



MDDA NEWS

Newsletter of Metabolic Dietary Disorders Association

Issue 53
2013



Merry Christmas and a Happy New Year!

Our office will close on Friday 20th Dec 2013 and reopen on Monday 13th January 2014.

This month not only do we move head first into our festive silly season, but we look back and reflect on some of our achievements for 2013.

This year our state based retreats have been a great success. I had the personal pleasure of participating in each of these and meeting many families with adults, teens or younger children with IEMs such as MMA, GA1, and PKU. Each retreat provided something new and different and I am truly grateful for the experience and the opportunity (for myself and my family) to have met so many wonderful and inspiring people.

Retreat highlights included...

- Seeing the transformation of individuals and families - as feelings of isolation and uncertainty faded and new friendships and avenues for continued sharing formed.
- Meeting many IEM adults sharing their personal journeys and current determination to manage their diets to optimise what they want to achieve in life.
- MDDA's 'Teen mentoring' and 'Wellness' programs taking shape and making positive differences to individuals and their life journeys.
- Mothers, fathers, adults, partners, maternal women, teens and younger children bonding and enjoying a fun weekend away, forging new friendships and leaving smiling, happy, confident and inspired.

With the support received from both Vitaflor and Nutricia, along with various member fundraising activities, MDDA has been grateful to be able to make attending these retreats affordable to many individuals and families.

Other recent highlights include our annual FNQ clinic, along with other state based 0-5yrs and social gatherings. We are forever grateful to the ongoing support from numerous members involved in the coordination of these activities and next year we hope to run even more across other states and territories.

In 2012 MDDA changed its mission to be three simple things ... Connecting, Enabling and Educating.

MDDA is certainly well on the road to realising this mission. Connecting individuals in the virtual world provides a fantastic opportunity for people of all ages and demographics. We understand face to face gatherings and associated travel logistics are not always an option for everyone. MDDA's private Facebook group has grown to become a positive source of support and information, with over 140 individuals now connecting online regularly. If you have not yet joined, we truly encourage you to do so!

At MDDA's upcoming AGM, we will share further successes of 2013 and outline our plans and ambitions for 2014 and beyond. We welcome and invite all members to participate in the AGM (taking place this year in Melbourne), as it will be a great end of year celebration and social occasion for all. For those that can't attend, we will post all proceedings to our website in the coming weeks.

We have many events and activities planned for 2014 and some of these are highlighted herein. I personally look forward to meeting many more families in 2014 and beyond through our various events and activities planned.

MDDA is blessed to have an active committee of management and volunteer base. I thank everyone that has contributed to the 2013 year to make it an enjoyable and rewarding year for many. Our thoughts and support are with those that have experienced hardship or loss in 2013, and we wish everyone a very Merry Christmas and a happy, safe and prosperous 2014.

Monique
Cooper

2013-2014
President
PKU Mother



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

WA MDDA Retreat



On Friday 22nd March to Sunday 24th March the WA retreat was held in Bindoon at the Orchard Glory Farm Resort. The resort was nestled among fruit trees and a large beautiful lake with some friendly (but rather loud) residing geese. It was the perfect surrounding for a relaxing weekend.

The Friday evening commenced with drinks and nibbles on the lakeside decking and provided an opportunity for everyone to get to know each other. Attendants included parents with PKU and other IEMs and PKU adults. A lovely dinner served in the function hall and the low protein options were very impressive and included roasted vegetables, risotto, chips (got to have chips!) salads, fresh fruit and a beautiful apple crumble served with low pro custard. After dinner the rest of the night was free for the kids to play games and the adults to relax and unwind over a few drinks.

Following Saturday morning breakfast there was an opportunity for kids (and the adults!) to see a sheep shearing demonstration. Some of us even got the opportunity to give shearing a go! After this, the day's program began and whilst the adults got stuck into mindfulness and wellness sessions the children were kept entertained in the kids club with lots of fun activities to do.

At lunch, and once again, the owners of the resort out did themselves by preparing an impressive low pro lunch consisting of garlic bread, pasta with Napolitano sauce, salad and of course we can't forget the chips!

Following lunch Mark Boyce facilitated a session on transition for parents and adults. The session discussed methods for preparing for and coping with the transition of life phases of children or adults living with an IEM. Break away sessions followed with participants attending one of three sessions; it's all

about food, The IEM Maternal Women's Wellness Program or Developing Independence.

Following the focus groups there was a cooking session held by Nutricia and led by Fiona Wedding. Split into several groups, with plenty of fresh ingredients and a recipe on hand, we were given the challenge to prepare a number of low pro meals for the evening's dinner. The challenge was fun, exciting and well...a little bit competitive for some!

Dinner was served and there was an amazing array of low protein food, that even the non PKU amongst us wanted to eat. The evening panned out into a relaxed and entertaining night, sitting outside under the stars amongst the peaceful countryside (well at least it was peaceful when the geese weren't honking and David wasn't responding with his own animal calls!).

On the Sunday it was time to get outside and get some exercise and sunshine. Mark Boyce led the group through a number of games and challenges. Again, the competitiveness was brought out of us all, but the activities certainly got the cogs in the brain moving.

The day concluded with a final thought provoking session which involved bidding for self attributes and circumstances that we wanted in life. We also got the opportunity to tell each other what we got out of the weekend and it was very clear that the retreat provided an excellent opportunity for families to network, make new friends and exchange loads of information with others who could understand what life is like living with an IEM.

A big thank you to the MDDA for holding a fabulous and thoroughly enjoyable weekend!

Maria Contera

WA Members—New Year Celebration

MDDA Committee member Maria Contera is hosting a New Year Celebration. We encourage all WA members to attend and meet with other families. David will have lots of stories and tips from his recent trip to the 2013 ESPKU conference.

When: 23rd February 2014 @ 11.30am

Where: Synergy Park (Sheook Lawn area) in Kings Park

www.bgpa.wa.gov.au/kings-park/maps/synergy-parkland-venues

BYO Picnic

RSVP: Maria—contera.maria@gmail.com
David—dcontera@gmail.com



WA MDDA Retreat—Member Feedback

We had some wonderful responses from members about their WA retreat experience.

Here are a few of them:

"This retreat was a wonderful experience. It was small enough for all participants to get together and bond in a fun, safe environment and network/share experiences. It's also big enough for the interactive sessions to be successful and engaging for all participants, not just those with an IEM. This retreat sums up the phrase "it takes

a village to raise a child" fantastically."

"Excellent, fun filled weekend that also gave us a forum to network with many other families and make new friends"

"It was a wonderful group. To be able to come together, share and support each other"

"It was refreshing to be able to enter into an environment where a discussion about PKU did not have to start at the very beginning. To know there are others out there sharing the same experiences gives you extra strength to tackle the

next challenge and the next.."

"The retreat was fantastic. It provided information for all relevant age groups, i.e. children – teens – adults. This mix of people and information is really important as the parents with teens share their experiences with the parents of PKU children and the PKU adults can share their experiences with the teens. This provides support, encouragement and the space to share feelings and experiences and alleviates the feeling of isolation with the diet."



WA MDDA Retreat—Member Story

I was so excited to have had the opportunity to attend the Orchard Glory Farm Resort organized by the dedicated MDDA committee.

Some of the questions and responses were:

After Periods of not managing the IEM optimally, how do you get back on track?

- Reduce Phe for a Few days
- Increase Calories
- Increase formula
- Order some Low Protein foods
- Reduce temptation and have a home day baking low protein foods so you have them on hand!
- Shock therapy by doing blood test
- Speak to friends particularly PKU ones
- Realize that you are human and had a bad day and tomorrow is a new day!

Managing the IEM what are some of your concerns?

- Losing financial assistance
- Losing PBS benefits for our formulas
- Ageing
- Passing the gene onto our children
- Having enough formula and food supply for days after a natural disaster
- Delivery delays of formula which sometimes occurs.

What gets in the way of managing the IEM?

- Death/tragedy/illness
- Lack of time, overseas holidays/ and travel generally
- Being away from home
- fast food restaurant/ Restaurants/ Take Away places
- Food places not being flexible about our dietary restrictions
- People's state of mind
- Incorrect food labels
- Money

- Sick day management refusing foods
- Stress, peer pressure,
- Desire to be normal,
- Attitude

When diet is optimally managed how does it affect you?

- Mood - stable, happy, content
- Relationship with others - more social,
- Feel like educating others
- Energy levels - alert, focused,
- Increased energy
- Self Esteem - positive,
- Fulfilled, confident, in control,
- Ability to fulfill role in the family,
- clear, minded.

I would personally like to thank all of the MDDA committee, for the opportunity to attend such a wonderful Retreat and to the IEM community in Western Australia and the MDDA for making me feel welcomed!

Debbie Colyer OAM

QLD MDDA Retreat 2013



Our first QLD retreat was held in September 2013 at Mount Tamborine amongst a beautiful rainforest backdrop. The weather, venue and company made for an enjoyable weekend. Over 70 attendees came from Brisbane, Gold Coast, Far North Queensland, New South Wales and Victoria.

Friday night was a casual meet and greet over a BBQ/ Pizza dinner. It was nice to catch up with friends we had met at previous retreats and introduce ourselves to our new members.

The official program began with a round the room introduction of all participants. How amazing and encouraging it was to hear everyone's stories. From our youngest member Willow (11 months) through all ages to our older members Debbie and Jill (age not disclosed!) Each person had their own unique journey however we were all brought together through our IEM. It certainly proved that an IEM was not holding anyone back in that room!

A panel of experts answered our "anything goes" questions. See Louise's "Help from the Experts" article for a full report. Our little treasures were lovingly taken care of by the wonderful child care team which allowed mums and dads to engage themselves into the breakout sessions. Parents were led through "Coping and preparing for the Transitional life phases of our children" with Louise. Adults met with Susi for "Self-Management: Sustaining the effort". Teens chatted with Katrina and Anita, they were then led out onto the high ropes course to test their skills. Aoife spoke with our maternal group where questions on pregnancy, health and wellness were tackled head on. Saturday late afternoon saw a "Master Chef, My Kitchen Rules" challenge. Well, there were some culinary

masterpieces produced! Who knew lettuce tasted good fried, hey Fin. Everyone participated in the activity which attendees mentioned as one of the highlights of the weekend.

Saturday evening was another tasty dinner. Chefs' Brent & Jenny were so accommodating and all the low pro meals cooked over the weekend were great.

Sunday morning began with a "Minute to Win it" game show hosted by Zoe. Zoe split us into groups and set out our challenges. These games used dice, icy pole sticks, plastic plates, blocks, string, skittles, pencils, golf balls, cereal boxes. It was serious business as points were awarded, there would be a winning group. The grand finale was a "Chant Off" of each group. There were cartwheels, high fives, splits and loads of laughter in between the group chant. The 'Teens' brought the house down with their chant and were unanimous winners. This was a fun way to end our weekend with our new friends. The MDDA would like to thank the following people for their voluntary contribution to the weekend:

Carmen Esparon, for participating in the 'Ask the Expert' panel, your honesty and willingness to share was very much appreciated.

Anita Inwood, Aoife Elliot, Katrina Jones thank you for your participation, your sessions were so valuable and we all learnt things we will take with us into managing our lives and those we love with an IEM.

Timothy Buecher who kindly stepped in at short notice to mentor our teens. All of those who know Timothy or met him at the retreat can testify what a wonderful young man and role model he is for all our young ones. We all

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QLD MDDA Retreat 2013 cont



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wish Timothy and Bianca the best for their upcoming wedding. We can't wait to see the photos. The MDDA would like to thank our sponsors for the weekend. Without the assistance from Nutricia and Vitaflo we would struggle to arrange these retreats.

Vitaflo and Robyn Walker thank you for sponsoring members to attend the retreat. The kind donations of Fate products, goodies for the take home bags and your participation were very much appreciated. We all enjoy your warmth and understanding of living with an IEM.

Nutricia, thank you for sponsoring members to attend the

retreat. Your funding enabled teens to attend and enjoy the weekend, many who would have been unable to attend without your assistance. Donations of LoProfin product and items for the take home bags were very much appreciated. Camila Reale and Winnie Woo thank you both for joining in the fun of the weekend, we hope you enjoyed your weekend away.

Thank you to all the attendees, we hope you all made new friends, learnt new ways and skills to manage living life with an IEM.

We hope to see you at the next retreat in Victoria February 2014.

Member Feedback

The QLD retreat was a fantastic experience for our members with some of the comments being:

"I am glad I came as I got to catch up with friends I already know and meet new people. I had a very steep learning curve on what NOT to do with my diet and had lots of support."

"Lovely time away networking with families of similar or alike disorders. A massive thankyou to child minders who took such wonderful care of my daughter so that I could enjoy and appreciate the retreat sessions."

"This retreat provided a great opportunity for all involved to learn more about PKU. Kids were able to bond with each other and learn more about their diet. While adults were

able to consult professionals and PKU adults on issues they may have."

"I had a great time here. I very much enjoyed the activities and discussions. I hope this can be an experience I have again in the near future. It provided everyone with the opportunity to connect with others."

"This was a great opportunity for us as a family and Indi in particular, to meet new friends with shared experiences. This will no doubt be a very looked-forward to, regular get-together, that will help forge a mind-set that an IEM can be a very positive thing. Thanks from the Bruce Family!"

"This was the first retreat we'd brought our girls to and it was fantastic for them to see/meet so many other people with PKU."

"I am inspired by the wonderful people who have lived through the challenges of IEM, also the pioneers especially."

"I love meeting more people, catching up with friends, learning about other people's stories, experiences and history. The retreats really connect people and we are able to make long lasting friends. Thanks so much to the committee of the MDDA for working so hard in putting on such a great event"

"I had a fantastic time at the retreat. It was wonderful to see so many teens, young adults and families. I enjoyed sharing experiences with other people and learning from the information sessions. Thanks so much to the MDDA for putting these camps on for us."



Help From the Experts

At the recent Queensland retreat we were very fortunate to have input from a fantastic panel of experts. Anita Inwood – Metabolic Nurse at Royal Brisbane Children's Hospital, Aoife Elliot – Metabolic Dietician at Mater Hospital Brisbane, Susi Hendricks – psychologist and PKU parent, and Carmen Esparon – adult PKU patient all generously shared their experience and wisdom with us. There were a range of anonymous questions as well as questions from the floor. Here is a sample of them. (Parental guidance recommended).

If I wake up with a hangover and can't stomach my formula is there any magic tricks to help me take it?

Unfortunately no magic tricks but a few good suggestions –

- Drink plenty of water before you go to sleep if you have been drinking – you will definitely feel better in the morning.
- If you can't manage it all at once sip it slowly throughout the day.
- Try lining your stomach with some simple bland food – e.g. a piece of toast before trying to have your formula.

Can I take drugs if I have a metabolic condition?

It was observed that if you are taking drugs then a metabolic disorder is probably the least of your problems. Anyone, with an IEM or not, using drugs is risking their mental, physical and emotional health. They can also damage their future employment opportunities and their chance to travel, as many countries do not grant visas to people who have drug related convictions against them.

Will my metabolic condition stop me from getting any jobs?

The only job you are limited in getting is in the armed forces in Australia. This has been tested going to the highest levels of the Defence Department with the basis of the decision being that most armed personnel are required to carry suitable food to the front line and it would not be possible to cater for such a restrictive diet in combat situations. Other than that making an employment decision on the basis of having an IEM could be

considered discrimination under Australian legislation.

This question generated some general discussion about how and when to tell employers that you have a metabolic condition. Input from a range of participants indicated that most people felt it was best to be upfront with employers and provide basic factual information.

It was great to hear from many adults with an IEM reported that employers had generally been receptive and supportive if they were frank and open.

What happens if an employer won't give me a break to take my formula?

Regular breaks are a legal requirement of employment conditions in Australia. Once you work more than 5 hours in a shift you are entitled to a break. If your shifts are shorter it is a good idea to plan taking your formula around that.

Is it necessary to stick to my diet? I am a teenager now, surely I can relax?

It is necessary to stick with your diet as research shows that not sticking to it can have a range of effects on you – including difficult emotions, poor concentration, ability to succeed at school, uni or work, negative impact on close relationships and feeling unwell. At this time a number of IEM adults in the room who had spent time off diet were able to tell us categorically that they felt healthier, happier and less anxious when they were on their diet. Carmen then shared with us a great story about her journey. She said that one time when she was struggling with her diet and complaining about it her Doctor told her – “PKU is always going to be with you so you can make friends with it or you can fight it all the time.” This was a breakthrough moment for Carmen who said when she accepted PKU managing it got easier and she felt much happier.

Will I have normal relationships like everyone else and be able to get a boyfriend or girlfriend?

(There was plenty of evidence at the retreat that people with IEM's successfully form relationships with three – very cute - babies with IEM

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parents in the room.)

There is no reason why a person with an IEM will not be able to form healthy and happy relationships (although they are likely to be happier if you are on diet – see previous question). The main thing our panelists recommended was being honest with people. In addition women with an IEM who are in a sexual relationship need to ensure that if there is any chance they may become pregnant they discuss this with their health professional to make sure it is well planned. Accidental pregnancies can have serious consequences for the baby if your levels are not right.

After the expert panel responded to this question we heard from a number of adults with IEM who were in relationships about how supportive their partner was of them and their diet. We even had a young, recently engaged couple who both have PKU in the room. We heard plenty of uplifting stories about supportive and caring partners.

This topic seemed to really hit a note with many people and once again a key theme in the responses we heard from people who have an IEM was the value of accepting and embracing your condition. It seemed that the more comfortable and positive about it

you are the easier it is to share it with others with no problems.

I feel like my clinic have 'given up' on me due to compliance issues and I don't get the support I need. What can I do to get the support I need?

The health professionals recommended that the best approach is to show the clinic how serious you are by setting a small and achievable goal and really stick to it. It could be doing your blood spot regularly or drinking your formula everyday but just pick one thing and stick to it. When you have done that go and ask them for support and talk to them about what you need.

It was also noted that retreats like the ones we have had this year and the MDDA can be great sources of support.

It was a great session and very useful for all of us. There was so much great discussion and sharing of experiences in the room. We were very lucky to have our expert panel and also so many people in the group willing to openly share their learning and experience. Thanks to our experts and everyone who participated – hope we can do something similar again soon.

Louise Heally



Transitions: Share your Wisdom

I recently attended the MDDA Queensland Retreat and as anticipated, lots of experiences were shared and information exchanged amongst us - which is what makes these Retreats so fantastic!

As part of setting up our MDDA Wellness Program I facilitated a session with some of the adults with an Inborn Error of Metabolism (IEM) and we discussed the challenges they face managing their daily eating plan and keeping healthy and well.



The topic of how to manage transitions came up – transitions such as moving from high school to university / TAFE / or Work; or from the family home to our own place; travelling overseas; as well as changing from the children's clinic to the adult clinic. All these transitions can impact the ability to maintain our daily eating plan and manage our wellness. Thank you to those who participated! I really benefited from this session and gained some insight as to what some of the challenges can be in managing an IEM as we progress through the life stages. The session provided some more 'Food for Thought' as to how we – the MDDA - can best provide resources for our members.

As we were only a small group at the retreat, I would love to have some feedback from those of you who were not able to attend the session. How does it work in your State / Territory – moving from the children's clinic to the adult clinic? What has made it easy to transition from one stage to another as

you or your child gets older, and what has made it challenging?

Let me know and share your wisdom!! You can either email me at wellness@mdda.org.au, or via the website / Facebook page. Looking forward to hearing from you!! All feedback will be treated in confidence when requested.

Susi Hendricks
MDDA Wellness



Parenting for LongTerm Compliance & Wellbeing



Once I managed to get over the initial shock of Evie's PKU diagnosis and got my head around managing her diet the question that has most played on my mind is; "What can I do now to establish the right mindsets and habits for long term compliance and wellbeing?" By wellbeing I mean she is happy, healthy and well-adjusted to her condition. Over the last few years it is a question I have asked doctors, dieticians, parents, teenagers and adults with a chronic condition.

It has become such a burning question for me that I have decided to complete a research project on it myself. My qualifications are in psychology and my professional role for the last 10 years has been helping business leaders to cultivate the right mindsets in themselves and others for long-term personal, professional and organisational success. Somehow, everything I have done up to now seems to be pointing me in this direction. The Queensland MDDA retreat gave me the perfect chance to get started on my mission to help myself and other parents of children with chronic conditions.

On Saturday afternoon I met with a group of parents and presented what I have found in the research so far and asked for their input, ideas and experience. Here is a short summary of our session:

Key Research Findings

On Kids

- Generally more likely to have a resilient response than a maladjusted response.
- Children with a chronic condition may be more sensitive to parental stress and anxiety.
- Positive self concept in relation to anxiety and belief that they had some control related strongly to adherence to treatment.
- Children who learn about their condition and about self care have better outcomes.

On Parents

- Positive parental adjustment predicts positive child adjustment.
- Parental anxiety is correlated with parental control and this is correlated with child anxiety.
- Anecdotal evidence suggests that a disciplined approach to the diet throughout childhood is a predictor

of compliance in adolescence and adulthood.

On Mums

- Mothers of children with chronic conditions are more likely to experience anxiety and depression (and also more likely to be 'hands on' in the management of the condition)
- Maternal distress is strongly associated with poorer adjustment in the child with chronic conditions.
- Maternal locus of control (i.e. how much control they believe they have) is related to how much control the child believes they have.

On Dads

- When the father is involved in managing a chronic condition in a positive way this has improved outcomes for the child, the father, the mother and the family unit.

What does all this mean for parents of kids with chronic conditions?

I think it potentially means lots of things, however here are the top three things from my perspective:

1. We need to look after our own reactions first.

One thing that strikes me is how, as parents, we often want our kids to demonstrate qualities we are struggling with. (For me it is patience – I often hear myself saying impatiently "Be patient"). I think it might be hard for kids to be resilient, positive and worry free (or patient!) about their condition if we are not. So the first thing I think we need to do to get happy, healthy and well adjusted kids is to work on being happy, healthy and well-adjusted ourselves. One of the best ways I have found to do that is mindfulness. It is a tool that allows you to be aware of thoughts, feelings and reactions and to make a choice about what you do about those thoughts feelings and reactions. A great start in cultivating the right mindsets on our kids is learning to be mindful. It is a skill that can be learned through exercise and practice – the good news is our brains are very responsive to learning through repetition. If you are interested in learning more about mindfulness I will post a blog on my web page with links to resources.

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2. Acceptance is essential.

Stress, anxiety and frustration arise when we fight reality. I think this was one of my first lessons as a PKU parent. I spent so much time focused on things I couldn't control (why her, how she would go at school, what a failure I was if her level was a bit high) and not enough on the things I could do (learn more, focus on the diet right now, enjoy my baby). For me this was disempowering and cultivated anxiety and fear of the future. Fortunately, I had a great friend who reminded me of this, and years of telling other people how to cultivate healthy mindsets, to help me quickly see the fruitlessness of this path. The best way to overcome habits of mind that don't serve you is to catch yourself doing it and quickly focus on something more useful.

3. Cultivate independence within clearly defined boundaries as soon as possible.

An interesting paradox has arisen from the empirical and the anecdotal evidence - it seems parents who are very strict about compliance but who are not anxious and controlling are more likely to have kids who have a healthy and balanced approach to their condition and it's treatment. I spoke to a number of young men and women who have been on diet for life and who have fantastic, positive and healthy attitudes to their condition. Without exception they reported to me how strict their parents had been about their diet but also how much responsibility they had been given for managing it. I feel that the balance between setting strict boundaries and handing over control might be hard to achieve! I think this is an area that needs much more investigation -

which I plan to do. But for now I am engaged in a live experiment of really encouraging Evie (5) to have a bigger role in managing her diet. Since the retreat I have been implementing the following:

- asking her for input on how she would like to allocate her protein allowance for the day (e.g. you have a party today you can eat that now or save some protein allowance for the party - what would you like to do?)
- encouraging her to read the nutritional panel on products I am using to get a sense of how much protein is in what she eats and to give us a chance to discuss the way I manage the diet.
- doing her blood spot test herself (she is very proud of this)

These are ideas that are appropriate for her age, strengths and personality - what are yours? I would love to hear different ways other parents encourage and support their child growing in independence and self management.

I got so much from talking to other parents during the session and went away with plenty of avenues to explore. I hope this is just the start of the journey and invite input from you all. I intend to provide updates as I discover more but would love to hear any ideas or insights. You can get in touch with me at louise@mind-u.com.au, or via my website www.mind-u.com.au or on Facebook.

Thanks to all the wonderful parents who participated and the quite inspirational young people on the retreat who shared their experiences with me.

Louise Healy



THANK YOU!

The QLD retreat held in September was a huge success. Over 70 participants enjoyed a full weekend making new friends, cooking, learning new ways to manage their IEM, sharing experiences and loads more. Thank you to all those who came along and participated. We would like to thank our generous sponsors Vitaflo and Nutricia. They both sponsored many individuals to attend and supplied product which Chefs Brent and Jenny whipped up into a delicious low pro food menu (the mushrooms were amazing!)



"The weekend away with the MDDA was a great time to make new friends and share experiences. The mix of babies, children, young adults and families made for great connections and learning in all stages of living a life with an IEM. Great fun was had by all. Looking forward to the next retreat!"





QLD MDDA Retreat 2013







MDDA VICTORIAN RETREAT

14th — 16th February 2014

Country Place, Kalorama

Located in the beautiful Dandenong Ranges with views over the Silvan Dam, 40 minutes from CBD Melbourne. Visit the website www.countryplace.com.au for details about venue.

Express your interest now!

The retreats are getting better and better! Don't miss OUT! Express your Interest today to attend. Final registration fee will be determined on numbers to be advised soon. The MDDA will be subsidising the event and there will be limited registration and travel funding available to assist selected members.

The MDDA is very excited to offer this family friendly fun weekend, combining a creative blend of education, socialising, cooking and fun activity for everyone.

The Program starts Friday night with a lovely informal dinner and a social meet and greet to all. Saturday will be a jammed packed day with facilitated break out discussion groups and presentations, teen mentoring and wellness program. Saturday evening, a cooking activity and social interaction. Sunday morning will be a fun team activity and wrap up session before we conclude with a nice lunch and farewells to our new friends.

Please contact the National Office on (03) 9723 0600 / 1800 288 460 or email office@mdda.org.au to register your interest. If you have any questions please don't hesitate to contact us, we are happy to assist you!





Join the new PKU Community!

PKU Connect is an exciting new way to connect, learn and share with other people and families living with PKU!

PKU Connect offers:

- News and advice on living with PKU
- A member forum to share and learn from others
- Fun upcoming events in your area
- Lots of easy and delicious low protein recipes, like this great Christmas recipe below

Registration is free, so sign up today! www.pkuconnect.com.au

Low protein Christmas cookies

Ingredients

100g margarine, at room temperature
 50g caster sugar
 160g Loprofin All Purpose Baking Mix*
 15g custard powder
 3-4 tsp Loprofin PKU Drink* or Milupa LP Drink* made up
 Approx. 16 boiled sweets, broken into small pieces

Makes approximately 20 biscuits.

Method

1. Pre-heat oven to 150°C / 300°F / Gas Mark 2
2. Place the margarine and sugar in a mixing bowl and beat well, until light in colour and texture.
3. Stir in the Loprofin All Purpose Baking Mix and custard powder.
4. Using one hand, stir and squeeze the mixture until it comes together, adding sufficient Loprofin PKU Drink to give manageable dough. Transfer to a surface lightly dusted with Loprofin All Purpose Baking Mix and knead the dough for about 30 seconds, until smooth.
5. Roll out the dough to about ½ cm thickness, on a surface lightly dusted with Loprofin All Purpose Baking Mix.
6. Cut out shapes, using a 7.5cm star, heart or tree cutter and using a 3.5cm cutter, cut a smaller star or heart from the centre of each biscuit. Re-roll the trimmings and carry on cutting out the shapes, until all the dough is used.
7. Transfer the biscuits to lightly greased non-stick baking trays and bake in a pre-heated oven for 15 minutes, until pale golden in colour.
8. Remove from the oven and spoon broken boiled sweets into the centre hole of each biscuit, return to the oven for a further 5 minutes.
9. Allow the biscuits to cool slightly on the baking trays, carefully remove from the trays and complete cooling on a wire rack.

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

*The Loprofin range are foods for special medical purposes for the dietary management of inherited metabolic disorders requiring a low protein diet. Always use under healthcare professional supervision.



Far North QLD Clinic Visit



Once again it is my privilege to go on the far north Qld Clinic Run, Ryan once again was my brilliant side kick. We started off with a cooking workshop put on by Nutricia on the Saturday, a great day of cooking, laughter and chatting. Dr McGill and Nurse Anita were there to lend a hand also.

Thank You Fiona our cook and the lovely Nutricia ladies. We really do appreciate you coming up our way and doing your awesome demo's

Ryan stayed home Saturday and mowed the lawn, while his twin Zane his girlfriend Alexis and Ryan's girlfriend Dannielle had a great day cooking, the girls loved the pizza scrolls, don't think the boys got too many.

New PKU bub William and his family where there also, they came in from Julia Creek, we had people from Mackay, Proserpine, Ayr, Townsville, Charters Towers and Cairns....many had travelled over 4 hours to come enjoy a day of cooking and catching up.

A lot of the families went out to tea on Sunday night, reports back that everyone had a fantastic time and learnt heaps. Thanks Amie for organizing the great venue.

Clinic started early Tuesday morning in Townsville. Wednesday Morning we landed in Cairns just after 7.30am to start our day at clinic.

This year I asked everyone the same question.

WHAT DO YOU LIKE ABOUT OUR CLINIC VISIT ? Or is there anything you'd like different

And here is what they said....

Townsville:

Jamie-Leigh Denison (18)

Discussing the diet and ways to improve it

Casey Lucas (18)

Reconnecting with the network and gaining that extra support

Melissa Smith (26)

Melissa is also expecting her first baby....Congrats Melissa. Low Protein cooking class was great, good ideas, discussing pregnancy diet planning... Great ongoing support by Anita and

Dr McGill

Angus Bamford (7)

Discussing ways to expand diet. Discussing positive behaviours

William Acton (4 mths)

Enjoyed chatting to Ryan and talking to other PKU families and knowing there is support out there, as this is all very new to us

Kurtis Sullivan (6)

Kurtis really enjoyed tasting all the new foods. Kurtis loves the new pizza scrolls. We also know Kurtis enjoyed catching up with Ryan. And Ryan is happy he has a new friend

Lucas Johns (4½)

I enjoy clinic

Stephanie Butler (24)

I like coming to clinic so I can talk face to face with people that have the same condition as me. Where I'm from (Ayr) there is no one to talk to, so to see Dr McGill and the others is very educating and exciting.

Mia Loudon (2½)

The things I enjoy at clinic are being around people who understand the situation that our family are going through and can offer advice. It is nice to be in an environment where you don't have to explain yourself, your child or your decisions.

Troy Giles (40)

I love the people, enjoyed the cooking workshop and loved all the food. Troy's mum also bought in a few recipes to share.

Sebastian Robinson (16)

I like being able to see everyone, and find out new stuff...Seb flew into Townsville from Mackay for his appointment on Tuesday.

Lee Mayfield (Adult PKU)

The cooking workshop was good. The opportunity to network with Adult PKU people in Townsville. It was good catching up with Dr McGill and Anita.

Charlie Harrod (5yrs)

Clinic is great for the personal 1 on 1 with the metabolic team. Also being able to talk with families as this is generally the only time families get together and seeing Kim Large, she is an amazing and positive part to clinic.

Arlie McGregor (25)

The Townsville clinic is great. The staff
(Continued on page 15)

(Continued from page 14)

are very helpful with every aspect. Also all the other patients in the waiting room are lovely. It's nice to catch up with other PKU people

CAIRNS:

Viesha (9)

All of the staff are very nice. I would like to talk to other kids my age who have to drink maximum
teenakipp@dodo.com.au

Javan (4)

Meeting others with PKU like me. Seeing Anita and Dr McGill and finding out about new products.

Shari Butler (18)

Catching up with Dr McGill

Amanda (Mum), Ella (1yr) Propionic Acidemia P.A

It's great to have face to face communications and touch base with Ella's specialists. I love the opportunity to show Ella off!

Emily Howard (7)

We love coming to clinic to give Emily and us the chance to catch up and network with other families, such as the Large's and of course to have face to face check-up and conversations with Dr McGill and Anita. It also gives our daughter Emily exposure to the system of clinic and reinforces the importance of her condition and how to manage it.

And very last **Ryan Large (24)**

I enjoy coming to clinic and if Mum and I can help the other families in some small way, that's very rewarding for me, as I know when Zane and I were growing up it was hard finding other families to talk to. And I think mum just loves showing me off to Amanda.

I know we are extremely thankful to have Dr McGill as our doctor and his side kick Nurse Anita.

And that's clinic for another year, A big thank you to all the wonderful families up north.

Kim and Ryan Large



Innovation in Nutrition

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Living a life with rare PKU

A young Wangaratta girl who has lived with a rare disorder since birth has been unable to enjoy the comforts of life, like chocolate. In fact, 12 year old Abby Delaney has Phenylketonuria (PKU) disorder that prevents her from eating nearly all supermarket shelf foods. PKU is a genetic disorder that renders the phenylalanine hydroxylase enzyme non-functional – an enzyme vital to breaking down amino acids in the body.

Abby's on a strict diet, her food can't be bought off the supermarket shelf and needs to be pre-ordered a fortnight in advance from suppliers. At three days old the hospital did a Guthrie test for PKU, a mandatory test for all babies.

When Abby was a week old the Royal Children's Hospital gave her Mum, Renee Meloury, a call, explicitly instructing her to stop breast feeding as a matter of life and death.

Renee was 23 years old at the time with two other children and she spent two weeks in Melbourne learning about PKU.

"Still 12 years later, I'm still learning about it and how to treat the condition." Renee said. "If we don't stick to the diet it causes cognitive problems, learning difficulties and a possibility of mental retardation."

The grocery bills alone are crippling to any family budget. A specially branded loaf of bread costs \$10, a box of cereal costs \$10.50, or a 500g packet of Abby's favourite meal penne pasta sets the family back



\$9.95, making the grocery bill expensive and tough on the family budget.

The pharmaceutical benefits scheme subsidised medical costs which would be \$1000.00 per month without. "If Abby eats the wrong food she gets lethargic and glassy looking if she's had a high hit of protein." Renee said. Due to the PKU's rareness of about one in 15,000 (depending on country of birth), Renee said research in Australia to find a cure is virtually non-existent.

She said more government support and awareness about the disorder is a must to help young people like Abby get through everyday life. But Renee said the number of people who have PKU doesn't seem to warrant the expense.

"In my opinion the health system, isn't that good when it comes to PKU because only 400 people have the condition in Australia." Renee said. "It should fall under funding streams for conditions such as diabetes, because it is similar in terms of dietary intake restrictions."

"More people in the North East of Victoria need to be aware of PKU because as far as we know Abby is the only child in the region with the disorder."

Steve Kelly

Article can be found at wangerattachronicle.com.au/2013/05/24/living-a-life-with-rare-pku



IEM GRANT

Unsure about the IEM food grant protocol's? Contact the MDDA National Office for assistance on (03) 9723 0600 / 1800 288 460 or office@mdda.org.au

Join our Facebook Group!

If you love connecting through Facebook and want to hear other member stories, get advice or just have a chat, join the MDDA Facebook group. Go to www.facebook.com/groups/metabolicdietarydisordersassociation and request an add to the group

Why Justine opts for difficult diet



May is national PKU awareness month and Myrtleford woman Justine Inglis, a sufferer of the rare disorder, is pushing for every parent to test their newborn for the condition. One prick of the heel as a newborn saved Justine Inglis' life. The Myrtleford nurse has phenylketonuria, otherwise known as PKU.

It's a rare disorder that renders the body incapable of breaking down an essential amino acid. Without early detection and treatment in the first weeks of life, it can lead to brain damage and a shortened life span.

Ms Inglis, 42, is keen to see all parents ensure their newborns are tested for the disease, especially where there are home births. PKU is often misunderstood. It's a condition that remains largely unknown despite it being part of mandatory newborn screening.

The small prick of the heel as a newborn might have saved Ms Inglis' life but it hasn't saved her from a lifetime of problems.

There is no cure for PKU and it requires constant monitoring. Sufferers have varying levels of intolerance to the amino acid phenylalanine, found in breast milk and used in the manufacturing of food and drink products.

People like Ms Inglis have to measure how much phenylalanine they eat every day. They must limit it so it doesn't cause neurological complications. But because it helps to form protein, they also can't do without it.

"I need protein just the same as everyone else, just not that much," Ms Inglis said.

Ms Inglis, who works for the Beechworth Health Service, sat in a cafe in Beechworth perusing a copy of a diet plan that takes the fun out of food. Every meal is like a science experiment with food weighed, mixed and supplemented with phenylalanine replacements.

Ms Inglis is doing what those in the know call being "on diet". Years ago, doctors thought PKU sufferers could be taken off the diet that restricts their phenylalanine intake without consequence.

When New Zealand-born Ms Inglis was 14, her doctor told her she could stop with the diet and live normally. The doctor also warned her it might affect her ability to bear children.

"At 14, I wanted to be normal so badly," Ms Inglis said.

"I thought, 'oh well, I just won't have children'".

But at 42 with no children, the meaning of not being able to bear a child is different from being a teenager and just wanting a normal life. Ms Inglis went back on diet nine months ago after she began to notice neurological changes such as memory loss, headaches and mood swings. It's her fourth attempt to go back "on diet".

Not only is good medical support difficult to obtain, fellow PKU sufferers are few and far between. Statistics show one in up to 14,000 Australians have PKU and 25 babies are diagnosed a year.

Ms Inglis met her first fellow sufferer in 2011. Today she speaks to bring solidarity, understanding and awareness, particularly for expectant parents considering home births. She urged them to weigh up the consequences of not having their newborn tested. "Compare brain damage to a pin prick," she said.

Tammy Mills

Article can be found at bordermail.com.au/story/1512623/why-Justine-opts-for-difficult-diet

About the MDDA

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.



www.mdda.org.au





New Arrivals



A beautiful baby girl

Congratulations to Alison, Geoff and Molly on the safe arrival of your adorable daughter and sister Genevieve. We look forward to catching up again with you all soon.



A gorgeous baby boy

Congratulations to Renee and Matt Flood on the arrival of their beautiful son Harrison Thomas Flood born Sunday 16/06/2013 at 12.27am and weighing 6lbs 4oz .

Victoria 0-5yo Get-together for PKU Awareness Day

We would like to send out a big thank you to Wendi Emmerson for organising the 0-5 year old get-together in celebration of PKU Awareness Day .

The get-together was held at Crocs Play Centre at Knox City Shopping Centre on Tuesday 24th July. Mums got together for a relaxing chat , coffee and a bit of story swapping while the kids had a lovely time playing in the specially designed Toddler areas. As pictured below, Harrison and Reef had a fantastic time getting to know each other in the ball pit.



Expression of Interest

MDDA NSW FAMILY RETREAT

3rd — 5th October 2014

Northern beaches location to be confirmed soon (Relaxed style venue ie: camp lodge). It will be held immediately following the NSW teen camp.

This retreat 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.

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

Fit for Genes Awareness Walk

The weather watch began a week out from the event. I asked the weather gods to be kind - and I must have done something to appease them because the weather was superb!

The small but devoted team met at Burleigh Hill on the Gold Coast at 9am. The sea of purple shirts, shorts, hats and capes was notable and the purple balloons and hair extensions for the kiddies was a touch that helped keep them entertained between playgrounds.

Those of you familiar with the pathway between beautiful Burleigh Hill and North Burleigh would know that its one of the most popular Sunday destinations on the Gold Coast with art and craft markets, BBQ spots, kiddies playgrounds and fitness activities running adjacent the beach.

The walk is not a long trek so we decided to spice it up along the way with some games and activities. The popular newspaper relay pinched from Mark Boyces' Melbourne retreat games was up first and helped get some attention from passers by. I was able to explain to some of the mummies with bubs in prams and some grand parents what we were doing and spread the word.

Other activities were "really hard soccer" as Otto called it which saw us crawling around like crabs after a soccer-ball and "minute to win it" activities. Anyone who has seen the minute to win it TV show might be familiar with some of the tasks that we had like the "breakfast scramble game" We cut a cereal box into 16 pieces and had to reassemble in 60 seconds. Its harder than you might think.

The final activity was a sandcastle building competition and the three teams scrambled to build the most impressive construction in a ten minute time bracket. The judging was made by an innocent bystander who named it a dead heat but congratulated us all on our quest to spread the word for Rare Genetic Disorders.

I had bottled water privately labelled for the walk and sold a few along the way to help raise some funds and finished at the surf club for a cool beer and some hot chippies for Cayden!

I would love to make this an annual event as everyone told me they enjoyed the walk so much and suggested next year we make shirts and banners. Sounds like a challenge - who wants to join me???

Zoe Mitter



MOST ADORABLE PHOTOGRAPHS

The MDDA would like to thank the very generous efforts of Most Adorable Photography for arranging a fundraising event for us on their Facebook page. Over \$750 was raised. Thank you to all those who participated in the auction and a HUGE thanks to Brittany for choosing the MDDA as their monthly fundraiser.

You might find some bargains for your little ones, please go to:

<https://www.facebook.com/#!MostAdorablePhotographs>



Product Updates



Notzarella Pizza Cheese contain 2g protein per 100g,



Salt & Vinegar	2.9g per 100g
BBQ	3.3g per 100g
Sour Cream & Chives	3.4g per 100g

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Christmas Pudding

Ingredients

½ cup (125ml) low protein milk substitute
1 teaspoon bicarbonate of soda
1 large over-ripe banana
2 cups (140g) stale low protein breadcrumbs (not dry)
2 cups (380g) mixed dried fruit
½ teaspoon ground ginger
½ teaspoon ground cinnamon



Method

1. Lightly grease a 5-cup (1.25 litre) capacity pudding basin.
2. Combine the milk and soda in a jug. Mash the banana.
3. Combine the breadcrumbs, fruit, spices, milk mixture and banana in a large bowl; mix well.
4. Spoon the mixture into the prepared pudding basin. Cover the top with pleated baking paper and foil; secure with some string or a lid.
5. Place the basin in a large saucepan with enough boiling water to come halfway up the side of the basin. Boil, covered, for 2 hours. Replenish with boiling water as necessary during cooking to maintain the water level.
6. Turn the pudding out and serve warm with sorbet and strawberries, if desired. This recipe can be made a week ahead; keep refrigerated.

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Members who have not received the new inserts (Birthday Parties, Dinner Parties, Finger Foods) please contact the National Office on 1800 288 460

MDDA News

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

Email to: news@mdda.org.au

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