevin & Mara Alexander as well as the Westmead Children's Hospital.



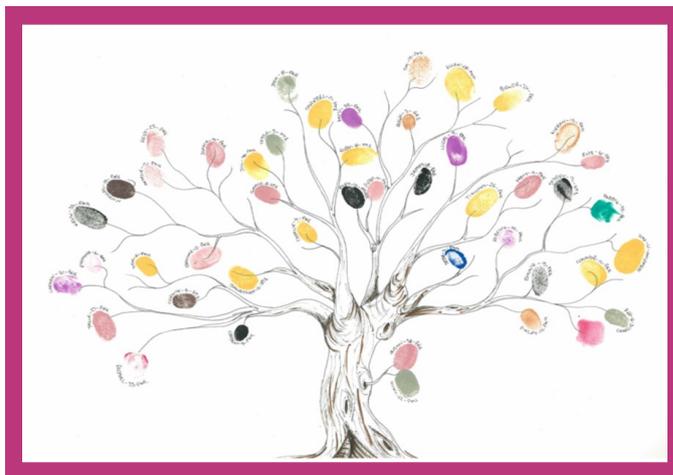
## Our IEM Tree - NSW Family Retreat

At the NSW family Retreat our IEM adults and children had the chance to add their fingerprints to a beautifully created IEM tree (pictured to the right).

You will be seeing more of this tree next year, and with each retreat and social occasion we plan to make it grow as our community and support network grows.

We would love to give our tree a name and welcome feedback from all our members with suggestions. You can email your suggestions to [office@mdda.org.au](mailto:office@mdda.org.au) or join in on our Facebook group discussion.

We look forward to hearing some inspirational ideas!



### Kevin Alexander - International PKU Advocate

We would like to thank Kevin and Mara Alexander for coming to Australia for the NSW Family Retreat and National PKU/IEM Youth Camp. Kevin is currently editing the IEM family stories filmed during his stay and we will be publishing these in the coming months as they are completed. So stay tuned.



### Major Sponsor for the NSW Family Retreat & National PKU/IEM Youth Camp

We would like to thank Nutricia for their generous support enabling Kevin Alexander to come to Australia for the NSW Family Retreat and the National PKU/IEM Youth Camp and for their generous product support.



# Presidents Report 2013 - 2014

The 2013-14 financial year has been a year of development and advancement.

In November 2013 the previous year's AGM took place in Melbourne, and saw the continuation of the current Executive Committee, with all existing committee members continuing in their existing roles. Long Term committee member Louise Healy joined Susi Hendricks to build on the wellness program.

## Organisations Structure

Committee structures were simplified in 2013 and the Executive team continued to focus on a number of operational matters to increase efficiency and effectiveness to members. The current executive committee of management is an extremely enthusiastic and proactive group with all members playing a very active role in helping to add value to members and achieve organisational objectives.

MDDA continued working with general committee members and state representatives in 2013 on strengthening clinic and state based linkages. In order to take the next step in achieving our long term vision, the committee has identified that a more coordinated approach amongst the various state representatives and also "other IEM" representatives outside of PKU is essential.

Office resourcing and output has strengthened with executive officer Jenny Briant able to take a more proactive role with the committee and MDDA member support due to the extra help being provided by part-time office assistance and acting news editor Karen Mills.

Given the increased activity and member engagement with the association, via various events, online activities, volunteer activity and membership growth, continued pressure has been placed on the executive committee to act in an operational capacity. Given this (and the strong financial sustainability of the organisation), MDDA plans to further increase paid office administration hours of the office assistance role, so as to free up Jenny and the committee to play a more active role with our members, volunteers, and state based representatives.

## Strategic Priorities

MDDA's strategic direction is defined and shaped by a strong, unified vision

that is being realised by the efforts of members, volunteers, committee members and supporters – and one that is personal in nature to us all.

### Our Mission...

*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.*

### Our Vision...

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

These words were written by parents and individuals living with or caring for a child with an IEM, and as a result provide for a very passionate and committed group of individuals and families - all working together, striving for a better quality of life for us all.

The vision inspires values of loyalty, unwavering commitment, energy and dedication. It is truly a pleasure to be a part of such a dedicated team of individuals who make up what is the MDDA.

## Key Organisational Priorities

**1. Education** — Through provision of more nationally aligned events and online resources, educating members on options & choices with the following focus areas:

### Research:

- Maureen Humphrey provided an update on her research project at the 2014 Vic Retreat

### Communications:

- 4 printed newsletters completed & the regular bi-monthly eNews.
- Backend rebuild of MDDA website completed with improved layout & functionality.
- Member only website section launched - member driven content strategy now ready to commence (for online recipes, forums, profiles etc).
- MDDA public facebook page maintained with over 200 likes.

### Awareness:

- Supported and encouraged member promotion of Rare Disease Day, and PKU/IEM month.
- Recorded IEM Power Videos at 2014 Vic retreat, promoting examples of IEM empowerment.
- Joined the National Newborn screening advisory group via Rare

Voices to develop national action plan for consistency of newborn screening

- Continued to liaise with ASIEM, HGSA, AGSA, GSNV, APSU, Rare Voices Australia, PKU NSW.

### Fundraising:

- MDDA and its member community raised in excess of \$35k which was donated directly to PKU research and John Christodoulou's probiotic research project.
- PKU&ME Gala Ball, February - Tiffany Dean
- PKU Music event, breaking down barriers, May - Justine Ingliss & Nicky White.
- Member donations and fundraising to contribute towards more effective MDDA projects. Initiatives included - Wendi Emmerson - local fundraising efforts, other smaller efforts - book club, entertainment book etc and several generous voluntary member donations upon renewal of memberships

### Advocacy:

- Continued to support PKU NSW in raising the profile of Kuvan via ongoing government lobbying.
- Proposed and obtained consensus with ASIEM and all state based IEM clinics on the need for a national agreed approach and set of guidelines for IEM management. Working groups already underway with priorities being maternal women and young adults.

**2. Connecting** — Through re-establishment of the MDDA Link Network and other "member community" initiatives:

### Non-Member Support Outreach:

- Designed and produced New MDDA brochure for release to all clinics, in order to generate awareness and new membership via newly diagnosed and families unaware of our existence.
- Formed agreement to forge a new relationship with PKU NSW with the intent to develop a combined national IEM support network.

### Member support initiatives:

- Conducted two national retreats in QLD (September 2013) and Victoria (February 2014) with around 70 individuals in attendance at each.
- Conducted end of year Christmas Parties in QLD, WA, Vic

*(Continued on page 7)*

# Presidents Report 2013 - 2014 cont

(Continued from page 6)

- Conducted FNQ clinic in Cairns and Townsville in May 2014. Attended by Dr Jim McGill and Anita Inwood and over 20 IEM families/individuals participated.
- Conducted 0-5 yrs catch-ups in Victoria
- WA get-together in Perth - April
- Over 220 participants collaborating on our private MDDA facebook group.
- MDDA online profile & private forums section setup and ready for launch.

## Peer to Peer Support:

- Established plan for a newly co-ordinated national peer support network (for specific identified member groups)

**3. Enabling** — Member capabilities and potential, through greater emphasis on transitional stages and member wellness and mentoring program.

## Wellness:

- Peer to peer support for different groups that have different needs – parents/carers, teens, maternal and adults.
- Holistic focus on healthy body, healthy mind and healthy relationships including resilience, coping strategies, understanding research, encouraging supportive relationships.
- Recipe database
- Cooking activities
- Menu plans
- Product database

## Financial:

- Continued advocacy and relationship management for IEM Food Grant
- With thanks to Vitaflor and Nutricia, local travel grants were provided to participants on local MDDA retreats.
- With thanks to specific funding from Vitaflor Australian, two MDDA members David Contera & Carmen Esparon attended the ESPU Conference – Nov 2013.

## Member Contributions:

- MDDA survey
- Seeking volunteers who have initiatives that will support our three key focus areas
- Volunteer providing support for key

projects e.g. recipe and product database

- Team MDDA fundraising activities that allow us to raise funds for research and to support specific programs will be a major focus for FY 2014/2015

## MDDA Member Survey

We received 64 respondents to our MDDA membership survey conducted in May/June 2014. The following is a summary of key outcomes and findings.

### 4 Clear priorities identified:

- Assist in getting a wider variety of low protein products available
- Lobby Government on issues for greater support/resources
- Cooking Workshops & Recipes
- Work with health professionals to gain more consistency for national IEM guidelines

### Biggest Transitional Challenges Faced:

- Transitions
- Ageing
- Building independence
- Keeping teenagers motivated to treatment

### MDDA Values:

- Peer Support
- Facebook connections
- Feeling connected and involved in a community (not isolated)
- Keeping things in perspective

## MDDA Retreat feedback

Feedback received from our 2014 Victorian retreat outlined the following clear priorities being requested by attendees:

- Greater clinic relationships & continuity
- National consistency (IEM management, blood tests, protein counting etc).
- More information on research
- Greater inclusion and involvement of other IEMs
- More educational resources – transitional factsheets, hospital stays, school starting
- More recipes & an active product library

## Our Partners

MDDA appreciates the ongoing support provided by our key product partners. In

particular Vitaflor & Nutricia for ongoing support of MDDA this year again enabling us to continue to provide a variety of opportunities and events to our members

**Nutricia** provided support to MDDA for the QLD & VIC retreat with the provision of travel grants for our members to attend our retreats, and also very generous donations of low protein products for cooking. These contributions ensure our members have the ability to attend our events.

**Vitaflor** provided the exciting support to MDDA members to participate in the ESPKU conference which took place in November 2013 and provided two of our members the opportunity to travel overseas and attend an international event and bring back information to share with the greater Australian IEM community. Vitaflor also provided financial support for our QLD and VIC retreats enabling many maternal aged women amongst others to participate in the events.

Product donations from both Vitaflor and Nutricia amongst other organisations such as Orgran, Basco, The Vegg, Vegan Perfection, Sipahh and 'PKU 2 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.

After the launch of Cambrooke back into the Australian market via **Cortex Health**, MDDA has been liaising with local directors and assisting with provision of member feedback to help ensure a successful launch and deliver much needed new products and choices into Australia.

## Our Clinics

MDDA thanks the ongoing support and services provided by our national clinics and IEM health professionals. Their ongoing knowledge and support of the IEM community is much valued and an essential component to our member achieving greater quality of life through effective IEM management, and awareness of the MDDA's existence.

## Department of Health & Ageing

MDDA thanks the Department of Health and Ageing for their ongoing support and financial grant that ensure our continued existence and ability to continue to provide a national support network for our community.

(Continued on page 8)

# Presidents Report 2013 - 2014 cont

(Continued from page 7)

## Our Members

MDDA would like to extend thanks to the following individual members:

- Namely my fellow executive committee members, Vice President Richard Drewitt, Treasurer Paige Moore, Secretary Katy Drewitt and Wellness Program directors, Susi Hendricks and Louise Healy for your hard work and dedication once again this year.
- General members who have supported us through various

fundraising activities, events and other volunteer support including: Maria Contera, Wendi Emmerson, Justine Ingliss, Nicholla Kinsher, Zoe Mitter, Tim Maneca, Tiffany & Peter Dean, Sonia Hellings and Melinda McGuinley .

- 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.

- 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.

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 2013/2014



2014-2015 MDDA Committee of Management (from left): Richard Drewitt, Katy Drewitt, Paige Moore, Monique Cooper, Louise Healy, Susi Hendricks and Tiffany Dean

## MDDA & PKU NSW "One voice for Australian IEMs"

On 4th of October at the MDDA retreat held at Ingleside, NSW, the presidents of the MDDA and The PKU Association of NSW signed a Memorandum of Understanding to explore the opportunities of merging our two Associations. This is the first step on a path we hope will end with "a unified voice for all individuals and families living with an IEM in Australia".

The goal of a unified voice will serve to:

- Help provide better support for individuals living with and those families with a newborn recently diagnosed with an IEM.
- Provide a unified and stronger voice to lobby Federal Government and State Health departments on grants, health management and prescribed PKU products and pharmaceuticals - all of which contribute to the quality of life for people living with an IEM's.
- Combine our unique strengths to provide better offerings to a national IEM community.

- Ensure the optimum utilisation of limited resources that have been available to both organisations and the elimination of duplicated activities.

The process of exploring a merger of our organisations is a lengthy process, which requires addressing membership, logo's, legal and financial issues to name a few. It is also important that as volunteers, the aspirations of our respective founders and the contributions made by present and past committee members are reflected in the merged associations DNA.

But more importantly, we need to ensure that current members feel confident and comfortable that a merger is in their best interests.

We are very fortunate to be in this unique position to chart the course as to how IEM's will be managed in the future. To commence the process, we would like to invite you to share your thoughts regarding a potential merger. To

facilitate this process, a unique email account [MergedIEM@gmail.com](mailto:MergedIEM@gmail.com) has been established in which your correspondence will be accessed by the Secretaries of both Associations.

We look forward to reading your opinions and providing our IEM community with our progress.

Monique Cooper, President (MDDA)

Andrew McDonald, President (The PKU Association of NSW Inc)





# NSW Family Retreat 2014



# NSW Family Retreat 2014







# NSW Family Retreat 2014



# IEM Grant - Frequently Asked Questions

The MDDA consistently receives enquiries from members asking about their eligibility and the reapplication process for the IEM Payment. Here are some helpful hints to assist with any questions you may have.

"The Inborn Error of Metabolism (IEM) Program provides monthly financial assistance to approved grantees with protein metabolic disorders to assist with the purchasing of low protein foods. The purpose of the IEM grant is to enable people with IEM to stay on strict diets and ensure long term health is maintained. Non-food items, such as medications and supplements, cannot be purchased with money provided under the Program."

## Eligibility

To qualify for financial assistance under the Programme, a patient must:

- Be an Australian resident living in Australia and have a current Medicare card;
- Be 6 months of age and over;
- Require a medically prescribed diet;
- Have been assessed initially by a metabolic specialist who is recognised by the Department of Health;
- Be re-assessed regularly by their metabolic specialist to confirm that the patient continues to have special dietary requirements.

## Review and Reapplication

Hyperphenylalaninemia and Phenylketonuria (PKU) must reapply for

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

Grant payments will cease if the reapplication documentation is not received by the Department within 15 months from the last application.

## Frequently Asked Questions

*What should the monthly grant be used for?*

The monthly grant is to be used to purchase appropriate foods only for approved metabolic conditions.

*Do I need to stay on my prescribed diet if I want to receive the grant?*

Yes, people receiving the IEM grant are required to inform the Department of Health if they stop their diet so payments can cease. People may be liable to repay funds if they fail to advise the Department of Health in a timely manner.

*I see a dietician on a regular basis, can they sign the IEM application form?*

No, a metabolic specialist is required to sign the IEM application form.

*Will the Department of Health accept faxed copies of the IEM application?*

Yes, the Department will accept completed application lodged via mail, email or fax.

*When do I get the monthly grant?*

The monthly grant is processed by the Department in the first full week of each

month and is for that month. Please allow a few days for funds to reach your account.

*I didn't receive a payment, what do I do?*

If you don't receive a payment, contact the Department of Health via email ([iemprogramofficer@health.gov.au](mailto:iemprogramofficer@health.gov.au)) or by telephone on (02) 6289 8980. The payment may have ceased because of out of date contact details or bank account details. If you do not contact the Department of Health to provide up to date details within four months, you will be removed from the programme. You will then have to submit a new application form to re-join the programme and no back payment will be applicable.

*What happens if my child is now over 18 years of age, but I am still receiving the grant on their behalf?*

If it is appropriate for the child to start receiving the grant and they are 18 years or over, the child needs to complete and submit a grant transfer application to the Department of Health. The Department of Health must be informed in writing that the parent no longer wishes to receive the grant. Failure to do this may result in an overpayment which will require repayment to the Department of Health.

For all enquiries regarding your grant please contact the department below:

IEM Programme Officer  
Grant Services Division  
Department of Health  
MDP 205, GPO Box 9848  
CANBERRA ACT 2601  
Telephone: (02) 6289 8980  
[iemprogramofficer@health.gov.au](mailto:iemprogramofficer@health.gov.au)

Department of Health ACCOUNTS SECTION GPO BOX 9848 CANBERRA ACT 2601	Contact Telephone: 02 6289 5556 Fax: 02 6289 5072 Contact Name: ACCOUNTS SECTION Contact E-mail Address: <a href="mailto:accounts.payable@health.gov.au">accounts.payable@health.gov.au</a>						
 Australian Government Department of Health							
<b>REMITTANCE ADVICE</b>							
Date: <input type="text" value="03/11/2014"/>							
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<b>Total</b>							

# Nat and Brooke Hellings - Travelling with PKU



In June this year our family and extended family went to Thailand.

First thing to do for us was to get the letters from the metabolic Doctors explaining about Nat and Brooke having PKU and why we needed to bring free food into Thailand and formula. It was lucky enough I had an appointment at the Royal Children's Hospital earlier in the year to be organised.

Next job was to buy 5 small carry on suitcases for each of us with bright labels so we could identify them as

they had 3 boxes of PKU coolers in them and the other cases had Loprofin flour, Loprofin pasta, Loprofin rice, 2min noodles gluten free, egg replacer, cake mixes from Aldi, lp-drink for milk, vegie chips and pancake shake a mix.

We decided to keep all these items in carry on just in case anything was lost. We arrived in Thailand and I was expecting to go through the x-ray machine with our hand luggage and be asked questions regarding coolers and food, Well all those sleepless nights were just silly because the x-ray machine man was too busy playing on his phone!

Our holiday started and we had a lovely time, We had a villa which was like a giant house so we cooked bread when we arrived and made a cake.

Every night before we would go out, Nat and Brooke would have an entrée at home then would have a main meal which consisted of vegetable spring rolls, rice, fries, tempura vegetables, salad and a

dessert of ice cream or sorbet.

We had such a great time in Thailand we would go back there again and next time we would bring more free food with us as they weren't that strict in checking our food on the way in. It was just on the way out that we were stopped and asked questions regarding why and what the products are and when we produced the letters it was too hard for them to understand and the line was getting longer so they moved us along.

*Sonia Hellings*



## Visit the brand new PKU Connect today!

PKU Connect has a fresh new look and some great new features, including:

- Lots of **new recipes**
- **New cooking videos** with our home economist Fiona Wedding
- **Local stories** about living with PKU
- Online **order processing** for Loprofin foods
- **Member only** benefits including **discounts and Loprofin specials**



Are you a member?

Don't miss out, visit [www.pkuconnect.com.au](http://www.pkuconnect.com.au) and register today!



# WA Fundraising Night

**O**n Saturday 25th October Western Australia MDDA members and friends enjoyed a night of laughter mixed in with some serious competition at the WA MDDA Quiz Night. There were loads of prizes and giveaways and of course the bragging rights to the winning table!

A huge thank you must go out to Scott & Fiona Greer, Maria & David Contera

and Vanessa Mekisic for organising this fabulous night.

Thank you also to Manning Rippers Football Club who supported the event and to all those who donated money, prizes, their time and bought tickets to the night.

It was a great night and another fantastic event to raise awareness of living with an IEM



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## WA Social Gathering - MDDA Executive Team Visit

**P**erth turned on some beautiful weather for MDDA president, Monique Cooper and myself to visit on Sunday 9th November. We had a great afternoon with several of the Western Australia IEM families at Walter Point Reserve Café. Walter Point Reserve is a beautiful spot by the river to escape the heat, and catch up with old friends and make new ones. We heard all about the success of the WA trivia night and discussed plans for MDDA events in WA.

Speaking of MDDA events in WA we spent quite a bit of time checking out possible venues in and around Perth for a retreat there next April. If you are from WA we look forward to seeing you there, if you are an east coaster it is well worth the trip to WA. Perth is a beautiful city and there are plenty of family friendly

activities in close proximity. We have found a venue we think offers something exciting and different for the next retreat. Stay tuned.

One of the main reasons to visit WA was to reconnect with the metabolic clinics to get their input to and support for MDDA initiatives. We would like to thank Shanti and her team at the Princess Margaret Hospital and Catherine and Damon at the Royal Perth Hospital for their valuable time and insights.

We will be visiting all the clinics around Australia in the coming month and this first visit gave us plenty to think about. The input of both teams will strengthen the peer support programs we are currently starting and has given strong focus to some of our planned lobbying activities. If you are interested in either

program please be in touch.

Monique and I both felt the visit was a great success. It was great to see and meet so many people from the WA community. We are really looking forward to the retreat next year.

*Louise Healy*



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## QLD Annual Christmas Party



**S**aturday 22nd November was our annual Christmas party in Queensland and I left the day feeling happy and blessed. It was a brilliant turn out with nearly 70 people attending and it was an especially hot day so the swimming pools got great use.

Families from far and wide came along, including one family from Cairns (great to meet you). We also

had three GA1 families who were able to 'talk shop' and share ideas. As always our wonderful team from the Children's Hospital were deeply involved in planning and partying!

I love seeing how the kids have grown each year we meet with them. They were all very excited to see Santa especially with his big bag of presents. After an unwrapping frenzy all the older kids were asking when the water bomb fight would start. It is a highlight for many – and apparently an opportunity to target Dr Jim and Anita!!! Even the parents got in on the act.

Great ideas for Christmas treats were loaded onto our low protein food table – thanks to everyone for contributing. There were cakes with creative Christmas decorations, cookies, salads, rice paper rolls and fruit kebabs. They were all delicious.

Thanks to Nutricia for sponsoring the Christmas party, MDDA for supporting it and the RCH Metabolic Clinic for promoting it. It is a great way to kick off the Christmas celebrations each year and my daughter loves going so much that she was dressed for it at 5.50am and ready to go.

Hope to see you all (and more) next year.

*Louise Healy*



# NPKUA Conference 2014

In February I started making plans to attend the third NPKUA National Conference, in Salt Lake City which was once again an amazing experience for me.

I flew out of Sydney on the 6th July. Virgin Airlines were great about my food restrictions, they served me fruit, salad, and of course I took snacks on-board to keep me going.

We arrived at the Hilton Hotel, Salt Lake City one and a half days early to help set up the research project that Dr Yano & Kathryn Moseley (USC Medical Centre Los Angeles) are working on. The research experiment was to test the level of melatonin in collected urine samples taken first thing in the morning. The objective was to determine whether levels of melatonin in blood and urine can serve as a peripheral biomarker to reflect brain serotonin synthesis in individuals with PKU. Results showed

significantly lower concentrations of these neurotransmitter metabolites in subjects with PKU compared with controls.

NPKUA Registration & a welcome ceremony with the low protein food companies occurred Thursday afternoon. Great products were sampled and enjoyed by all who attended with a couple of research tables set up to involve people in their studies. That evening we went to the Leonardo Museum for the welcome dinner. There were many salads and low protein foods on hand.

Topics presented during the conference were Medical and Dietary Guidelines for PKU "Reaching New Heights", PKU & The Brain, Artificial Liver In PKU Mice, What is Advocacy?, Cooking with PKU, and Placental Stem Cell Transplant Improves PKU Symptoms in Mice. All of the presentations can be found on the NPKUA.org website.

San Diego, The Mission, and The Science Museum.

I would like to thank the NPKUA committee for hosting such a fabulous conference. They always work so tirelessly for PKU and other allied disorders. Thank you also to my good friends Kathryn Moseley, Jean Koch, who took me on such a great road trip, Virginia Schuett, who has launched howmuchphe.org, available at the moment for US PKU individuals for now but will include other countries in the near future, Robyn Walker from VitaFlo and the team in the US, David & Lyn Paoletta for their magnificent trade tables and drinks.

I had such a fabulous time!

*Debbie Colyer OAM*

The full story can be found at [www.mdda.org.au](http://www.mdda.org.au)



On Saturday night the NPKUA hosted a dinner to honour Dr Levy who has been working for PKU with his patients in the Boston area. Many of his patients and their families did a video to honour him which was lovely. The dinner was great as I interacted with many people.

The time flew by very quickly and soon the conference came to a close and we had to say goodbye to each other until next time.

We started our road trip back to Los Angeles staying at Las Vegas and sightseeing La Brea tar pit, Dana Point,



## Love a bit of online shopping?

Want a new way of helping out the MDDA and members without leaving home?

Then check out <http://www.shopnate.com.au/charity/metabolic-dietary-disorders-association> and register for FREE today.

When you do your online shopping the online stores will donate back to the MDDA at no extra cost to you. Every time you shop online through the Shopnate website at your favourite stores you will be raising money for the Metabolic Dietary Disorders Association.

Don't forget to share this link with all your family and friends and they can feel good about helping us out too!

Go shopping at Expedia, The Iconic, Adairs or hundreds more stores to purchase your Christmas presents and support the MDDA at the same time for free.

# ASIEM Moves to Develop Standard National Treatment Framework

In July this year MDDA and PKU NSW made a joint submission to the Australasian Society for Inborn Errors of Metabolism (ASIEM) requesting that they consider implementing standardised National Treatment Guidelines for the management of IEMs, in particular PKU. Our submission covered areas such as food lists, guidelines for testing, prescription medications including Kuvan, and guidelines for safe levels.

The submission was in response to your feedback and the direction the international IEM community is taking. You indicated that more consistency in treatment approaches and advice would provide you with certainty and confidence in your treatment.

We are pleased to announce that clinicians and dieticians had already begun this dialogue within the professional community and were very receptive to the proposal. A group of clinicians and dieticians had already begun work on standard guidelines for adult IEM patients and this will continue.

Working groups looking at paediatric and maternal guidelines will form and commence work on developing evidence based guidelines.

We are really excited about this development. We hope that consistent guidelines will mean that MDDA can provide better support to our members and that it assists all

people managing an IEM to have certainty about their treatment.

To read the full ASIEM submission by MDDA & PKUNSW and the ASIEM response by Chair refer to the following link <http://www.mdda.org.au/news/article/2014/08/31/asiem-moves-to-develop-standard-national-treatment-framework>



## PKU & Oral Health

Due to the nature of the PKU diet there has been some discussion recently about the impacts of the PKU diets on the oral health of PKU kids. The PKU diet is typically low in natural protein, high in carbohydrates and has the addition of a phenylalanine-free protein supplement, that is consumed three to four times per day.

Dental caries is a complex problem and a disease of bacterial origin. Simply when we eat carbohydrates, these ferment and feed the bacteria in our mouth causing an increase in the acidity of the mouth. These acids then cause demineralisation and breakdown the surfaces of our teeth.

A study completed in 2009 in Melbourne investigated the erosive potential of 5 different amino acid supplements commonly prescribed for the management of PKU. This study found that flavoured supplements tend to be higher in acidity compared to their

unflavoured counterparts. Interestingly they compared the formulas to Coca Cola as well with Coco Cola falling between the both.

The study found no significant differences between the PKU kids and the non-PKU kids when comparing for dental caries, with 75% of the children examined being caries free. However, the study did note that 33% of PKU children demonstrated signs of tooth wear compared to 24% of controls and that PKU children are less likely to regularly see their dentist.

Here are some helpful tips to help ensure your kids maintain optimal oral health;

- Aiming for a minimum of 6 monthly reviews by your dentist
- Trial using a fluoride toothpaste – fluoride strengthens the teeth and prevents decay
- Keep fizzy drink, juices and cordials for special occasions only

- Following formula, rinse your child's mouth with water.
- Try not to sip the formula across the day – take your formula in 3-4 doses.
- Try not to graze or snack on foods during the day – aim for three main meals and 2-3 separate snacks. This will give your teeth a break.
- Make sure your kids are brushing their teeth twice a day (morning and night)

What does this research tell us? This research highlights the importance of regular dental check ups for PKU kids and all other children consuming large amounts of metabolic formula. Also by following some of the steps above we can all work together to keep kids teeth healthy.

Amy Thompson,  
Paediatric Dietitian  
Dietetics and Food Services Department  
[www.brisbanepaediatricnutrition.com.au](http://www.brisbanepaediatricnutrition.com.au)

## “My Anguish: I Can't Breath, Mum”

Earlier this year Take 5 published a story on a 12-yr-old with PKU. ASIEM have contacted us with a statement regarding the information contained in the article:

“The ASIEM Committee and the Director's from each state metabolic unit would like to make it very clear that the information in this article is both inaccurate and misleading in regard to PKU.

There is no known association between PKU and aspirin nor does aspirin place individuals with PKU at a greater risk of developing Reye Syndrome than any other child.

We would like you to reassure members of the MDDA of its inaccuracy. It causes health professionals great concern when careless publications such as this generate so much anxiety amongst a small population.

It should be noted that aspirin is not recommended for use in children.”

Anita Inwood  
ASIEM - Chair  
Metabolic Clinical Nurse Consultant  
Department of Metabolic Medicine

All MDDA members are invited to apply for this exciting opportunity

## 2015 VITAFLO INTERNATIONAL TRAVEL GRANT CONFERENCE OF YOUR CHOICE!

**Open to all IEMs; MSUD, UCD, OTC, MMA, MCAD, GA1, GA2, MA,  
PKU, Tyrosinaemia and others**

We are pleased to announce the generous offer by **VitaFlo Australia Pty Ltd** in offering travel assistance grants to attend a **2015 International Conference** for **any IEM**. This is a wonderful opportunity for any family member or adult dealing with the daily complex issues of living with an IEM to expand their knowledge, experience and gain a further understanding of their disorder.

Research what **international** conference you would like to attend in 2015. The Grant sponsorship will help to cover the cost of your proposed trip including any event registration fees, airfares and accommodation.

Submit your application to the MDDA, it's that easy!

Guidelines can be accessed via our website or phone the office and a copy will be mailed to you.

Once again we would like to thank VitaFlo Australia Pty Ltd for giving MDDA members this fantastic opportunity.

Applications are now open and can be sent via email: [office@mdda.org.au](mailto:office@mdda.org.au)

or post:

MDDA, PO Box 33, Montrose Vic 3765

All queries can be made to [office@mdda.org.au](mailto:office@mdda.org.au)

(03) 9723 0600 or Freecall: 1800 288 460



Innovation in Nutrition

## WA Family Retreat 2015

Expressions of Interest are Open



Friday 17th to Sunday 19th April, 2015

Point Walter Recreation and Conference Centre, Bicton, Western Australia

Overlooking the Swan River the Conference Centre is 20 minutes from Perth CBD.

The venue will allow for a weekend of family adventure with plenty of activities and fun to be had onsite as well as informative presentations and discussion sessions.

MDDA retreats are designed to be relaxing weekends away to enjoy the company of other families and members of the MDDA, to make new friends, learn new ways of coping, learn new food ideas and leave with a sense of wellbeing and empowerment. They are also highly educational and provide all attendees with direct access to selected IEM healthcare professionals and other specialist presenters.

For further information and registration refer to our website or call our office on 1800 288 460

## Fate Shortbread

### Ingredients

375g Fate Low Protein All Purpose Mix  
75g Custard Powder (not instant mix)  
150g Caster Sugar  
300g Block Margarine (at room temperature)  
Extra Fate Low Protein All purpose Mix for kneading  
Extra Caster Sugar to sprinkle  
22cm x 32cm Baking Tin

### Method

1. Preheat oven 325F / 160C
2. Place the Fate Low Protein Mix, custard powder and sugar into a bowl and stir.
3. Add the margarine and rub in. Keep mixing until it comes together as a dough (can be done easily in a mixer or food processor).
4. Lightly dust hands with Fate Low Protein Mix and knead dough until it is smooth and pliable.
5. Roll out dough on the work surface or press the mixture into the tin with your hands and use the back of a spoon to level the surface.
5. Mark into squares or fingers and then lightly prick the surface with a fork.
6. Bake in pre-heated oven for 45-50 minutes until lightly browned.
7. Take out of oven and recut the portions then sprinkle with a little caster sugar.
8. Leave in tin for about 5 minutes and then remove to a wire rack to cool.
9. Store in an airtight container or in the freezer.



## Vegie Christmas Parcels

### Parcel Ingredients

Olive oil  
1 Onion finely chopped  
Garlic to taste  
2 small zucchinis diced  
1 stalk celery, finely chopped  
3 small mushrooms  
1 medium carrot, finely diced  
Salt and pepper to taste  
1 teaspoon dried thyme  
90g dried apricots, soaked overnight  
½ cup low protein breadcrumbs  
Lemon rind & juice of 1 small lemon  
Short Crust Low Protein pastry

### Method

1. Gently fry onion and garlic,
2. Add zucchinis, carrots, celery, mushrooms and cook until tender. Season to taste. Remove from heat and add lemon rind and juice, breadcrumbs and apricots and mix to a sticky consistency.
3. Make pastry and roll out to a rectangle. Transfer to a metal tray.
4. Spoon vegetable mix onto half the pastry, dampen edges and fold to make parcel crimping edges to seal.
5. Brush pastry with a little Rice Milk or low protein milk substitute.
6. Bake in a moderate oven for 180°C for 35 minutes.
7. Serve with Cranberry Ginger relish.



### Basic Pastry Recipe

#### Ingredients

200g Low Protein Baking Mix  
50g Hard margarine/butter  
50g Lard  
Cold water to mix

### Method

1. Place Low Protein Baking Mix in a large bowl, cut margarine and lard into small pieces, rub into the mix until the texture resembles coarse breadcrumbs.
2. Stir in sufficient water to give a firm, manageable dough.
3. Transfer the dough to a surface lightly dusted with Low Protein Baking Mix and lightly knead the dough for 30 seconds, until smooth. Knead lightly.
4. Roll out the dough on a surface lightly dusted with Low Protein Baking Mix.
5. When making pastry keep ingredients as cool as possible due to the high proportion of fat in the recipe.
6. In warm weather, it may help to chill the pastry dough for a couple of hours before use. Alternatively rub the fat into the Low Protein Baking Mix and leave the pastry crumbs overnight in a fridge, in a sealed container.

### Cranberry Ginger Relish

#### Ingredients

500g fresh or frozen cranberries  
1 tablespoon finely grated orange rind  
185ml fresh orange juice  
170g honey  
2 tablespoon finely chopped fresh ginger

### Method

1. Place all ingredients in a large pan and bring to boil,
2. Simmer for 10-15 minutes, stirring occasionally, until berries pop open,
3. Cool. Store in covered jars in fridge for a week to allow flavors to blend.

# Product Updates



Vitasoy Coconut Milk contains 0.15g protein per 100ml  
Available at Woolworths



Pure Harvest Organic Corn Cake Thins contains 0.5g protein per unit



Bob's Red Mill Finely Ground Tapioca Flour 0g protein per 100g



Tablelands Dairy contains 0g protein per 100g,  
Available at Coles



Orgran Gluten Free Apple & Cinnamon Pancake Mix 1.1g protein per 100g



Veggie Straws 25g serve contains 1g protein



Fruit for Life Straps/Slices  
Mango - less than 1g protein per 100g  
Apple - 1.6g protein per 100g  
Banana - 2.1g protein per 100g



Cobs Sea Salt Popcorn 1.7g protein per 20g serve



Simply Wise Puff Pastry Sheets contains 2g protein per 100g



Simply Wise Potato Pastries contains 2.5g protein per 100g



Eatapizza gluten free pizza base contains 1.8g protein per 170g pizza base

## CONTACT US

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Montrose VIC 3765

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## 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

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