



# MDDA NEWS

Newsletter of Metabolic Dietary Disorders Association

Issue 59



*Merry Christmas and a Happy New Year!*



MDDA has celebrated a **year of triumph** with a number of state events being held around the country. Members have enjoyed park picnics, pool parties, fun with inflatables, visits from Santa and delicious low pro pizzas in a box. It was great to see many old and new faces meet for the first time or re-kindle friendships and reflect on a year of great community spirit.

Our AGM took place in Melbourne on November 14, with MDDA President Monique Cooper and Treasurer Paige Moore presenting our annual report, outlining a number of achievements made throughout the year and reporting a financially neutral result.

We are pleased to enclose for you a **copy of our Annual Report**, and recommend you find the time to have a read and reflect on the many wonderful achievements our very active and committed MDDA office, volunteer committee and extended network of volunteers have made to our community. **Over 6000 hours of MDDA executive volunteer time** have gone into the past financial year and we are very proud of our results.

## MDDA trip to Canberra

On November 26, MDDA President Monique Cooper and Advocacy and Wellbeing Director Louise Healy visited Canberra to meet with key Parliamentary officials and express our gratitude for the IEM Grant reinstatement as well as share our plans and priorities for 2016 and beyond.

At Parliament House, we met with Liza Davis, Senior Advisor to Minister Sussan Ley who had a key role in changing the decision to cease the grant, and spoke to many of our members to understand the importance of the grant and implications of its cessation.

We also met with Stephen Spencer, Senior Advisor to Shadow Minister for Health, Catherine King (unfortunately Catherine was an apology due to ill health). We specifically thanked Stephen and Ms. King for the role they played in having the grant reinstated. Ms King was one of the first people to respond to our concerns, she spoke to the media in support of IEM grant recipients less than 48 hours after we were notified by the Department of the grants cessation, drawing significant attention to our plight. Ms King, Mr Shorten and several of their colleagues, repeatedly used Question time and other parliamentary forums to request that the government reinstate the grant.

The MDDA really appreciate the time Ms Ley, Ms King, and their senior advisors took to personally meet or speak with our members and the MDDA and understand our concerns. It was great to be able to acknowledge this whilst in Canberra and show true appreciation to both sides of parliament on this matter.

There are still more people we hope to thank in person including



**Left:** Liza Davis & Louise Healy **Right:** Angela Vaughan, Monique Cooper & Lynda Hurley from Department of Health

Senators Di Natale, Wang and Lazarus and hope to do so during future opportunities, as well as local member representatives from all sides government that provided very proactive support and had a significant influence on the outcome (too many to name here).



Stephen Spencer and Louise Healy

Having support and understanding from all sides of politics was essential to having the grant reinstated and is important for our community into the future. It is great that we have so much interest across political parties to be involved in supporting our IEM community and we intend to keep them actively involved in the coming year as we launch our Miracles of Newborn Screening Campaign in 2016.

Whilst in Canberra we also met with the Department of Health and IEM Food Grant Program Directors and discussed with them matters concerning the ongoing provision and management of the grant and the importance of the role MDDA plays in keeping our members informed and up to date on the status of the grant. This was a very positive meeting and has paved the way for more open and direct liaison between the department and MDDA.

Our visit to Canberra was highly valuable and demonstrated the benefits of a constructive and bipartisan approach to our Government relations. Through the efforts of all MDDA volunteers and our member community, we have been able to strengthen these very important relationships and look forward to developing these further into the future for the greater long term benefit of our IEM community.

Monique Cooper, President MDDA

**Our office will close on Tuesday 22 Dec and reopen on Monday 11 January 2016. For the remainder of Jan the office will be operating with reduced hours.**

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

**Disclaimer:** Information presented in this newsletter is intended for general purposes only and should not be construed as advising on diagnosis or treatment of any medical condition, if you have interest in any of the foods or treatments contained in this newsletter check first with a qualified health professional.

# End of Year Events

## Vic end of year family fun night

The 14th of November was the MDDA Annual general meeting and our end of year family fun night. Once the business end of the night was out of the way it was onto relaxing and having fun. The venue was Inflatable World in Ringwood, Victoria. It proved to be a fantastic venue, suitable for all ages...there was the ball pit for the

little ones, the sticky velcro wall for those a bit older and plenty of jumping and sliding obstacles suitable for all ages! Age was certainly no limit!

The kids were all very excited to see Santa arrive with a big bag of presents and the delivery of low protein pizzas from

Oban Rd Pizza shop was a huge hit.

Thanks to Paige Moore for making the low protein pizzas and Monique Cooper for organising them to be cooked, boxed and delivered from a real pizza shop!



## PKUNSW end of year Picnic

Our annual PKU Association of NSW Inc family picnic was held at Centennial Park on Sunday 29th November 2015 and like previous years, it was such a pleasure meeting new faces and catching up with old ones as well.

Although the day started out cloudy as the day progressed the weather cleared up and the kids really took advantage of the weather by participating in games such as cricket, mini golf and climbing trees to locate cicada shells (eweeeee).

Everyone brought a plate of food and unfortunately we did not have enough



time to take decent photos of the spread as they were pretty much gobbled up as soon as they were put on the table. There were amazing stuffed mushrooms, fresh salads, antipasto and we cannot go past the incredible ginger bread men that Vanessa Towers made....

Also a big thank you to Vitaflo for their continual support supplying the PKU advent calendars for the children, every afternoon in December my children (one PKU, one non PKU) enjoy tucking into the daily chocolate treat.

Bridie Melham

## QLD Clinic & MDDA Christmas Party



I recently went to the annual Christmas party, as usual, it was a blast. The party consisted of all the annual events from the lolly hunt to Santa giving out presents. There was also the epic water bomb fight where we all tried to bomb Dr Jim. Even Anita had a go, but her aim was pretty bad (sorry Anita).

At the party I also met a couple of people that I met at the QLD retreat as well, so it was cool to see my mates again. One of the best things about the Christmas party was the food - it was really good because there was a ton of low protein options for everyone.

These Christmas parties keep getting better and better each year and I can't wait for the 2016 one.

Damon Redknap Age 14

*The PKU Christmas party was a great success. Lots of fantastic food. I love the swimming, water bomb fights and santa coming.*

*Thank you to all those people who helped arrange a great Christmas party. Merry Christmas!*

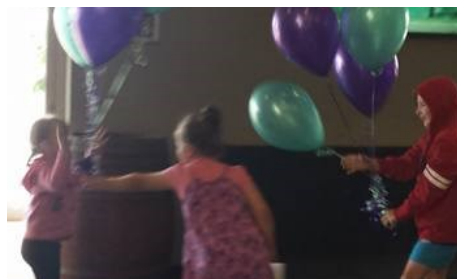
Evie Duce Age 7

Thank you to Louise Healy for organising and ensuring everyone had a great time.

## WA Christmas Party

Unfortunately the rain dampened the turnout for WA's event, but fun was still had by those that attended. Thanks to Scott and Fiona Greer for organising.

If you are in WA look out for details on our facebook group and website for a get together in February.







## Cook @ Home Low Protein Master Classes!



The month of November saw some of our members volunteer to host a low protein master class in their home. Thank you to these wonderful hosts, Monique Cooper - Victoria, Bridie and Paul Melham - NSW, who kindly opened up their homes to an invasion of eager (wannabe) chefs looking for new recipes and tips on cooking delicious low protein foods.

It was also great to have some new members come along to these events and experience what being in the MDDA community is all about; - to educate, connect and enable, in this case, in a relaxed social environment.

These events were made possible by the sponsorship from Nutricia. A big thank you for the product donations and great aprons!



Monique's demonstrations amongst other things included risotto balls (with thanks to Kathy and her wonderful chef skills) gnocchi and delicious popping chocolate crackle slice.

Bridie and Paul cooked up a storm with some Mushroom stroganoff, mushroom and leek pies and amazing meringues. It was safe to say that no one left these masterclasses hungry and many left with supplies for the next couple of days! Recipes can be found on our website under resources.

If you are interested in hosting one of these events in the future please contact the office@mdda.org.au



## PKU Education Day at Westmead Children's Hospital

On Wednesday, 4th November, the Genetic Metabolic Disorders Service (GMDS) at The Children's Hospital at Westmead (CHW) held an education day for patients with PKU aged 7-13 and their families.

Six families attended the day with each bringing low protein foods and recipes to share (such as low protein versions of panna cotta, cookies and veggie patties) for an enjoyable morning tea. The parents received an informative presentation by Professor John Christodoulou about some of the latest PKU research, followed by a facilitated discussion, led by social worker Kimberley Barry. This was very well received, as it provided a great opportunity for parents to share concerns and provide support or suggestions to each other.

Meanwhile, the children got messy in the kitchen making low protein pizzas with Nutrition Education Assistant, Sarah Slack. They all did an excellent job of their pizzas and chose at least one new vegetable that they had never tried before, to include on their pizza toppings. Dietitian, Ashleigh

Mitchell led an educational lunchbox activity where the children were asked to put together a lunchbox containing no more than 3g of protein using the foods provided.

The children impressed us all with their label reading skills and ability to correctly point out counted, free foods and foods high in protein that should be avoided. Clinical Nurse Consultant, Rosie Juneke ran an interactive session with the children, about the importance of taking blood tests and after a demonstration, the children were all brave enough to take their own blood spots for testing.

Overall, PKU Education Day at CHW was a great success, particularly as it enabled patients and their families to meet and network with each other, provided an opportunity to learn from health professionals and empowered the children to be more involved in their treatment of PKU.

The GMDS at Westmead hope to hold similar events in the future.

*Sarah Slack*



### News from the Dietitians

We are delighted to welcome Sarah Slack as our part-time Nutrition Education Assistant (kindly funded by VitaFlo Australia). This role has been crucial in allowing us to develop resources and practical advice around food for metabolic conditions, as well as hands on cooking with children and parents. We are also delighted to welcome Tess Stanway, Dietitian to work along with Ashleigh Mitchell and Sue Thompson in a part time capacity in Metabolic Disorders. To contact the Dietitians it is best to ring 9845 2225 or email all 3 Dietitians so that the Dietitian covering that day can respond.



## Rotary Charity Golf Day 23rd February 2016

Watch PKUNSW facebook and website for further details to come.



## SYDNEY NSW 2016 FAMILY RETREAT AND YOUTH CAMP



30 Sept-2 Oct  
Register your  
interest NOW!

Email [office@mdda.org.au](mailto:office@mdda.org.au)  
if you wish to receive  
updates and secure a spot!



## PKU Association of NSW Inc, Annual General Meeting Sunday 6th March –10am,

Northbridge Baths,  
Widgiewa Rd, Northbridge.  
Baths have BBQ and picnic area.

Come along to discuss the PKU Association of NSW Inc. moving forward, we would love to hear your feedback.

All members are encouraged to consider nominating for a position.

Nominations are open for the following  
Committee positions:

- President
- Vice-President
- Secretary
- Treasurer
- Public Officer

Sub-Committees:

- Communications Officer
- Fundraising
- Youth Camp •Kuvan / BH4

If you would like to join the committee for 2016 or can assist us in any capacity please let us know.

## CONTACT US

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## COMMITTEE OF MANAGEMENT 2015 - 2016

### President

Monique Cooper  
(PKU Parent VIC)  
[President@mdda.org.au](mailto:President@mdda.org.au)

### Vice-President

Richard Drewitt  
(PKU Spouse VIC)  
[VicePresident@mdda.org.au](mailto:VicePresident@mdda.org.au)

### Treasurer

Paige Moore  
(PKU Parent VIC)  
[Treasurer@mdda.org.au](mailto:Treasurer@mdda.org.au)

### Secretary/Public Officer

Melinda McGinley  
(PKU Parent VIC)  
[Secretary@mdda.org.au](mailto:Secretary@mdda.org.au)

### Health & Wellbeing

Susi Hendricks / Louise Healy  
(PKU Parents VIC & QLD)  
[Wellness@mdda.org.au](mailto:Wellness@mdda.org.au)

### Adult Program

Katy Drewitt  
(PKU Adult VIC)  
[Adults@mdda.org.au](mailto:Adults@mdda.org.au)

## Fundraising activities

MDDA would like to thank  
**Sasha Johnson**  
and her work place -  
**Terri Scheer Insurance**  
for their continuing support and  
fundraising efforts.

Thanks to **Scott Greer**  
and  
**BNI Riverside Business Group**  
for organising gold coin donations and  
fundraising throughout the year in the  
workplace.

## Entertainment books 2015.

A wonderful effort again this year  
by Tracey Scott in coordinating the  
sale of the Entertainment books in  
support of PKU Research  
- thank you!

Funds raised will be donated  
towards PKU research  
and the MDDA.

Look out for details early 2016 on  
how to purchase the new edition  
and benefit from the discounts  
vouchers available in these books.



## St Marks Anglican Community school —Market day—



Thanks to the student group **POPSHAKES**  
for their creative fundraising efforts and  
for help in raising awareness in their local  
school community.

## Have a fundraising idea?

Contact the office  
[Office@mdda.org.au](mailto:Office@mdda.org.au)  
and we can help get your idea off the  
ground!

## 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.

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