



MDDA NEWS

Newsletter of Metabolic Dietary Disorders Association

Issue 51
2012



Merry Christmas and a Happy New Year!

Our office will close on Thurs 20th Dec 2012 and reopen on 14th January 2013.

I would like to express MDDA's appreciation of the support and efforts that so many of our volunteers have gone to this year. MDDA acknowledges that we all have hectic lives and often challenges that can take on lives of their own within our busy worlds. Especially with many of us facing living with (or raising a child with) an IEM – to think life wasn't hard enough! So from the bottom of our hearts thank you to everyone that has played a role this year no matter how big or small the contribution may have been.

I would like to quote our (newly appointed) Vice President Richard Drewitt and husband to our gorgeous Secretary Katy Drewitt (PKU Adult) when recently in Sydney together meeting with Nutricia and PKU NSW and gave me some insight into his personal journey and dedication to MDDA...

"MDDA and PKU is my life as much as it is Katy's now. We are in this together for the long haul, and I want to absolutely ensure the best options, the best support and the best opportunities are made available to Katy and the prospect of my future kids"

These words sum up so much for where MDDA is right now and in

many ways have become the personal motto of the committee. Thank you Richard for your ongoing dedication and inspiration to us all.

Educating, Connecting & Enabling!

No these are not just words, these are the absolute core fundamentals of why MDDA exists and where we are driving 100% of our energies into from this point forward!

MDDA is a team of individuals JUST LIKE YOU! We consist of a national secretariat and committee of volunteers all living with or caring for someone with an IEM. We are in this for no other reason than to make our lives (or the lives of our children) richer in every way possible.

I believe, we each have an extremely important and valuable role to play within our community and I personally want to achieve more from us all. Our community is unique – let's face it there are not many of us to be all that selective... and so my view is we have all already been selected!!

It is with this the MDDA has formed a very action oriented and member focused plan and set of priorities to take us forward into 2013.

We have been listening, watching and acting on many of the great

feedback and suggestions received from you all, (including from our member survey where over 40% of you responded some time ago now providing us with a wealth of information).

We have not been sitting dormant I can assure you. We have been in action mode all year, and it is now time to turn these actions into an exciting program of events & activities for you all to start enjoying.

On behalf of myself and the executive committee I wish you all a happy, healthy and restful summer holiday with your loved ones.

*Monique Cooper
2012-2013 President
PKU Mother*

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

It's not just biological . . .

Wearing my 'Psychologist hat' I recently attended a seminar organised by The Mental Health Professional's Network aimed at health professionals treating individuals with Diabetes. The presentation by a Clinical Psychologist, Christina Hendrixcks, outlined the role of psychology in the treatment and management of Diabetes (both Type I and II).

As part of her presentation, Ms Hendrixcks provided an informative account of her experiences in her role as Clinical Psychologist in a Belgium hospital, where patients first diagnosed with Diabetes (both Type 1 and II) were admitted, and her level of involvement with the patients over the course of their treatment.

Amongst her assessment of patients when she first met them was a question which struck a chord with me, both as a Psychologist and as a mother of a 12 year old son with PKU: "How do you feel about having been given this diagnosis?" I realised that I had never really thought about this question for myself when our newborn son was diagnosed back in 2000. I do still remember very clearly the day I received that phone call from the Metabolic Specialist, advising us of the positive result for PKU; I remember trying to grapple with what PKU actually was and what it would mean for the health of our child; the steps I had to take to get him back to the hospital;

our various conversations with the Specialist and Dietician, and I even remember our first questions "Will he be able to eat ice-cream?" "Will he be able to drink beer?"

I remember it being surreal in a way - here we were with a healthy baby boy who was going to be absolutely fine as long as we made sure his prescribed diet was strictly adhered to and we controlled the amount of protein he consumed, especially in those early years; and if we didn't we would seriously compromise his mental development. Really? wasn't just being a parent enough of a responsibility without that too?

I remember how a few days later after we'd had the meetings with the relevant health professionals, had bought the bottles, had the formula, and were shown how to do a heel prick test, I felt like it would be ok and we would deal with this and that all would be well. So why couldn't I stop crying? The question of "how do you feel about this diagnosis?" never came up although clearly there was a lot I was feeling, and not really expressing, it was all about the doing. I did pull myself together after a couple of days and managed to get on with it again. It is fine and we do have a healthy, happy well adjusted child (I think!); however what a journey it's been and I'm sure will continue to be as we manage through the various transition periods.

I've realised that as a mother, I've never asked my son that question, although as a Psychologist I ask it of my clients in different scenarios each working day. My son and I have certainly talked lots about having PKU and what that means to him, his health and well-being; however how he actually feels about having the condition - we've not really touched on until now. I've asked the question, and it's an insightful conversation to have. The answer helps provide some insight into how the person who has the condition actually feels about it on a day to day basis, and helps us to understand how those feelings may impact their day to day management of the condition.

Personally I think there's no right or wrong answer, it's just about what is - and what that actually means to them.

I'd love to hear your thoughts about this whether you're a Parent / Carer / Family Member or a young person who has been living with the diagnosis since birth and as you get older think more about it.

"How do you feel about having this condition?"

You can email me via the office on office@mdda.org.au or add a comment on our MDDA Facebook page.

Susi Hendricks

About the MDDA



www.mdda.org.au

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

Have a sensational summer!

Get ready for endless sunny days, clear blue skies and yummy festive treats!

In fact, our versatile Loprofin range can be used to make all sorts of magnificent treats, so we've done some digging and found some holiday recipe inspirations for you.

Right now, we're also developing a new creative recipe collection, to connect you with all sorts of new low protein goodies that you can make all year round (meals, snacks, desserts and more)! We'll have recipe videos for some of these too!

For now, enjoy your summer and we'll be in touch soon.

From the Nutricia Metabolics Team

Apple slice

(Serves 10)

Per serve
Calories: 442 cal
Protein: 0.47g



Ingredients

3 cups Loprofin Baking Mix
1 cup brown sugar
1 tsp cinnamon
200g margarine, melted
400g can diced apple
2 cups Loprofin Loops, crushed

Preparation

1. Preheat oven to 180°C.
2. Place baking mix, cinnamon, brown sugar and melted margarine in a bowl and mix together. Set aside about 1 cup of mixture to use as the topping.
3. Firmly press the rest of the mixture into a greased slice tin. Smooth with the back of a metal spoon.
4. Bake the base for 5 minutes.
5. Place apple on top of partly cooked base.
6. Mix the crushed loops with the reserved 1 cup of remaining mixture.
7. Sprinkle the loops mixture over the apple.
8. Bake for 30 minutes.
9. Cool and cut into squares.

Shortbread Biscuits

(18 biscuits)

Per biscuit
Calories: 92 cal
Protein: 0.19g



Ingredients

50g butter (room temperature)
50g hard margarine
50g caster sugar
175g Loprofin Baking Mix
2-3 tsp cold water

Optional flavourings

(to be added at Step 2)

Grated rind of 1/2 lemon
Grated rind of 1/2 small orange
1 tsp sweet spice
(i.e. ginger, cinnamon, mixed spice etc.)
50g currants* or other dried fruits*
Few drops of vanilla or almond essence*
Add 50g finely chopped cherries*

*Please check with your Dietitian.

Preparation

1. Place the butter and margarine in a mixing bowl and beat well. Add the sugar and beat together until light in colour and texture.
2. Stir in the Loprofin Baking Mix and any optional flavourings (see optional flavourings above).
3. Using one hand, squeeze the mixture until it comes together, adding sufficient water to give a manageable dough. Transfer to a surface lightly dusted with Loprofin Mix and knead the dough for about 30 seconds until smooth.
4. Roll out the dough to about 1/2 cm thickness on a surface lightly dusted with Loprofin Baking Mix.
5. Cut into desired shapes (e.g. circles, ovals, animal shapes or others).
6. Transfer the biscuits to lightly greased baking trays and bake in a preheated oven at 150°C for 20-25 minutes until pale golden in colour. Remove from the baking trays whilst still warm. Cool on a wire rack.

For more information, please contact the Nutricia Clinical Care Line on 1800 060 051



ANNUAL GENERAL MEETING OF MDDA

Minutes of Meeting

Held 24th November 2012 at 6.30pm
At 247 Dendy St, Brighton East, Victoria 3187

Meeting opened time 6.38pm

Members Present

Kathryn Drewitt, Richard Drewitt, Susi Hendricks, Paige Moore, Tracey Scott, Monique Cooper, Michael Hendricks, Dean Cooper & Jenny Briant.

Apologies received

Maureen DiPetta, Dragana Slisko, Wendi Emmerson, Phyllis McIntosh & Lyn Campbell

Approval of Minutes

 from the 2011 AGM.

The minutes of the previous annual general meeting were distributed on the table.

Motion: That the minutes of the 2011 AGM meeting be accepted.
Moved: Katy Drewitt
Seconded: Paige Moore

Presidents Report

 was distributed on the table.

Report was presented by Monique Cooper.

Motion: That the Presidents report be accepted.
Moved: Susi Hendricks
Seconded: Richard Drewitt

Treasurers Report

 was distributed on the table. A summary was presented by Paige Moore.

Motion: That Treasurers report with Jensen & Associates audit be accepted.
Moved: Katy Drewitt
Seconded: Tracey Scott

Election of office bearers and Executive Committee for 2012/13.

The number of nominations received was equal to the number of vacancies, therefore all persons nominated are deemed to be elected.

President:	Monique Cooper	Nominated: Paige Moore	Seconded: Tracey Scott
Vice President:	Richard Drewitt	Nominated: Susi Hendricks	Seconded: Monique Cooper
Secretary:	Katy Drewitt	Nominated: Monique Cooper	Seconded: Paige Moore
Treasurer:	Paige Moore	Nominated: Katy Drewitt	Seconded: Tracey Scott

Appointment of Auditors

Motion: That the MDDA continue with Michael Jensen as auditors for the MDDA.
Moved: Richard Drewitt
Seconded: Paige Moore

Appointment of Public Officer

Motion: That Richard Drewitt be appointed Public Officer.
Moved: Paige Moore
Seconded: Monique Cooper

Meeting closed

No further business raised the meeting was declared closed at 7.15pm.

MDDA Presidents Report 2011-2012

The 2011-12 financial year has been a progressive and fruitful year for MDDA, on many fronts.

National Conference 2012

The financial year commenced with a few busy months by the 2011 committee and National Office with final preparations for the National Conference. This conference took place in October 2011, at Seaworld, with the theme "Celebrating You". Over 150 members, dietitians and health professionals attended the event which ran for two days and two nights and featured an array of educational, social and networking sessions.

With assistance from FACHSIA, MDDA provided 24 IEM families in difficult circumstances with financial assistance to be able to attend the event. This support was very much appreciated by MDDA and the recipients.

Key partners Nutricia and Vitaflo played important roles at the event assisting with speaker recruitment, providing product displays and product donations and Nutricia also conducted a cooking workshop/competition for all delegates to enjoy, learn and share latest cooking tips & techniques. These suppliers along with other MDDA product suppliers participated in a product display throughout the event.

Presentations and facilitated sessions were conducted by; Jim McGill, Bruce Lord, Barbara Cochrane, Trish Rutherford, Aoife Elliott, Maureen Humphrey, Sue Thompson, Annabel Sweeney, Siobhan Brown, Mark Boyce, Rachel Sharman, Louise Healy and Shona Browne.

MDDA thanks all speakers and sponsors that participated in the 2011 national conference. In addition, MDDA also extends thanks to the previous committee for their efforts in helping to pull together the event. Special thanks goes to (since departed) committee member Beth Engwirda for her tireless work on the conference and pulling together a valuable line up of speakers and product suppliers.

These conferences are now bi-annual events for MDDA, with the next one soon to be announced to take place in October 2013.

2012 AGM

The October 2011 AGM took place at the conference, and saw the forming of a new Executive Committee, with all members new to the executive team other than continuing Vice President Susanne Hendricks.

In addition new and continuing general committee members were signed up around the country.

Operational Priorities

The first task of the new committee was to conduct a membership survey immediately following the conference to obtain a clear perspective on member needs & priorities. This survey received a remarkable response rate of 40% which is an outstanding result. Findings from this survey became key to driving all future initiatives of MDDA and also became the basis of formulating MDDA's new strategic direction.

In addition to this survey, MDDA conducted a rigorous review of its financials with new treasurer Paige Moore in place and new budgets were established with a viability analysis conducted.

This newly formed team (in conjunction with national office staff) then spent following six months, focusing on two key objectives:

Ensuring MDDA has a reliable, sustainable and financially viable future

Ensuring MDDA delivers increased member value whilst simultaneously achieving operational efficiencies

To achieve this, the executive team (all Melbourne based) met monthly with MDDA National Office staff for the remainder of the financial year and each member individually took on an extended role in actively working towards achieving these objectives.

The following operational outcomes were achieved via this process:

- Re-negotiated Government Grant funding – securing ongoing funding for next three years.
- Re-negotiated funding from Nutricia and invigorated renewed interest in MDDA future plans
- Revised internal MDDA office operations and roles for improved efficiencies and better delivery against member priorities.
- Replacement of Office IT systems – with new server, workstations, remote access with our own email address capabilities.
- Analysed and prioritised member survey results and in addition to utilising these results in the formation of our new business plan, we made immediate changes and improvements in key areas of online services and communications.
- Re-Launched new MDDA newsletter format – more streamlined and affordable to produce format, without compromising on content.
- Launched MDDA eNews (electronic Newsletter)
- Launched MDDA Facebook site (enabling private online sharing by members & approved subscribers)
- Launched "Team MDDA" community awareness and fundraising program
- Scoped new database and website for deployment in current financial year.

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General Committee role

In order to achieve these above outcomes, the executive committee suspended General committee meetings in place of monthly Executive Committee meetings in order to focus the team on these key priorities. In turn general committee members were utilised for local state based member events & fundraising activities so as not to be burdened with operational matters. Some states performed well under this structure, whereas others were fairly hands off throughout the year causing some states to have less activity that desirable within those states.

Organisational Structure

MDDA also saw further organisational change with the voluntary stepping down of Kerri Carboon from Executive Director into a (reduced hours) advisory capacity as she took on other job opportunities aside from MDDA. With this change in role, MDDA's Office Administrator Jenny Briant increased her hours to take on some of the administrative components of the ED role. Further to this each of the Executive committee took on additional roles to their appointed position to help ensure MDDA continued to achieve results and deliver member and key stakeholder value.

This revised structure is not sustainable long term and has created issues with MDDA unable to deliver key organisation requirements in a timely manner and has put pressure on the executive committee being able to perform all functions of their roles effectively. As a result MDDA is conducting an organisational review and will be implementing a new structure in calendar year 2013 to ensure that National Office is more suitably resourced moving forward.

2011-2012 Programs and Initiatives

Outside of these operationally focused matters and resource challenges, MDDA has been active across the year in various ways...

Events & Initiatives

In addition to the Seaworld Conference, MDDA held numerous social events around the country, including, 0-5 catch ups, Christmas and Easter celebrations, local fundraising events and participation in cooking demonstrations by Nutricia.

Special thanks go to MDDA committee members Cass Graue, Zoe Mitter, Wendi Emmerson, Tim Manea & Susi Hendricks for their coordination of these activities.

Looking forward, MDDA has some exciting events planned for 2012-2013 to complement the existing events program.

Further Recipe Book Inserts have been funded by VitaFlo and are in the process of being distributed to our members for inclusion in our PHE-Nominal LOW PROTEIN Celebration Cookbook. These inserts will prove to be a further resource to our members whom

all agree access to low protein recipes for everyday use is a real priority.

MDDA also thanks Telstra for their contribution of funds towards the printing the third edition of these recipes inserts.

Thank you to Kerri and Jenny and fellow committee members (in particular Richard) for the production of these recipe inserts, in what has been a difficult task with limited experienced volunteer involvement in the proofing & editing process.

Fundraising & Awareness

Fundraising and awareness efforts by our committee and members have continued to be impressive.

- Cleopatra's Temple once again ran its annual fundraising ball A Night at the Colosseum in October 2011, raising an additional \$10,000.00 for MDDA. Special thanks to Claudia & Rocco Mazzone of Cleopatra's Temple Spa & Beauty Centre and Maria & David Contera for their efforts in making this event a great success
- As recognised and presented to at our 2011 AGM, a very close friend of mine and my husband's, Dean Tulloch set out to raise \$50,000 for MDDA by taking on running the Gobi Desert Ultra-Marathon in July 2011. Dean raised over \$30,000 in his efforts, and made a pledge to MDDA that we would get that up to \$50k before he was finished with his mission.
- Our RundayRun champion Dean Tulloch also took on the North Face 100 ultra-marathon in May 2012, raising additional funds and taking us closer to his \$50,000 pledge. Dean has also conducted several presentations to local schools and rotary groups, spreading the word about IEM's and MDDA, and raising continuous funds for the organisation. Dean continues to be an inspiration to us all and we thank him for his contribution.
- WA member Diana Mazzone organised a local Pasta Lunch and raised \$1630
- WA member Tim Manea organised a school PKU awareness day and raised \$1000.00
- Vic member Wendy Emmerson held a workplace morning tea educational session on IEMs and helped to generate increased awareness for MDDA.
- PKU Awareness Day took place in May and MDDA encouraged members to get involved in local awareness activities and events being held globally. South Australia supported the day with an information day at a local kindergarten organised by Cassie Graue.
- Whilst the activities took place in this current financial year, it would be remiss of me to not acknowledge, QLD committee member, Zoe Mitter who from the beginning of the year has put in an exceptional amount of time and effort in planning and pulling of a fabulous Christmas in July event raising an impressive \$5,750 for MDDA. In addition to this event, Zoe has since co-

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ordinated a local sausage sizzle and managed to get some great publicity throughout the year further promoting MDDA & PKU amongst the local and national media. Zoe's efforts this year have been tireless and have been extremely appreciated, and she has extended herself to go above and beyond in helping raise awareness and funds for MDDA.

- MDDA supported PKU NSW this year in helping to raise funds for PKU Research at the Children's Hospital Westmead. Through this effort, MDDA and members donated \$3000.00.
- 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.

Members

Membership renewals continue to be received from our members, and are expected to pick up in the new year with the launch of our new business plan and program of events and activities. The financial year saw our membership base grow with 26 new members joining the MDDA. Over 180 members renewed their subscription and generously donated over \$7,000.00. This year's renewal notice also allowed members to donate to a Research body. We are looking at continuing this option tradition in future years.

Acknowledgements of past members

On a sad note, we have unfortunately had 4 members pass away this year, which has certainly exposed the raw reality of the very sad circumstances some of our members are faced with. We will continue to support these families in any way we can, and I extend my sincere sympathy to all.

Our Partners

Our sponsors also provide significant contributions and are greatly appreciated for their support of MDDA.

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. MDDA had the opportunity to meet and present to the entire Metabolics team at the end of financial year 2012. This provided a great opportunity for MDDA to get to know the Nutricia team and forge closer relations as we had the chance to share our strategic directions.

Vitaflo is also an ongoing supporter of MDDA and provides valued support with key initiatives and projects taken on jointly throughout each year. The most recent initiative has been the our PHE-Nominal LOW PROTEIN Celebration Cookbook insert additions for 2012 soon to be released to members, but in addition to this Robyn at Vitaflo has been an ongoing support to MDDA on many occasion providing access

to international speakers for our conferences and supporting MDDA events and providing low protein products (goodies) for members.

MDDA has also maintained ongoing relations with other product suppliers including Orgran, Basco & Cambrooke just to name a few.

External Liaisons

MDDA has continued to represent the needs of its members in the continuance of the Inborn Error of (protein) Metabolism Food Grant, the Carers Allowance and Newborn Screening and Genetics issues, our input continues to ensure continuance of these resources to our members.

MDDA Priorities

MDDA Survey results, coupled with ongoing enquiries received via the MDDA national office and facebook site, continue to outline the unmet need of young adults and maternal women with IEM's. The closure of the adult clinic in Victoria has caused increased volume of calls from adults expressing concern for their on-going care.

Through this MDDA has identified the need for further support programs and resources for these transitional phases for our members.

MDDA has been working hard behind the scenes on its business plan looking forward to 2013 and beyond. With this a new Strategic Direction has been set for MDDA, coupled with some key new programs we are hoping to seek further support and funding for, to help pave the way forward to achieving our plan.

Thank you's

I would like to say a particular thank you to many people this year that have been instrumental in helping us to achieve our objectives:

- My fellow executive committee members, Vice President Susanne Hendricks, Treasurer, Paige Moore, Secretary Katy Drewitt and IT Guru Richard Drewitt for your hard work, dedication and enthusiasm to the cause as volunteers.
- A very special extra thank you to Richard for the huge amount of work he has put into our IT and Communications systems and processes, coupled with his generous in kind donations of fundamental IT equipment and resources. In addition to this Richard took on the role of News Editor this year and produced 3 outstanding newsletters. In changing the format of the newsletter he has halved the production and printing costs. MDDA has been most fortunate to have his involvement this year.
- Jenny Briant for stepping up to the challenge this year of an extended role, and being a tower of strength to the team and always happy to help and take on new challenges. You have been a

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pleasure to work with this year and I personally really admire your passion and dedication to the cause.

- To Kerri Carboon for having the courage this year to step back and pursue other interests enabling others step up to the cause. Your knowledge and experience with MDDA and IEM's is second to none, and we appreciate your continued support and advice that you provide whilst juggling the hectic life of holding another job and raising three teenagers (two with PKU). We also thank and acknowledge Kerri's family in the many previous years of support they have provided Kerri and MDDA, and hope that they will continue to participate in and benefit from all future MDDA programs we have planned for in the future, whilst having a little more of their Mum back to enjoy.
- General Committee members with particular reference to Zoe Mitter, Cass Graue 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, the Conteras and Mazzones, Sonia Hellings, Fiona Wallace-Xu, Judy Hiscock
- Our Advisory Council and LINK Network members for their continued involvement and support of MDDA.
- And finally 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. We continue to strive toward meeting the obligations we set out through this arrangement with our members, supporters and other key stakeholders.

2013 Plans

As I draw to the conclusion of this 2011 -2012 report, I would like to take a moment to share with your our plans for 2013 and beyond. Our revised business plan is now available for circulation and will be provided to all members and key stakeholders electronically in the coming days following this AGM.

In Conclusion

I am excited to be able to look forward to 2013 and beyond with a clear plan and direction and a group of extremely committee individuals making up the Executive Committee that will be instrumental to the success of us realising our vision.

I would like to encourage all MDDA members to consider taking a more active role in the organisation in a volunteer capacity of any kind.

I look forward to a very active remainder of this financial year ending 2013.



Monique Cooper
MDDA President 2012

Our New 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 Key Priorities & Objectives . . .

Education	Through provision of more nationally aligned events and online resources – educating members on options & choices.
Connecting	Through re-establishment of the MDDA Link network and other “member community” initiatives”.
Enabling	Member capabilities and potential, through greater emphasis on transitional stages and member wellness & mentoring program.

Our New Vision . . .

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

MDDA Treasurers Report 2011-2012

The final audited Income and Expenditure Statement; the Balance Sheet figures are available by contacting the MDDA Office. The information contained here is a summary of the actual Treasurers report for year ending June 30, 2012.

Summary

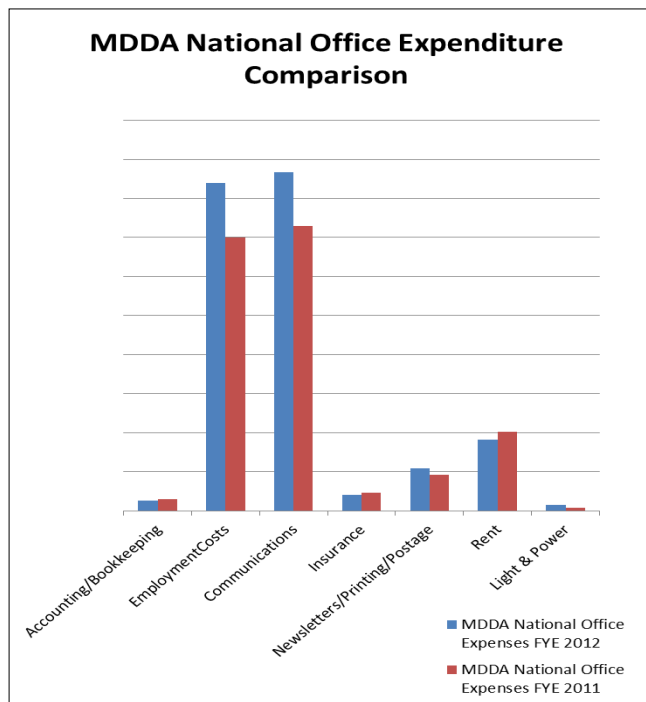
During the FYE June 2012 the MDDA has been focusing on delivering services to our members and fundraising in order to support our members and keep the organisation active.

Major Fundraising that occurred was the RUN DEANO RUN ultra-marathon in the Gobi desert in which raised in excess of \$40K and the Cleopatra's Gala Ball held by the WA members raising in excess of \$11K. A National conference was also held on the Gold Coast in October 2011 bringing together members, health professionals, product suppliers and other support personnel. Other smaller events and fundraising efforts were also held in different states such as Easter Picnics, raffles and cooking demonstrations.

Income & Expenditure Breakdown

The MDDA recorded an overall loss for FYE June 30, 2012. It can also be noted that the MDDA is currently set up on a Cash – Accounting system and not accrual. There is income within the previous Financial Years Data that is relevant to the year 2011/2012.

Although the MDDA recorded a loss, many areas of expenditure have been improved on and we did have a jump in income although not proportional.



The graph shown is comparing the National Office Expenses from YE 2011 to YE 2012. The Accounting/ Bookkeeping, insurance and rent all decreased.

Expenses

The majority of the other expenses stayed in parity with the previous years figures. You will note increases in the following:

Communications

These costs include phone, website and internet costs. The MDDA is moving towards a more tech savvy operation with the upgrading of systems internally in order to reach our members and harness their needs. As the MDDA is a national organisation for rare Inborn Errors of Metabolism (IEM's); the people affected by these disorders are in small pockets throughout the country. As one of the Executive Committee is an IT professional, the costs involved in these changes are extremely low for the services and products that we have been receiving as an organisation.

Employment Costs

This has been identified by the Executive Committee and the MDDA is currently restructuring in order to reduce these costs.

Newsletter/ printing/ postage expense

Highlighted as an area of increase. This has also been addressed by the executive committee with the role out of a new format for the newsletter with a huge reduction in the printing cost and the introduction of E-newsletters and more web based communications.

MDDA Conference 2011

It can also be noted the conference ran at a loss. This was due to the highly subsidised pricing for members and their families. The conference although was a huge success with a large attendance, highly respected and informative speakers and a wealth of education and support provided to the delegates. This was measured in surveys conducted at the conference.

Income

With regards to Income, the MDDA increased its income in the area of fundraising. We also did not receive very much in the way of sponsorship during the FY 2011-2012. This has been recognised by the executive committee. The current situation is the MDDA is in the final stages of securing sponsorship from various entities. The MDDA has also taken a more active stance on fundraising with the introduction of the TEAM MDDA initiative and the Cleopatra's Gala ball becoming an annual event. The committee and employees of the MDDA are also active in seeking grants for specific projects. The committee are also reaching out to the members and enabling them with the tools and resources to be able to hold events themselves as members are spread so far and wide.

Conclusion

Although the MDDA has recorded a loss, the MDDA executive committee is very active in decreasing the expenses and increasing income in order to provide quality services to our members. We have confirmed Wellness Retreats for our members to begin in early 2013 and we also are planning our next National Conference to be held later in 2013. Looking forward to the next 12 months, many projects are underway.

Paige Moore
Treasurer



South Australian 0-5yo Catch Up

We could not have asked for a nicer day for it! The sun shone beautifully for our 0-5yo get together.

On Saturday 22nd September, Paul, Leah, Katie (PKU) and myself were joined by Anthony, Alice, Leo (PKU) and Sid McDonald, and Michael, Kim, Sophie and Ava (PKU) Baker, along with Kim's Mum, Marcia Valodze at The Big Rocking Horse, in Gumeracha, SA.

The Big Rocking Horse was a great location. The kids all played really well together and enjoyed the cubby house and play area right along side of the cheeky Galahs, while parents relaxed and talked about all things PKU. There was no shortage of ideas regarding how to keep meals interesting, birthday parties, batch cooking and getting organized in the kitchen, to how we all handle the low protein diet with Day Care and Kindy. I was amazed at the different things that worked for different families. They may all have the same metabolic condition, but the rule still applies, no two children are the same. After lunch the kids were able to buy bags of feed and walk through the enclosure feeding the large variety of animals and birds in the wildlife park.

This was a lot of fun, despite some over enthusiastic sheep when it came to feeding time! I got so much out of the day. It was great to meet families who are taking day to day life with PKU in their stride, with a positive attitude in tow. It was a wonderful exchange of ideas and fantastic to talk to people who understood. I really look forward to the next get together and hope more will be able to join us.

Cassie Graue

NSW PKU Camp

On the 1st to the 5th of October, 18 PKU children aged 8-16 from Queensland, Melbourne, Canberra and NSW came together for the bi-annual PKU NSW CAMP hosted by the PKU NSW ASSOCIATION.

It was the 5th PKU camp for myself, and 4th at NSW Sport and Recreation Centre in Narrabeen, about 20 minutes out of Sydney. Most campers had been to previous camps so it was great to see our friends from other states. The only new camper being 8 year old Jasmine from Melbourne who fitted in well with the older campers!

We had around 6 supervisors including an ex-policeman who kept us in line and dietician and chef whom were of great use when it came to the catering. The food was great, aimed at the kids living with classic PKU so low protein pizza, pasta, lasagne, French toast, garlic bread and pancakes filled each camper's plates at mealtimes. We discussed low protein fruits and vegetables, made our own bread in groups and were encouraged to fill out diaries each meal time to ensure we were sticking to diet. The menu really broadened my horizons in relation to food choices and from discussion, many other campers agree.

The small group of campers got along really well and the recreational activities were a great opportunity to further



those relationships and take our mind away from PKU. These included Archery, Low Ropes and High Ropes course, Canoeing, Sailing, Swimming, Rock Climbing and Basketball and Soccer. We also had a motivational speaker, paralympian Don Elgin come and speak to us which was very valuable. He had a very relative story to all of us and the moral being to not let PKU get in the way of you doing things as Don didn't let having one leg get him down.

At the conclusion of the camp, I was very hesitant to leave as I knew it was my last due to the next scheduled camp being during VCE. I knew I wouldn't have the opportunity to see my interstate friends for a while and I have been motivated ever since to get a camp up and running in Victoria as it is a great concept. I am currently speaking with committee members to make this plan a reality.

Maddy Craig

Expression of Interest

FAMILY RETREATS

VIC 22 -24th Feb 2013 WA 22 - 24 Mar 2013

Venues to be confirmed (Relaxed style venue ie: camp lodge)

These retreats will provide an invaluable opportunity for people with inborn errors of metabolism and their families to meet in a social environment and build positive relationships with other members of the MDDA community.

The proposed outline will have emphasis on community support, interaction and sharing. The focus is for a relaxed, informal environment where you will make new friends, learn new ways of coping, learn new food ideas and leave with a sense of wellbeing. We would like to offer a range of sessions and breakout groups to build a foundation for your new skills. We invite you to submit ideas of what you would like to see included.

These events will be heavily subsidised by the MDDA. Please register your interest with the National Office on office@mdda.org.au or 1800 288 460

2012 NPKUA Conference in Philadelphia USA

The 2012 NPKUA Conference was held at the Crowne Plaza Hotel in Cherry Hills, New Jersey, USA. 529 people from 8 countries and 32 states of the U.S spent a wonderful time soaking up the excitement. We all enjoyed being able to meet up and exchange stories of our lives, network and make life time friendships.

Kevin Alexander a PKU adult did many interviews with medical professionals, a few PKU adults, and parents at the conference which was really great. The interviews are on www.npkua.org, under patient power videos. I was asked to do an interview which was exciting! I spoke about my history, my parents and being awarded the Order of Australia Medal for services to the health community through the PKU Association of NSW, Inc.

It was so special to see those honoured at the PKU Heroes and PKU Pioneer Award Banquet for the work they do for the health and wellbeing of PKU people worldwide. This year the 2012 PKU Heroes honoured were Virginia Schuett - MS Nutritionist Director., Dr Phyllis B Acosta - MS DrPH RD Nutrition Consultant Inherited Metabolic Disorders and Pediatrics - (Dr Acosta wrote letters to my mother during the early 1960's) Professor Louis Woolf MD (Who has published an article about amino acid formula and low protein diet was the way to treat people with PKU)



A tribute was given by the NPKUA to the late PKU Hero Dr Richard Koch (Dr PKU) with a home video called "Measure Of A Man" so inspirational and moving!

We were really fortunate to have Jean Koch who is so inspiring, as they say "behind every great man there is a great woman" which Jean is! I am thankful to have shared lots of great memories with such wonderful people!

I was lucky to have my great friend Jill travel with me. We had a wonderful time spending the first four days in Dallas, then at the NPKUA conference in New Jersey. We were able to see Philadelphia and enjoyed some lovely home cooked meals with Jennifer Crowe who was on the planning committee of the NPKUA conference.



Jen Crowe took us to by train for our one and a half hour trip to New York, we stayed with a PKU Adult Katie McQuire who showed us New York city & West Point. We took a three and a half hour train trip to Boston to see Cambrooke Foods. Then to LA to stay with Jean Koch and Kathy Moseley and attended the CCPKUAD family day at Huntington Beach California.

We were so fortunate to be invited to spend time with David, Lynn Paoella Blair Robertson and the rest of the team at Cambrooke Foods in Ayre near Boston MA. We had a great time meeting David and Lynn's family, going out on Lynn's boat and having lots of fun!

We had such an amazing time and made many more friends throughout our trip! Thank you so much ASIEM for giving me such a wonderful opportunity to attend the NPKUA conference and the CCPKUAD family day!

My life is so wonderful through the many opportunities I have been able to experience and will keep on experiencing - living with PKU.

Debbie Colyer OAM



NSW PKU Tour of Westmead Research Institute

On 6th August 2012, the Research Institute at the Children's Hospital Westmead opened its doors to the PKU Association of NSW for the 2nd time this year.

The event was hosted by Professor John Christodoulou, who with his research team, have been progressing with their unique research into alternative PKU treatments.

Following an introduction to the Research Institute by Murray Stone groups toured the research laboratory, where an orientation of the scientists work environment was provided, together with demonstrations of the powerful microscope and scanning equipment used by the researchers. Followed by a tour of the mice husbandry facilities where they got to see up close our marvellous PKU mice colony.

Upon completion of the tour, Professor Christodoulou answered questions from the group about what they had seen on the tour. It was at this time we took the opportunity for a retrospective photo opportunity recording the presentation of the \$200,000 research cheque from recent Fundraising efforts.

Andrew McDonald

Vicario Twins — GA1

When I was first told I was pregnant with twins, I was in shock and asked them to do the ultrasound again, when they confirmed I asked for a second opinion, but they were right. Chelsey and Addison were born at 31 weeks, on day 4 they had their Guthrie test which revealed they had a metabolic condition called Glutaric Aciduria Type 1 (GA1). Dr Andrew Martin, paediatrician from Princess Margaret Hospital came in to see me to advise of what they had diagnosed, at the time I just thought it was nothing. Once I recovered from 2 surgeries the doctors and dietician came back to see myself and my husband and gave us the rundown of what GA1 actually was, it shocked us and we didn't really know the full extent of the condition, but it was something we had to start to think about and live with, nothing we could do about it. We were told 1 in 80,000 babies are born with it every year and in 2008 I had 2 of them.

The girls could not eat any protein, so they were to have a monitored low lysine diet. Their bodies could not break down the amino acids Lysine and Tryptophan from the food they

eat. They were to have carnitine 3 times a day to help counteract any protein that their body had produced. Any extra protein in their body could potentially attack their brain and cause damage.

The girls came home after 9 weeks and all was good. They could not fast for more than 4 hours, which was very tiring with 2 of them, but we managed. Their feeds had to be done on time and measured for every feed, they originally came home on infant formula which then changed to a special formula called XLYS Analog and as they got older and started to drink out of a sipper cup they now drink Maxamaid twice a day with their meals, and this gives them all their vitamins and minerals they require to help them grow and develop.

At 6 months old Chelsey became very ill with high temps, but by the time we got her to hospital and she was seen to, Chelsey had a seizure. She had an IV put in and on glucose straight away. After several tests and an MRI, 2 days later, the doctors had told us that Chelsey had several seizures and there was damage to her Basal Ganglia, which affects your



movement and speech, and then the most horrible news ever was that Chelsey had cerebral palsy, it was devastating and broke our heart. The doctors had her on antiseizure medication and several others. We travelled to and from the hospital every day with her twin sister Addison and their older sister Monique, which was very hard for them. Chelsey was then fed by a nasal gastric tube. After 4 weeks Chelsey came home, but still needed to be fed via a NG tube and did so for approx 8 months.

(Continued on page 13)

Check out Vitaflo Australia's new website at:

www.vitaflo.com.au

Features include:

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



Vicario Twins cont.

(Continued from page 12)

Over the course of the year Chelsey spent at least a week in hospital every month, which was very stressful for the whole family and herself as she had to endure IV 's every single time. Not only did we have issues with Chelsey, Addison chose to stop drinking as well which resulted in her having to stay in hospital for a few days to be fed via NG tube.

GA1 is a very nasty and rare condition, if the girls get the flu, any virus, start vomiting, fever or stop eating they can become catabolic and it could then become a metabolic crisis, which we try to avoid, so they are then admitted to hospital and are there for approx 4 days.

Once Chelsey came home we started physiotherapy at PMH, after about 6 months Chelsey started to crawl, a little delayed to Addison, but the best thing to see. The intense physio really helped. Not long after that Chelsey was referred to The Centre for Cerebral palsy, where she continued her physio, then speech therapy and her OT. A couple of days before Christmas in 2010, Chelsey took her first steps and hasn't stopped since she is now walking independently and talking, she has finally reached her milestone and can now keep up with

her sisters, and also has a very positive attitude and is very independent, she wants to do everything herself and is always smiling.

The girl's diet was very hard to manage but as time has gone on it has become alot easier, with alot of help from their dietician. They are now eating alot better and without any dramas, they even tell people that they can't eat meat. They still require medication twice a day for the rest of their lives and will also need to drink their maxamaid.

It has been a very hard 4 years with the twins having GA1 and Chelsey having Cerebral Palsy, but they are a joy to have around and at the end of the day the condition is very manageable. With all the ups and downs we have dealt with we wouldn't have it any other way.

The girls are off to kindy next year and they can't wait. The school is aware of the condition and is fully on board with us, the canteen has even added to their menu to accommodate the twins so they can buy from there. We take day by day and as life comes, they are a joy to our family.

Nat & Jo Vicario



Low Protein Christmas Pudding

Recipe makes 2 ramekins of Low-Protein Christmas Pudding.

Scant 1/2 cup mixed dried fruit
1 Tbsp. brandy
soak fruit in brandy overnight

30g butter, softened
60g light brown sugar
1/4 tsp vanilla extract
1/4 tsp fig jam
1 tsp egg replacer
2 Tbsp water

Cream butter and sugar together. Add vanilla and jam and stir to combine. Combine egg replacer and water, mix together. Add around 2/3rds of egg mix to butter and sugar mixture.

30ml pouring cream (count protein on label)
combine with 30ml Pro Zero milk
1/4 tsp. bicarb soda
1/4 tsp. cidar vinegar

Combine bicarb soda with vinegar and add to milk mixture and combine well.

In another bowl combine
80g low protein baking mix (flour)
1/4 tsp. baking powder
1/4 cup low-protein bread crumbs (freshish)
pinch of salt
1/4 tsp. mixed spice
1/4 tsp. mace

Add to butter-sugar-cream mixture along with fruit. Stir to combine. Pour into 2 greased ramekins lined on bottom with baking paper. Place ramekins in saucepan with egg rings in the bottom (to keep bottom of ramekin from touching bottom of saucepan). Fill with water halfway up sides of ramekins. Simmer 1 – 1 1/2 hours. Freezes well.

Cass Grave

ITEM GRANT

Just a reminder that to remain eligible for this grant you have individual responsibilities such as maintaining your diet as evidenced by regular blood tests and keeping clinic appointments. Failure to comply may mean your access to the grant could be removed. Any questions please contact the Department directly on (02) 6289 8980. Or contact us at the office.

Our PHE-nominal Low Protein Celebration Cook Book



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

MDDA Member Price
Includes postage

\$33

You can order Cookbook from the Office.

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

A Night of Fiesta 2012 WA Gala Ball

It was all happening on the night of Saturday the 27th of November 2012 at the Duxton Hotel in Perth for the third annual fundraising gala ball sponsored and hosted by Rocco and Claudia Mazzone of Cleopatra's Temple Spa and Beauty Centre – "A Night of Fiesta".

It was an explosive night as a Brazilian carnival themed event. It began in true carnival style as the glamorous guests met in the luxurious foyer of the Duxton Hotel for pre-dinner drinks. The champagne was flowing and the room was filled with an air of electricity.

The entertainment began with a parade of Boleza Brazilian drummers weaving in and out of the guests in a congo line beating out some contagious rhythms that made you want to join in. The drummers opened the event by leading the guests up the red carpet in to the grand ball room where we had to pass under a colourful array of balloons formed into a bridge. The ballroom had been transformed into a vibrant fiesta.

Each table was decorated in a manner that was so bright that even though the room was dimly lit you still, almost needed sunglasses. There were instant smiles and laughter as we entered the room and you just knew this was going to be a good night. The drummers continued banging out there funky beats up on the main dance floor while all the guests found their allocated seats and tables.

Once everyone was seated the two main ballroom doors were once again opened and in entered the exotic Sambafusion dancers to introduce the MC, Sharon.

Sharon was fantastic throughout the whole evening, keeping the guests involved with all the different activities and entertainment that was taking place.

There was a silent auction, with many great items donated generously...Just to name a few was a diamond ring from Michael Hill Jewellers, A signed guitar from INXS (framed), Signed and framed records from ACDC and the list goes on. These auction items were sourced by Bernadette Risenborough, who went to a lot of time and effort to do so for such a great cause. Thank you Bernadette.

After all the formalities and housekeeping issues for the evening were explained, I was then introduced as the Official Representative of the MDDA. Upon my introduction, I explained my story on the MDDA and how my 2 ½ daughter Sophia had been diagnosed with PKU. I went on to show an exert of the Kevin Alexander - You Tube video prepared by Monique Cooper- The MDDA President. All I can say is this was amazing. The majority of people in the room, before the night, had no idea about IEM's and Metabolic Disorders. After showing this video clip and explaining my story and what the MDDA is about; there was hardly a dry eye in the room....including mine.

On leaving the stage and walking back to my seat



A Night of Fiesta 2012 cont.

many people stopped me and shook my hand. This, I would have to say, was one of the most touching experiences I have ever been a part of.

After the speech and presentation the nights festivities were then revitalised with dinner beginning as we were entertained by Spanish dancers, Casa Del Compas, and the raffle commencing.

Maria Contera and Dianna Mazzone worked that room tirelessly on the evening selling the tickets. People were literally throwing money at us. The raffle tickets sold out before we could go through the room of over 200 guests. I would like to thank the exceptional efforts of the Contera's and the Mazzone's for being a huge part of co-ordinating the event.

After dinner we were then entertained by Perth's premier band RETRO who really got the party started with a packed dance floor. After their second set there was a balloon drop from the ceiling which concealed some more giveaways and gift vouchers donated to the evenings cause.

I would just like to say the whole night was a complete success and I would like to thank all those who attended and gave so generously to the cause. I would also like to make a special mention to the beautiful Olivia Sanganetti who was the only individual who had an IEM at the ball. Olivia you made such an impression on me and I do hope to see you soon at another MDDA event.



I would also like to thank again the efforts of Rocco and Claudia Mazzone who do this completely from their hearts and again for the efforts of Maria and David Contera and Dianna and Frank Mazzone. The world is defiantly a better place because you guys exist. The enthusiasm from you and your families is astounding.

Paige Moore



David & Maria Contera, Paige Moore, Diana & Frank Mazzone



Product Updates



Streets Paddle Pop Scribbler, Cyclone and Fruit Stack contain 0g Protein

Potato, Beetroot and Cucumber Salad with Dill Dressing

Ingredients

450g waxy potatoes, diced
4 small cooked beetroot, sliced
1/2 small cucumber, sliced thinly
2 large dill pickles, sliced
1 red onion, halved and sliced
Dill sprigs to garnish

Dressing

1 garlic clove, crushed
2 tbsp olive oil
2 tbsp red wine vinegar
2 tbsp chopped fresh dill
Salt and pepper

Method

1. Cook the diced potatoes in a saucepan of boiling water for 15 minutes or until tender. Drain and leave to cool.

2. When cool, mix the potato and beetroot together in a bowl and set aside.
3. Line a salad platter with slices of cucumber, dill pickles and red onion. Spoon the potato and beetroot mixture into the centre of the platter.
4. In a small bowl, whisk all the dressing ingredients together, then pour it over the salad.
5. Serve the salad immediately, garnish with dill sprigs.



Melon & Sweet Chilli Salad

Ingredients

1 small rockmelon
1 small honeydew melon
1/4 watermelon
2 tblsp sweet chilli sauce
1/4 cup white wine vinegar

Method

Remove skin from melons
Cut melons into 2.5cm pieces
Put in a large bowl, and toss to combine.



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