



MDDA NEWS

Newsletter of Metabolic Dietary Disorders Association

Issue 49
2012



www.mdda.org.au

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.

Time to get active

Like most things in this world you need to aim high. Well that is what Dean Tulloch did last year when in June 2011 he ran a gruelling 250km through the Gobi Desert. Well **Dean Tulloch is at it again!** This time Dean is taking on the North Face 100km non-stop race through the Blue Mountains of New South Wales. This Run Deano Run #2 challenge sets the scene for us to launch the Team MDDA with Dean as our Ambassador. So get behind Dean as he undertakes his second Ultra-marathon in order to raise much needed funds for MDDA.

As you have just read we are **Introducing Team MDDA**. This brand new initiative is about giving it a go—one challenge at a time. We are encouraging all members to get involved with this exciting addition to the MDDA community. It is expected to generate some inspirational stories, entertainment and fun for us all. Expect to hear a lot more about Team MDDA as the year progresses. We encourage you all to consider how you might want to get involved. Whether it be as an individual, a family or a whole community, there is an Team MDDA Challenge for everyone.

Talking about challenges its always good to see our various members getting active. This edition includes stories of **Nat & Brooke Hellings** with their dancing and sports aerobics, **Connor @ Karate** and a great article on **Health and Fitness for Life**. We would like to congratulate our members on their achievements.

Dealing with Pregnancy and PKU or any IEM for that matter can be extremely challenging task to take on. The article **Maternal PKU: I'm pregnant! What happens next?** discusses the various phases of pregnancy and helpful tips and coping strategies to help maternal women cope

better and allow them to have a safe and well managed pregnancy. We also have a **NSW Adult Clinic Update**.

The story of **Reef Emmerson - the First Year** attempts to give you an insight of what parents face when first exposed with a child with an Inborn Error of Metabolism.

Any newsletter isn't complete without the usual **Product Updates** and a recipe. This month, Nutrica have included the **Vanilla layered CupCakes** which was the winning recipe from the MasterChef challenge from last years Conference. They were just about as good as the chocolate bunnies from the **Easter in Vic 2012** picnic.

For all our members its time to get active. The MDDA Executive have been busy with it's weekend planning sessions and have set a program of exciting state-based events and fundraisers. Do your part and get involved with Team MDDA—The challenge is yours. Your time....starts.....NOW!

Monique Cooper
MDDA President

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

Donations over \$2.00
are Tax Deductable

Nutricia, MDDA and Masterchef

Last year, Nutricia partnered with the MDDA to host the very first Masterchef Challenge during the MDDA Conference on the Gold Coast! Having held successful Nutricia Cooking Workshops around the country for many years, Nutricia wished to continue to offer members the opportunity to increase their cooking skills whilst spicing things up to get some creative juices flowing!

The idea of the Masterchef Challenge was based on the combined popularity of the Nutricia Workshops and the multitude of reality cooking shows currently on television. However this time, all the recipes had to be low protein! Conference participants enrolled on a "first come first serve" basis, and in fact, the event was so popular, there was a waiting list full of eager, budding cooks hoping to get the chance to show off their skills!

The challenge itself consisted of two teams, each with 8 participants, competing against each other to win the ultimate prize of best recipe. Each team of 8 was then divided into pairs and asked to nominate a captain to oversee the cooking and proceedings. Each pair was given a standard recipe using Loprofin Baking Mix or Loprofin Rice and asked to think outside the box and come up with a sweet or savoury option that was creative, innovative and most importantly, great tasting.

Nutricia's Home Economist, Fiona Wedding was there to lead the event and the final products were judged by an independent panel of tasters. The results were amazing! There were so many talented low protein cooks. It was such a fun day and so many people said it was the highlight of the conference!

Nutricia would like to thank all participants for their enthusiasm and support – we are so happy we got the chance to be involved in such a fun and energetic event!

For more information and to see these great recipes please visit

www.nutrition4me.com.au and register.



Winning recipe!

Vanilla layered cupcakes

with custard & strawberry jam

100g margarine *
100g caster sugar
1 tspn vanilla essence
1 tspn egg white replacer *
1 tbls water
2 cups Loprofin baking mix
3 tspn baking powder
200 ml Milupa lp drink



Winning cupcakes are the four in the middle!

Method

1. Preheat oven to 180°C.
2. Cream margarine and caster sugar.
3. Add the vanilla essence, egg white replacer and water. Mix well.
4. Combine the Loprofin baking mix and baking powder.
5. With a wooden spoon add the baking mix and Milupa lp drink alternatively and mix until combined.
6. Spoon cake mixture into cupcake paper cases and cook for 12 minutes or until cooked. Cool on a wire rack.
7. After cooling cut a hollow from the centre of the cupcake (without cutting through to the bottom). Add a dollop of thick custard (refer to custard recipe included) followed by a teaspoon of strawberry jam. Place the cupcake "lid" back on and dust with icing sugar.

Custard

2 tbsp custard powder *
1 tbsp caster sugar
400 ml Milupa lp drink
Vanilla essence to taste

Method

1. Place the custard powder and caster sugar in a saucepan.
2. Slowly stir in sufficient Milupa lp drink to make a paste. Continue adding the Milupa lp drink and stir until the dry ingredients are dissolved.
3. Heat gently over low heat and stir continuously until the custard thickens and boils.
4. Add the vanilla essence to taste.

*Calculate as guided by your dietician.



Delicious sweet pastry invention!



A pair of smiling, budding chefs!



www2.thenorthface.com.au/100/

Run Deano Run

www.rundeanoorun.com

Dean Tulloch is at it again!

Having in June 2011 ran a gruelling 250km through the Gobi Desert in China to raise awareness for MDDA and the many rare diseases it supports. Dean is about to embark on his second big Team MDDA RunDeanoRun challenge.

Although Dean works full time, has a wife and three young children of his own he puts himself through these challenges in the name of his little mate Charlie. Charlie was born in Melbourne on 11th February 2010 with PKU to his best mates Dean and Monique!

On 19th May 2012 Dean runs the North Face 100 in the magnificent Blue Mountains of New South Wales. The 100km race runs non-stop through some of the most spectacular scenery in Australia.

MDDA would like to thank Dean for putting himself through these challenges. We are also very grateful to have Dean Tulloch on board as our Team MDDA ambassador.

Introducing Team MDDA

Team MDDA is an initiative that provides the opportunity for all MDDA members, families, colleagues and friends ... and anyone else ... to get behind supporting the 883 currently known individuals in Australia diagnosed with an Inborn Error of Metabolism.



You too can be part of Team MDDA. You are invited to take on a challenge that might consist of a fun run, walkathon, triathlon, city to sea, golfing/

tennis tournament or any other activity that requires a bit of stamina and endurance to complete (not necessarily limited to sporting events either). Whatever it might be, we are happy to get behind you and support you - no feat will be considered too small for Team MDDA.

If you want more information on Team MDDA or are interested in signing up for your own challenge, please contact teammdda@mdda.org.au or visit www.mdda.org.au and we can get you on board straight away with your very own Team MDDA Welcome Kit to get you started.

What can I do?

You are encouraged to join Team MDDA by taking on a challenge of your own! You can also assist the MDDA by contributing - either a once-off or a ongoing donation. Donations can be made online via GiveNow.com.au/mdda or by contacting our office on 1800 288 460.



the north face 100

Australia's premier Ultra Marathon trial running event - a 100km race non-stop through the World Heritage listed Blue Mountain National Park.

Stage 1 - Fairmont Resort to Narrow Neck. Includes stunning views, rainforest and waterfalls - 18km.

Stage 2 - Narrow Neck to Dumphys Camp. Includes The views, the tarros ladders and the trails through the open forest - 20km

Stage 3 - Dunphys Camp - Six Foot Track. Includes Ironpot Ridge, stunning checkpoint - 16km

Stage 4 - Six Foot Track - Katoomba Aquatic Centre. Including The Six Foot Track stairs - 11km

Stage 5 - Katoomba Aquatic Centre - Queen Victoria Hospital. Including Clifftop walk to Echo Point. Giant stairway, Dardanelles Pass - 24km

Stage 6 - Queen Victoria Hospital - Fairmont Resort. Including Wentworth Falls, the bbq, the warm blanket anda beer - 11km

All up 100km non-stop race!

NSW Adult Clinic Update

The adult metabolic disorders clinic at Westmead hospital has now been up and running in its new form for 12 months and we have made a good start to providing a clinical service to adults with PKU across NSW. We run weekly clinics at Westmead hospital every Thursday morning, as well as clinics five times a year in the Hunter and monthly on the fourth Friday at Prince of Wales hospital in Randwick.

Currently we know of 209 adults in NSW with PKU, although there are sure to be more people out there who have "dropped off the radar". We have seen 107 of these in 2011 and a further 59 have been seen in previous years. We would like to see everybody that has PKU in NSW, although not everyone will need to be seen every year.

There are a number of important reasons to touch base with the clinic periodically – getting help with diet ideas, trying to lower your Phenylalanine levels is easier with help and having lower levels means better concentration and less anxiety, eating a low protein diet without taking enough supplements is risky for your health, and lastly getting the financial assistance program from the government relies on being seen by a registered clinic like ours.

So I would encourage all the adults out there with PKU to come and see us at one of our clinics; we like to see you and help where we are able. We can be contacted for an appointment on (02) 98450780.

Dr Michel Tchan
Staff Specialist, Genetic
Medicine, Westmead Hospital

Maternal PKU: I'm pregnant! What happens next? (Part 2)

Planned Pregnancies

On discovering pregnancy contact your metabolic team as soon as possible. They will usually request that you send bloods at least weekly for Phe & Tyrosine monitoring. It is important to be readily contactable by phone for results and discussion about changes in diet.

Unplanned Pregnancies

Over 50% of all pregnancies in the general population are unplanned! While this may not be the ideal situation for maternal PKU it is important on discovering the pregnancy that you contact the metabolic unit immediately- every day counts. You will be asked to do a blood as soon as possible and if the Phe levels are raised it will be treated as a medical emergency. An appointment will be arranged to come to clinic. Management at this time requires close blood monitoring. If control remains poor an admission to the local maternity hospital may be recommended.

What can I expect in the First Trimester (1-12 Weeks)?

During the first trimester your Phe exchanges are usually low and increase fairly slowly over the first 12 weeks. It is a critical period for baby's organs, including its heart to form. Many women experience a temporary spike in levels somewhere between 6-10 weeks. This is usually short term and may be due to a number of reasons. Management of morning sickness and ensuring an adequate calorie intake to avoid losing weight is important at this stage.

"Levels can spike at times but as long as they are bought under control quickly all is okay."

How much weight should I gain for a healthy pregnancy?

Monitoring your weight throughout pregnancy is important for your health and your baby's health. Women who gain too much weight during pregnancy are more likely to have longer hospital stays, caesarean sections, high blood pressure and diabetes. Women tend to gain 1-2kg only during the 1st trimester. The recommended amount of weight gain during pregnancy depends on what your weight is before you become pregnant. Your dietitian can calculate your body mass index (BMI) and this is used to calculate your recommended amount of weight gain over the course of your pregnancy. If your BMI is within the healthy weight range you should expect to gain 11.5-16kg during pregnancy.

What about exercise?

Moderate intensity exercise of approximately 30 minutes per day is encouraged during pregnancy. Examples include low impact aerobics, walking, swimming, yoga and Pilates.

"Get into a life routine.....learn to eat at the same times, sleep at same times, exercise and take bloods etc. at the same times of each day of each week. This will help in being more organised and life will flow more steadily and will be easier to manage."

Morning Sickness- what can I do to help manage it?

Morning sickness can occur at any time of the day. Symptoms usually disappear or become milder by 16 weeks. Try to identify your triggers and the time of the day it most affects you. Try small regular carbohydrate snacks, e.g., dry LP toast, crackers, cereal, fruit especially before getting out of bed. Avoid large heavy meals- try 6 small meals instead of 3 larger meals (an empty stomach can cause nausea). Continue to consume all your prescribed Phe exchanges and synthetic protein substitute. Very occasionally a hospital admission may be recommended for severe morning sickness when levels are not able to be controlled.

Second Trimester (13-26 weeks)

During the second trimester your baby is developing and growing rapidly. Your Phe requirements will increase gradually over this trimester. You may require higher exchange foods to meet your daily requirements. Try swapping higher protein foods for their lower protein equivalents to avoid adding too many extra calories. Useful foods to consider including in the diet as part of your Phe exchanges are measured amounts of low fat cheese, yoghurt, milk, regular bread crackers, pasta and legumes. Carefully weighed amounts of lean meat may also be used -discuss with your dietitian. Remember these foods will not be part of your diet after delivery! Additional tyrosine may also be required during this trimester. It is usually taken as a powdered supplement which can be added to your formula taken over the day.

"Your diet may change quite significantly as your pregnancy continues with an increase in protein exchanges. For those of us who have always been on the diet this can be a bit daunting and after so long being so careful about finding Low pro foods, you'll suddenly find yourself at the supermarket looking for yoghurts and real milk!!!"

(Continued on page 5)

Third Trimester (27-42 Weeks)

Time to start getting organised for baby's arrival! Ensure you have a full order of low protein foods to have available at home for when you return from hospital. Consider having a make and bake day to help fill your freezer. Pack your synthetic protein substitute, tyrosine and favourite LP foods in your hospital bag. You may also need to organise your inpatient LP menu with your dietitian in advance.

What can I expect after my Baby is born?

As soon as your baby is born it's time to return to your usual pre-pregnancy Phe exchanges. Continue to take your synthetic protein substitute. Decrease or discontinue any additional tyrosine you were prescribed during pregnancy as per your metabolic team. It is important to continue to check Phe and Tyrosine levels regularly. Good metabolic control may help to reduce risk of postnatal depression and may assist in coping with your new baby.

Can I breastfeed?

Yes! Breast feeding is encouraged! You do not need to wait until the results of the newborn screening test are known. Phe requirements increase to produce breast milk so you may be allowed more Phe exchanges. While breastfeeding you will have increased fluid requirements (2.6-3.5 litres/day) and increased nutrient requirements including vitamins A, C, many B vitamins, zinc, copper, selenium and iodine therefore it's important to take your full amount of synthetic protein substitute.

"Breastfeeding is not an issue with those with maternal PKU and is also a way to help shed kilos early on. At the Mater, on about Day 2 they did the newborn screening, the test for PKU and a number of other things, and this was rushed through so that we knew straight away whether my son had PKU. He doesn't. The likelihood was pretty low."

Will my baby have PKU?

In most cases of maternal PKU your baby will not have PKU. A baby can only have PKU if both the Mum and Dad carry the specific gene for PKU. Genes contain the instructions for making proteins that our bodies need to perform their daily functions. If you have PKU you will always pass on one non-working gene for PKU to your baby. A person with 1 non-working gene is called a "Carrier for PKU". Carriers of PKU are healthy and do not have PKU. If Dad does not have PKU and is not a carrier, none of your children will have PKU but they will all be carriers.

If Dad is a carrier of PKU then there is a 50% chance for each child you have together will have PKU. If Dad has PKU and you have PKU then all of your children will have PKU.

Checklist for Planning a Pregnancy when you have PKU

- Get organised!
- Arrange a metabolic clinic visit
- Take the full prescribed quantity of synthetic protein formula
- Stick to the prescribed number of Phe exchanges
- Send weekly bloods
- Ensure you and your partner are well informed
- You may require extra bloods taken at clinic
- Ensure Phe levels are approximately 60 – 250 μ mol/L before conception-goal levels may vary slightly between Metabolic Clinics
- Contact your local Metabolic Clinic on confirmation of pregnancy
- Minimum weekly bloods during pregnancy
- Keep active aim for 30 minutes per day
- Spread your exchanges and formula out evenly over the day
- Take adequate calories (but not too many- avoid 'eating for two'!)
- Take tyrosine as prescribed
- When your baby is born return to your pre-pregnancy exchanges & reduce/stop tyrosine- as per advice from your metabolic team
- Minimum recommended 2 – 3 clinic visits during pregnancy

"It's probably a given but It's worth all the work in the end!!"

The emphasis on being organised and pre-planning everything, having confidence in yourself was important for me, we were lucky to have great professionals around me throughout the whole journey – trusting in them (mostly You) is what got me through!!

Aoife Elliott
Dietitian Team Leader
Paediatrics & Neonatology
Mater Health Services
Mater Children's Hospital.
South Brisbane

You will find Part 1—**Maternal PKU: Planning for Pregnancy** in our last newsletter—Issue 48.

Christmas in July Bazaar @ QT Gold Coast

Get festive and help us raise funds for the MDDA.

Live Performances from
Australia Idol Finalist "Casey Barnes" / Nu Jazz Flamenco duo "Deep Dreamer"

Saturday
21st July 2012 12 noon

\$90 per person or
\$80 per person for a table of 10 or more

For bookings call Zoe on
0423 237 376



USA Conference

Learn about new advances in research, treatments, and management that improve the lives of children and adults with Urea Cycle Disorders.

www.nucdf.org/events.htm

----- IEM 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.



Nat & Brooke Hellings

I would like to reintroduce Nat and Brooke Hellings who are 9 year old twins with PKU.

They love to play basketball having just been selected for a rep team. However their other passion is dancing and sports aerobics. They have represented their school throughout the year having come 2nd in the Australian National competition. Their dance routine was even up against some 11- 12 year olds.

We are very proud parents and it so rewarding to see the girls grow up and achieve so many challenges. In the last year they have been doing really well with managing their dietary requirements, their new PKU cooler formula, fitness and health. They are happy go lucky little girls not really knowing what they have already achieved for their age.

Its amazing how hungry they get with all their exercise. They often enjoy a free snack of toast with jam, a shaker cream on it or their loprofin square biscuits with jam. They enjoy a light snack of pasta with mushrooms, grated carrots with free pasta tomato sauce. They also have weighed rice, broccoli along with other free vegies and for dessert they enjoy ice-cream which of course is weighed.

Sonia Hellings

Member Stories

Reef Emmerson - The First Year

Reef had a 'Tropical Reef Pool Party' for his 1st birthday, and what an awesome time he had! The 1 year mark has been an emotional time for me – more so than I expected. I have spent much time reflecting on his first weeks – the call from the Royal Children's Hospital asking us to take Reef in the next morning for some testing. I was slightly concerned, but honestly thought he would have another test, it would be clear, and that would be the end of it. Boy was I wrong! We took the PKU diagnosis as all do really, shocked and upset, but got on with it and coped reasonably well – we had extra bottles to make up, but no big deal.

At the introduction of solids is when we began to realise the work involved, but of course for our little Reef to be well we would do anything! Along with a stubborn little eater we struggled for many months to get his PKU Gel in, his food intake up and his weight in a healthy range, but finally at 1 year we are going well – Reef is finally



eating lumpy vegetables and pasta bakes and drinking his Anamix Jnr like a champion!

I still get stuck every few weeks for recipe ideas that Reef will enjoy and be able to eat without a mouthful of teeth yet, which gets me down at



times, but I am trying to work on my attitudes towards PKU as Reef enters into an age where he wants to eat what others are eating, and will soon be wondering why his foods are sometimes different.

It has been a huge year of learning – we feel like scientists when explaining PKU to others, and the best part being that we have made life-long friends, and lots of play -friends for Reef with whom he can share his PKU journey forever".

I chickened out on making a birthday cake, and actually ordered an ice-cream cake from Cold Rock – they do 3 layers of ice-cream, and I actually got 1 layer of sorbet which was classed as free. The ice-cream was 0.5gm p for a 25gm scoop which is plenty for Reef anyway!

Wendi Emmerson

We will feature Reef's Second Year in the next newsletter.

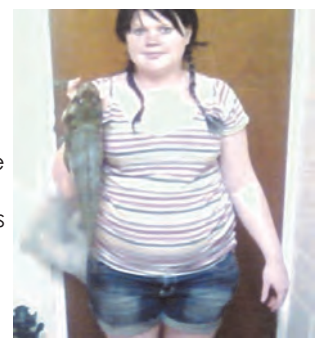
Health and Fitness for Life

On the 3rd October 1988 I Stephanie Butler was born, three days later my parents and I were sent to Brisbane Royal Children's Hospital. When we arrived my parents were told that I was diagnosed with phenylketonuria (PKU).

I first met metabolic specialist, Dr Jim McGill at the annual Special Children's Christmas Party when I was one. In 2009 I was contacted by Dr McGill he told me it was urgent that I see him for an appointment about my PKU as I had not seen anyone since I was 14 years old, so I arranged to fly to Brisbane. I was a bit nervous about seeing him as I had not been on diet for three years and I was scared about what he would say. When I arrived at my appointment with Dr McGill he asked me what I had been eating, I told him that I had gone off diet when I moved out of home and that I was eating anything that I could afford. He was not surprised at all as he told me how nearly all his PKU patients

had gone off their diets. He explained that he was tracking us all down to check if we were eating right or not and to get us back on track.

While I was there I had a blood test to find out how high my protein levels were. When my results came back they showed that my levels were at 1700, a healthy PKU adult's protein levels should sit around 200-250. Dr McGill explained to me why I had been experiencing certain mood swings such as frustration, impatience, tiredness and forgetfulness, he said that they are all symptoms of high protein levels in PKU adults.



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(Continued from page 6)

Dr McGill had arranged an appointment for me to see a dietician. When I was talking to her she told me that if I ever wanted to have children I would have to get my protein levels down to 200 and keep them there for 6-12 months before conceiving. We talked about what food I would have to immediately cut out of my diet. They included; meat of any kind, nuts, eggs, dairy and soy foods. I am only allowed to eat low protein pasta, rice, biscuits and cereal. When it comes to fruit and vegetables I can only eat one serve of potato, corn, banana and avocado per day. I also can only have 3 grams of protein per meal and I have to have 3 of my formulas per day. I then told her that I wanted to lose weight as I weighed 85 kilograms; she told me to first focus on eating correctly then try to lose weight. She told me that as a PKU adult it will be hard for me to lose weight and not to expect to lose more than half a kilogram a month. Just before I left she told me that I had to send them weekly blood tests so my levels could be monitored. After getting home and putting all this into practice, I found the initial stage the most difficult.



In July 2010 I started working at the Burdekin Centre for Rural Health (BCRH) as a Business Administration Trainee, there I met Luis Bello the Senior Fitness Trainer for Burdekin Community Rehabilitation (Rehab) Centre. While working with him he told me about his own

health and fitness personal training business called New Directions which he runs after hours, and how many of his clients had lost weight. I was very intrigued about what he said so I decided to ask him if he could help me lose weight. I told him about my PKU and he was excited about helping me.

Over the next few weeks Luis and I researched everything about my condition, I even gave him my PKU hand book to read. In September 2010 Luis suggested that I join the Rehab Centre to start mild progress exercises while he did more in-depth research on what sort of training I could undergo. When I started Rehab training Luis wrote a mild exercise program for me to see what my strengths and weakness' were. I went to Rehab training Tuesday and Thursday mornings at 7:00 am for an hour before work. My exercise program at the Rehab Centre included weights, squats, sit ups, dips, exercise with therabands and exercising on machines.

Although difficult in the beginning I soon started to feel fitter.

December 2010 I started circuit training two days a week with Luis through New Directions it was harder than Rehab but I did get used to it. One night after training Luis and I sat down at his house to make a start on my food plan. The first thing we did was go through a nutrition book that he owned. We worked out how much protein was in the food and how much per serve I could eat. I wrote it all down in an exercise book so I could refer back to it when working out my food plan. The next step was to work out how much protein I was allowed to eat per day and how many formulas I needed to take. We then split my meals into six meals a day only eating 3 grams of protein and 63 grams of my formula per meal, adding up to a total of 18 grams of protein and 375 grams of formula a day. Next I had to create a three day meal plan, writing out in detail for all six meals for each day including the quantity and protein in grams in each meal. Then adding up the total protein and adding the formula which contains 10 grams of protein substitute. Once the three day meal plan was completed I then put it into practice by starting my food plan on Monday then repeating it on Thursday, Sunday being a more relaxed day not so strict. Monday – Saturday all food was to be weighed correctly and all formulas to be taken.

After 3 months was when I really started to lose weight thanks to my food plan combined with training five days a week. I concentrated my training plan between Monday to Friday, with circuit training Monday, Wednesday and Friday nights and training at the Rehab Centre on Tuesday and Thursday mornings.

When I started I weighed 84.9 kilograms, I lost five kilograms in five weeks that was an average weight loss of 1 kilogram per week and I have lost a total of 9.5% of my body fat. I now weigh 74.8 kilograms and I have cut back to four days of training a week. I still keep up with my food plan. Due to all this success I have managed to bring my protein levels down from 1700 to 740. So even though my dietician and Dr McGill didn't want me to get my hopes up as they knew that it is very hard to lose weight with PKU, I have shown others that it is not impossible. I hope that I have inspired other PKU patients out there to get healthy, fit and lose weight.

Stephanie Butler
North Queensland



Connor @ Karate

Connor McSwiney is 8 years old and has PKU. Connor successfully obtained his black belt as a Thunderbolt at Kimekai Karate June last year. He started at Kimekai when he was 5 years old and attended his classes anywhere from 2-4 times a week during that time.

Our decision for starting Connor in Karate was not only for fitness and co-ordination but to help improve his confidence, self discipline and concentration. It has certainly done that as it took close to 3 years and at times difficult to keep up the enthusiasm. The instructors at Kimekai always detected when Connor and other kids were losing interest and would work on their motivation by making the classes rewarding and fun.

We sincerely hope Connor continues on to achieve his next level black belt. It will take some time, but the outcome is one that is positive and confidence building and will give Connor the skills to help him reach his full potential in life.

Robyn McSwiney

Feedback!

Do you like the changes to the newsletter? Let us know by sending us an email to news@mdda.org.au

Easter in Vic 2012

Our casual picnic was held at Norton Park, Wantirna South—a great park with wide open spaces to kick the footy and paths for the kids to ride scooters and bikes. We had a great turnout of around 30 people with a lot of new members, family and friends. It was quite amazing to see the effort and diversity in the low protein dishes. A quite impressive creation of a lo-pro jam doughnuts were a big hit with the kids. There were some delicious fruit platters and savoury dishes as well. Our raffle raised \$50 for the MDDA. Thank you for your

contributions. A special thanks to Vitaflo for supplying us with the Chocolate Easter Bunnies.

It was great to see everyone celebrating Easter together, sharing recipes and tips about cooking meals and basic diet management. Having brought my mum and aunt to the picnic they were amazed at the different snacks and dishes that people

had come up with. It was great for them to meet other families who are effected by an IEM. It is not just immediate family but extended family and friends that can feel the pressures of a metabolic disorder. My mother, who is a grandmother of a PKU child (Sophia) got to meet and share their experiences with other grandparents. It is this type of interaction that really does become invaluable.

The great thing about these get togethers is you don't have to explain the disorder to everyone as you are catching up with people already understand and share similar emotions, feelings and experiences. I would like to thank everyone who came along and we hope to see you all at our next get together. I hope everyone had a Happy Easter and the Easter Bunny was kind to you all.

Paige Moore



Product Updates



Orgran Original Crimpers
3.6gm protein per 100gm



Leda Choc Chip Cookies
3.7gm protein per 100gm



Healthieries Wiggles
Bickies (Honey)
6.8gm protein per 100gm



Orgran Salt & Vinegar Crimpers
3.6gm protein per 100gm



Leda Golden Crunch Cookies
4.2gm protein per 100gm



Healthieries Wiggles
Fruit Bars (Apple)
3.7gm protein per 100gm



Orgran Choc Pockets
4.6gm protein per 100gm



Leda Dunk-ins
5.6gm protein per 100gm



Healthieries Kids Care
(Potato Stix Chicken)
4.7gm protein per 100gm

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MDDA News

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

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