



MDDA NEWS

Newsletter of Metabolic Dietary Disorders Association

Issue 61



Educating and getting active - all in the name of IEMS!

Spring is here and time to get out of your winter clothes, enjoy the sunshine and get active! Talking about getting active, in this edition you can read about our member **Philip Acton** and how he and his family took on a challenge of a life time and organised a fundraising bike ride and spread awareness for all IEM's across Queensland. It was an amazing effort that raised much needed funds for the MDDA to continue to develop and run our programs for all members. We have been overwhelmed by the show of encouragement from supporters, friends, families, MDDA members and strangers, all who have given so generously. **The MDDA are so grateful to Philip, Sarah and their gorgeous boys for their generosity and spirit in wanting to make a difference and support all those living with an IEM.** You can read about Philip's journey and see the photos captured inside.

Some of our adult members have also been challenging themselves with the new MDDA pilot initiative 'Wellness Program' launched last month. With

Fitbits on and goals set we have twelve adults striving to achieve 'Being your best You'. So far the feedback has been great!

The MDDA Family Retreat in NSW at the Sydney Conference & Training Centre, Ingleside, is most likely underway as you read this newsletter. This will be our 9th family retreat held and is shaping up to be one of the best yet! The program is jam packed with educational and fun sessions. The retreat will kick off this year with a festive like environment on the Friday night as a casual means of meeting and greeting all attendees. We have also been able to provide an active kids program and think we may find a few adult *kids* joining in! A full run down and photos of the retreat will be in the next newsletter.

Thank you to the Chinnery family and Jill Butler for sharing their stories with us and our newsletter isn't complete without the usual product updates and recipes. You will find low protein recipes for all the family to enjoy!

Planning for our end of year

celebrations and catch-ups have begun. NSW and QLD already have their dates locked in, you can find details in the newsletter. If you would like to organise an event in your state contact the office for assistance.

Get moving and get active!

this issue

Wellness Program	P.2
HGSA 40th Annual Scientific Meeting	P.2
Genetic Disorders Awareness Launch	P.2
Low Protein Cook@home Masterclass	P.2
The Chinnery's - Living with GA1	P.3
North Queensland Clinic 2016	P.4
IEM Adult News - Jill's story	P.5
The Children's Hospital Westmead	P.6
Ride with the Acton's	P.7
Spring Recipes	P.10
PKUNSW Updates	P.11
Product updates	P.12

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

Wellness Program - "Being your best You"



In line with the MDDA's goal of achieving positive health outcomes for individuals living with an IEM we are excited to have launched our Pilot Wellness Program tailored to adults living with an IEM. The Pilot Program was limited to 12 participants and we received a great response. The cost of the Pilot Program is funded by the MDDA, and the price of the Fitbits was subsidised.

Facilitated by Susi Hendricks, (Psychologist & mother of teen with PKU), the 8 week e-coaching program is designed to help achieve your plan for wellness. The aim is to educate, encourage and guide your ability to improve your vibrancy and energy. Based on the scientific principles of Positive Psychology, and using the technology of Fitbit, we are exploring:

- creating healthy habits
- harnessing positive emotions
- identifying strengths

- boosting fitness and energy levels
- practicing mindfulness
- connecting with others

Graduation of the 8 week program will be celebrated at the NSW Family Retreat (30 September – 2 October 2016).

"The wellness program has been going well for me. I have been able to look at myself in a whole new light and figure out what I need to prioritise in life. The only downside is that the fast pace of it has left me a few weeks behind. The other people I have been doing the program with have been so supportive and open and honest which is very lovely. Susie is very real and makes sure we can apply the theory in practise".

Nicholla

Human Genetics Society of Australasia (HGSA) 40th Annual Scientific Meeting

On the 29 August 2016, Monique Cooper & Louise Healy attended the Human Genetics Society of Australasia (HGSA) 40th Annual Scientific Meeting in Hobart. The theme for the conference was 'Integrating Genomics in Healthcare'. There was also an important focus on rare disease registries.

The HGSA conference program included a plenary session on 'The Development and Establishment of Rare Disease registries in Australasia' which was run in collaboration with Rare Voices Australia and the Human Variome project. RVA also facilitated a post conference 'Rare Disease Registry Workshop'.

The following excerpt from the rationale presented to the HGSA LOC by SMAC Chair Prof Alan Bittles: "... The establishment of

interactive National disease registries for specific disorders will facilitate more accurate and reproducible disease estimates, improved and accelerated disease diagnoses, and treatments that are notably more cost-effective.

Access to comprehensive RD registries also will be of major importance to the identification of affected people resident in different States and Territories of Australia, and in New Zealand, thereby allowing the efficient design and testing of customised drug therapies for individual rare disease."

The MDDA see the benefit of a National Metabolic Inborn Error of Metabolism Registry and will be further investigating the possibility, implementation and sustainability of what can be done.

Wellbeing in Chronic Conditions Low Protein Cook @ home Masterclasses

MDDA again has the opportunity to provide people with the chance to host their own Low Pro Cook @ Home day!

These events are sponsored by Nutricia, and with their support, the MDDA will provide each selected host with a shopping voucher and Nutricia low protein ingredients to make some wonderful low pro creations of your choice. Hosts will be selected based on their ability to provide a suitable cooking venue (home or elsewhere is fine) at a locale that enables others in the area to

come along. Each event will be promoted by MDDA and open to any MDDA members to attend at no cost. Attending will provide not only the chance to meet new friends and experiment with new recipes, but walk away with a freezer load of delicious low protein food for you to enjoy.

Please email office@mdda.org.au if you are interested in attending or hosting a cooking masterclass.

23rd Genetic Disorders Awareness Week Launch - 7th September



MDDA were privileged to attend the Genetic Disorders Awareness week launch at the Parliament of NSW. The theme for the event was *Australian Patients and Families' Perspectives on Genome Sequencing: survey results, translation & implications*. Tara Morrison parent of two boys diagnosed with Classical Homocystinuria (HCU) not picked up via Newborn Screening, gave a personal insight to the numerous challenges and questions her family faced before the eventual diagnosis of HCU. Tara founded the HCU Network with the aim to achieve meaningful progress and best health outcomes for the HCU community.

Congratulations to Genetic Alliance Australia and Executive Director Dianne Petrie OAM for a wonderful informative evening.

The Chinnery's - living with GA1

Describe your family/How many in your family, ages etc?

Ty (Dad), Alana (Mum), Hugh 5 years old, Franklin 3 years old and Maisy is 1 year old.

Describe a regular day in your family's life?

There is no regular days in our lives. Hugh is at preschool two days a week at the moment, he also does Little Ninjas and the boys (Hugh and Franklin) do swimming lessons each week. Alana and Ty run a firewood business and Ty works a full time job for the local council. We also have a farm with sheep that we manage but a very small property.

Who has the IEM/What IEM?

Hugh has GA1 (Glutaric Aciduria Type 1). He cannot break down Lysine and Tryptophan.

Describe the journey to diagnosis?

Hugh was diagnosed at new born screening. We had a wonderful local paediatrician who was very supportive in the diagnosis and then we travelled to Westmead Children's Hospital where we met our amazing team, headed by Professor Ian Alexander.

What does the treatment for Hugh involve?

Hugh is managed through diet, he is currently on 20 grams of protein a day. He can eat quite a lot of foods and we only count potatoes, peas and corn out of the vegetables and bananas out of the fruits. This however can change when Hugh becomes unwell with the common cold or any illnesses. GA1 is at particularly high risk when unwell. Hugh has a daily protein formula, we are currently trying to transition to something new and it isn't going well but we will get there. He is also on L-Carnitine.

How do you go incorporating Hughs diet into family meal times?

We eat a lot of fruits and vegetables and so basically he gets similar to us but with replacements, so when we have steak and vegetables, Hugh has vegetables and pasta or rice or some other low protein food.

What is Hugh's favourite food?

Hugh's favourite food at the moment is mandarins. He loves to peel them and get the stickers and put the sticker on his drink bottle, he has quite a collection.

What does Hugh want to be when he grows up?

Hugh currently wants to be a spy when he grows up.

What is his favourite thing to do?

He loves to play outside, he loves crafts and is a typical boy in that he loves playing superhero games.

How does GA1 impact on your family outings?

We are always very housebound when Hugh is unwell, we believe that the best way to recover is to rest but this can be very isolating at times. But in saying that when the sun is shining we try to get out and about because we know how important sunlight and fun is for the immune system and the family.

What is the family's favourite thing to do together?

We love to go out to our farm and check the sheep, we love taking the kids on quad bikes and to the park.



Are there any major difficulties you have experienced/Has having GA1 made any family activities difficult?

Just the illness factor can make it hard particularly through winter.

How did you go about educating family/friends/teacher/classmates about GA1?

We just keep communication open, we have letters that we have given Hugh's preschool for them and for them to display for other parents. We have just enrolled Hugh in primary school for next year so I know there will be a lot of education there. We are hoping to meet the principle in the next few weeks. Our families know as much as we can explain.

What would you like everyone to know about a family living with GA1?

We have embraced it and it has helped us to appreciate things a lot more. We eat healthier as a family which is a positive thing that has come into our lives through GA1. We do struggle with the angst around sickness and with each sickness we have the risk of Hugh being hospitalised which is heartbreaking but Hugh is a very strong little person and we know that GA1 has brought a lot to our lives.

Any tips for future parents in incorporating living with an IEM into their everyday life and ensuring it is as easy as possible.

I think staying positive despite the challenges. We do this so Hugh doesn't see his IEM as a setback in life, it is just a part of who he is and whilst it has ups and downs it isn't everything that is him and our family.

Alana Chinnery

North Queensland Clinic 2016

Kim and Roy Large kindly represented the MDDA once again at the Far North Queensland Clinic that was held in Townsville and Cairns over the 17th & 18th May. The MDDA sincerely thank Kim and Roy for taking the time to volunteer and help spread the support of the MDDA and educate those newly diagnosed about the MDDA. Here is Kim's account of the Clinic trip this year.....

This year Roy and I drove from Proserpine to Townsville on Saturday 14th May. It is always a nice drive and it takes approximately 3 hours for the start of our Far North Qld Clinic Adventure.

We had a busy few days in Townsville & Cairns as you will read in our diary of events!

Saturday

To start it off this year I did a Wine & Cheese Skincare event on Saturday night with a few awesome PKU families @ The Densions Residents in Townsville.

What a great night, laughter, skincare and lots of chatting, and a wine or two. We shared family pku stories, recipes and lots more, a great relaxing event. It is something I've been doing the last few years outside of clinic, it is always an awesome catch up for us all.

Sunday

On Sunday we had the choice of a morning or afternoon Cooking Workshop with amazing Fiona and our lovely Nutricia ladies. We tried pumpkin gnocchi with basil pesto, bread, vegetable dip, and rice pudding just to name a few! We had full workshops, Bamfords, Tharra's, Grandma Alice, Actons, Stef & Bronson, Lee, Larges, Jamie-Lee & Warwick, Tanya, Giles, Gavin & his wife, Lorraine, and Em Crause, - great to see so many faces.

Sunday Night

We had a Metabolics family get together at the Townsville Sailing Club. It is a great catch up with mums, dads and kids. Nurse Anita comes and joins in the family fun.

Monday

Day off for Roy and I. On Monday we spent the day exploring with the new honeymooners, Ryan & Dannielle Large, checking out all the great walks and waterfalls that the area has to offer.

Tuesday

Tuesday morning starts at The Townsville Base Hospital from 8am. Families travel from Mackay, Charters Towers, and Townsville District to see our Metabolic Doctor and Nurse Anita once a year, and to catch up with the latest medicine with our Dietitian Catherine.

We chatted to Alison & Lucas, Veronica & Troy, Melissa, Em & Erin, Cassie, Billy & Kurtis, Jamie-Leigh & Luke, Acton Family, Madonna & Mitchell, Stephanie Butler, Lorraine, and Gavin. It's great to see so many familiar faces each year and catch up on the last year events.

Everyone was so excited as our Doctor this trip wanted full bloods....Not a lot of happy faces.....

Roy and I chatted to our last family at 4 o'clock. We then got into our lovely hire car and headed for Cairns, arriving about 9.30pm. We settled into our hotel on the Esplanade with a cuppa and bikkie.

Wednesday

Wednesday morning we arrived at the Cairns Base Hospital ready to meet more wonderful families.

We chatted to Emily, Helen & Aaron, Lily, Caleb and Mum Tonia, Javin and Mum Diana, Stevie, Shari and a few families that were in and out so quickly we didn't get to chat to them this year.

After leaving Clinic we stopped in on the outskirts of Cairns to visit Tracie & Murray who have 2 PKU boys Glen & Mark.

Mark now lives with his wife in Brisbane and Glen lives with his girlfriend in Finland.

It is always a pleasure catching up with families all over North Queensland. As I say every year it is always a real privilege to be able to spend time and connect with so many wonderful families. I know for myself I loved clinic every year so I could meet other families and my boys got to see other wonderful kids just like them. If I can give a bit of my time each year and make a difference in someone else's world than I'm truly blessed.

*'till next time
Kim*



Congratulations to
Ryan & Dannielle
Wishing you a
lifetime of love
and
Happiness!

IEM ADULT NEWS - Jill's Story

I was born in September 1966 at Cowra, in rural NSW. My brother (non PKU) and I grew up on the family farm, 26 kilometers south of Cowra at a little known village called Morongla Creek.

In this time in rural NSW the wet diaper test was distributed to mothers through the baby health nurse and this was the way I was diagnosed with PKU. At the time of my birth my parents were entering the busiest time of the farming year. My mum was one of the few women of her time that worked alongside her husband doing the outside work on the farm. After she received the wet diaper test she placed it in the drawer in the nursery. When the harvest came in December my grandmother came to stay and while she was looking through my clothes she found the wet diaper test and drew it to my mother's attention by saying "lets get this test done just for fun".

When the results came back my mother was notified by phone with the Doctor informing her that the test proved positive for PKU. Mum had a lot of questions which the doctor could not answer. He told mum that I needed to be rushed to The Royal Alexandra Hospital for Children at Camperdown, Sydney. In those days doctors didn't know if I would live or die so I was christened and baptised before I went to Sydney. As Dad was harvesting on the farm he wasn't able to go with us to Sydney so my grandmothers went to support mum. Since Sydney was a 4 hour drive from Cowra we decided to fly there. When we were waiting to see the doctor my mother was thinking at the time "why me" until she looked up and saw a

father carrying a baby with his head larger than a baby's head should be. She thought "What do I have to complain about". I spent my first Christmas in hospital as mum had to find out what I could eat before we returned home.

During the 70's the medical professionals were starting to take individuals off diet which seem to be the trend for clinics around the world as they believed that we grew out of this disorder. I was one of the fortunate ones that was kept on diet. After a brief three months with taking formula and trying high phe foods my mum put me back on the PKU diet after medical advice. I am very grateful for this as my quality of life would have deteriorated and it would have been extremely hard to go from being totally off diet to do the maternal PKU diet so I could have children. I really believe to be able to have a good quality of life you need to keep to a healthy PKU diet.

I left school at year 10 because I didn't feel I would be able to do year 11 and 12. In 1983 I went to Cowra TAFE and did secretarial studies. At the end of the course my two friends and I went to celebrate the end of the year at the 2GZ disco road show at the golf club, that evening I met my husband, David. We married in 1987 three years after we met. Four years later our first daughter Lauren was born on our Wedding Anniversary. Our daughter, Jen was born three years later in May 1994. My generation was the first generation of women to have babies before this women were told that they could never have children. Doctors had to terminate many women's pregnancies at this time mainly due to high phe levels which caused damage to the babies.

Over the years I have done a lot of voluntary work in the community Meals on Wheels, camouflage make up with the Red Cross, Community Transport, school reading and Canteen duties etc which I have thoroughly enjoyed. During the time I was living at Emu Heights in the west of Sydney I met my friend Debbie Colyer at the PKU Association of NSW Inc Children's Christmas party. Debbie invited me to attend the PKU Association Meeting and since then I have been involved with the PKU

community. I have been helping supervise at PKU children/teens biannual camps since it started in 2000. I'm looking forward to this year's camp and retreat.

Over the last 49 years there has been incredible changes with PKU. The decades have come and gone and so much has been learned about our disorder and the management of it has changed too. Now there are so many products we can use for our diet both low protein and on the super market shelf compared to when I was growing up. The taste of the low phe products is much better too and I'm only comparing the products of the 90's and present day as I wouldn't eat any of them as a child and teen and there wasn't much around.



*My Daughters Jen & Lauren and my grandson Zach—all PKU free.
My greatest achievement*

Last April I became a grandmother to a dear little boy his name is Zac and so a new generation begins. Thanks to the introduction of the wet diaper test that Jill Colyer fought so hard to bring to the country I have had a wonderful fulfilling life that would not have happened without it. I'm healthy and so are my girls and my little grandson.

Jill Butler



My mum and I

The MDDA welcome any adult with an IEM to contribute their story to this section.

Our aim is to keep you informed, updated and most importantly, learn from and support each other. We look forward to your stories, management tips and experiences.

The Children's Hospital Westmead - PKU Cooking & Activities Group



Muesli Bars

Makes: 8 bars (0.6g protein/bar)

Ingredients

- 1 cup low protein flour
- ½ cup dried cranberries
- ¼ cup sultanas
- ½ teaspoon cinnamon
- 1 teaspoon baking powder
- 2 ½ cups rice bubbles
- ¼ cup brown sugar
- ½ cup coconut oil
- ½ cup honey
- 1 teaspoon vanilla

Method

1. Preheat oven to 180°C.
2. Line a 20cm cake tin with baking paper.
3. In a large bowl, mix together flour, dried fruit, cinnamon and baking powder.
4. In a measuring cup, stir together sugar, oil, honey and vanilla. Add this mixture and rice bubbles to the baking mix mixture. Mix well.
5. Pour into baking dish. Press well in the pan.
6. Bake for 25 minutes.
7. Cool completely before cutting into bars.

The Children's Hospital at Westmead (CHW) held two group sessions earlier this year for patients with PKU, one for primary school age patients and another for adolescent patients. The groups invited patients to participate in low protein cooking demonstrations held by Nutrition Education Assistant, Sarah Slack as well as activity-based discussions run by Social Worker, Kimberley Barry.

The adolescents had fun learning how to prepare meals and snacks for school lunches including low protein muesli bars, veggie patties and rice paper rolls. The group also shared some enjoyable conversations over lunch and participated in strengths-based activities.

The primary school aged group got hands-on in the kitchen making low protein garlic bread and vegetarian lasagne. They also learnt how to make parsnip fries as a lower protein alternative to the ever so popular potato chips. The garlic bread was especially a hit! The group also put together some very creative play dough sculptures of themselves and excellent collages representing what it's like living with PKU.

Patients who attended the groups gave positive feedback regarding learning new skills and ideas as well as having the opportunity to meet others with PKU.

CHW will be running more education groups later in the year, including:

Wednesday 2nd November

Clinical Nurse Consultant, Rosie Junek will conduct a session on "Taking your own blood". Please call (02) 9845 3255 if you are interested in attending.

Wednesday 30th November

Dietitians, Ashleigh Mitchell and Tess Stanway will be running an education group, targeted at preparing families with PKU children who are starting school next year (invitation-only).

Hope you all enjoy the muesli bar recipe!

Sarah Slack
Nutrition Education Assistant, Nutrition & Dietetics



Ride with the Acton's

Philip, Sarah and their 3 boys, Thomas, William and Harry Acton embarked on a journey to help raise not only funds for the MDDA but most importantly to raise awareness for all IEM's. William and Harry both have Phenylketonuria (PKU). We all find it challenging to step outside our comfort zone at one time or another and Philip decided to take on his own personal challenge and push his body to the limit. He has spent his life in a stock saddle in outback Queensland and until recently had never ridden a road bike. The MDDA are extremely thankful to the Acton's and funds raised will enable the MDDA to continue offering support, education and services to help all IEM members lead a life at full potential.

The ride took place on Saturday 2 July and saw Philip ride into Lady Cilento Children's Hospital in Brisbane, where William and Harry attend their PKU clinic, on the 19 July. 18 Days pedalling for PKU and all Inborn Errors of Metabolism - 1512km! Here is Philip's story....

After attending a leadership course in Brisbane in April this year I had to come up with a project that would inspire and lead people.

When we were told at the course about the required project the ride to Brisbane entered my head straight away, however due to the supposedly crazy idea I was hesitant to tell anyone.

After approximately a week and thinking about it all the time it became clear to me that I had a clear purpose. I just had to find a bike, learn to ride it, get fit and plan a ride to Brisbane.

After 4 days of thinking and talking to people that were familiar with this sort of endeavor I had purchased a bike and had my first ever ride on a road bike on the 6th of May 2016 which was 28km.

With just 8 weeks to departure there was a lot to do in regards to the bike riding and the fundraiser side as well which I had never been apart of either. Both parts gave me great opportunity to learn which people really want to help and which are not interested.

We set a fundraiser target of \$20,000 which we surpassed a week out from the departure date. At present it over \$45,000 with two known parties still to donate.

The ride itself from Townsville was reasonably easy compared with juggling the training, organising the fundraiser and helping with the children while Sarah was at work.

Throughout the whole time from preparation to arriving in Brisbane and still now it has been overwhelming to see peoples generosity, with their time and genuine interest in the challenge we the IEM community live with every day.

My inspiration and determination throughout the 'Ride with the Actons' was as any dads, **I wanted to be a good role model for my three boys and show them that you can give anything a go you just have to have a bit of heart.** As William and Harry both have PKU which will be with them for life, I want them to be proud of this and never hide it. I wanted to bring awareness to the MDDA and the IEM's as they will both be a big part of our family's lives.

Philip Acton

Below are some of Philips facebook entries and supporters messages during the ride.
To read more about his journey log on to www.facebook.com/ridewiththeactons
Donations can still be made at www.givenow.com.au/mddaridewithactons

Day 15. 16th July - The day of the mostest!!!!

The most rain.

The most wind.

The most cold.

The most distance, 154.1km. ...

The most meters climbed, 1809m.

All with an average speed of 24.1km, pretty good.

No more rides over 100km. HOME RUN!!!!!! Philip

Day 18—19th July—LAST DAY

Morning everyone !

This is the last day,

can't wait to see Sarah and the boys.

A little bit of navigating through traffic
and I'm there!

Unofficially the fundraising is up to approximately \$46,000
and I don't think it's finished yet!!!!

Couldn't have done it without everyone's help.

The main reason for this ride was to spread
awareness and to let the IEM & PKU community know
they're not alone and not to feel isolated. ...

See you at the finish line. Philip

"Phil you show all of us that anything is possible! You, Sarah
and your family are all amazing ". Dianne

"What an amazing achievement young man. I have no
doubt that your family are so very proud of the determination
which you have displayed to raise awareness for the
metabolic disorder your family deals with on a daily basis. It
has been a great pleasure to share your journey"!! Gayle

"Well done Phillip and all concerned great Job for great
cause". John

"Phil, it was a pleasure to ride with and get to know you.
You're doing great things, stand tall and be proud of your
achievements, good luck with the rest of your ride. Look
forward to seeing your family at the end of it...will be a
special moment". Cheers, Cameron

Thank you to all those individuals who supported and donated along the way and to all the major sponsors..



Ride with the Acton's Oh the places you go....



Ride with the Acton's ..and people you see



Spring Recipes

KFC—Kentucky Fried Cauliflower

Serves 2 – 4

Ingredients

1/3 cup olive oil
1/2 head cauliflower broken into medium size florets
1 cup low protein flour
1/2 cup low protein milk replacer
1 teaspoon apple cider vinegar

Herb and Spice mix:

3 teaspoon paprika
1/2 teaspoon salt
1/2 teaspoon black pepper
1 teaspoon vegetable stock powder
1 teaspoon oregano
1 teaspoon tarragon
1 teaspoon parsley
1/2 teaspoon thyme
1 teaspoon chives
1/2 teaspoon garlic powder
1/2 teaspoon onion powder
1/2 teaspoon celery salt

Method

1. Preheat oven to 200°C.
2. Blend all herb and spice mix ingredients together in a bowl with flour.
3. In separate bowl, mix together milk replacer and vinegar.
4. Dip cauliflower pieces in milk mixture, then in flour spice mixture. Re-dip in milk mixture and again in flour spice mixture. Place on greased baking sheet.
5. Bake 10 mins then turn over and bake for another 10 mins.
6. Remove from oven. Allow to cool slightly. Enjoy!



**Calculate as guided by your dietitian*

Mushroom Tikka

Ingredients

1 tablespoon oil
1 Clove garlic
1 1/2 tablespoon Tikka spice
1 teaspoon turmeric powder
2 tablespoon fresh, roughly chopped coriander
1 teaspoon tomato puree
1 x 400g tin tomatoes
200g button or closed cup mushrooms
Salt and pepper to season

**extra Tikka spice if you like it hot!*

Method

1. Heat oil in pan and sauté onions. Add garlic and cook for a further 2 minutes.
2. Turn heat down and add in Tikka spice and turmeric. Cook gently for a couple of minutes.
3. Add coriander and tomato puree. Then stir in tin of tomatoes..break them up with the back of the spoon.
4. Season with salt and pepper
5. Place lid on and leave to cook for 15-20 minutes.
6. Add the mushrooms and simmer for a further 5 minutes.
7. Serve hot with low protein pitta bread and green salad.



**Calculate as guided by your dietitian
(adapted from Eileen Green—Fate Special Foods)*



OUR MDDA IEM BABY BEARS ARE BACK!

A big THANK YOU to Laurel Tulloch who kindly donated, knitted and sewed our IEM baby bears. It is such a lovely gift to be able to send out with our new member kits for those with newly diagnosed children. We know these bears get very well loved!

If you are a new member in the past year and didn't receive one let us know.



QLD Clinic & MDDA Christmas Party

Sunday 20 November 2016

10:30am - 3:30pm

Taylor Range Country Club,
Ashgrove, Brisbane

If anyone is keen to help out can you please email Louise Healy — louise@mdda.org.au. More information can be found at www.mdda.org.au under Event tab. More information closer to the date.

If you or you know someone who would like to help us with some product donation or sewing please contact office@mdda.org.au or phone 1800 288 460.



PKUNSW UPDATES

Friends of Rotary Ball

A huge Thank You to Douglas Partners, Perich Group and The Rotary Club of Narellan for their generous support.

The PKU Association gratefully accepted a donation of \$10,000 at the Friends of Rotary Charity Ball on Saturday 13th August 2016.

The funding is for Research being undertaken at The Children's Hospital at Westmead towards better treatment for individuals with PKU.

CITY2SURF 14th August 2016

What a wonderful and memorable day City2Surf 2016, Team Phen had an absolute ball. I'm sure there were a few sore legs later that evening.

A big thank you to everyone that donated to our research through everyday hero. We raised \$1100.

Also a huge thank you for the entertainment provided by Paul Melham and Andrew McDonald in our Phen suits!

Such a fantastic effort!

END OF YEAR PICNIC



Sunday 27 November 2016 - 11am
Plough and Harrow East, Western Sydney
Parklands

Join us in a family friendly park for a picnic catered by the committee and meet others families & friends with PKU.

Enjoy a relaxing day out with the family.

Bring a plate of PKU food to share. We will also be providing a picnic lunch. RSVP by 18th November to Micaela by email info@pkunsw.org.au



Guthrie-Koch PKU Scholarship - Applications close by October 15 each year.

Who is eligible:

Scholarships are open to any college-age young person with PKU who is on diet treatment and is not in graduate school (the scholarship is now open only to undergraduates, a change from previous years due to financial reasons). Residents of any country are eligible to apply, but the application must be in English or translated into readable English.

Applicants must be accepted to an accredited college or technical school before the scholarship is awarded, but may apply for the scholarship before acceptance is confirmed.

Who will review scholarship applications:

A scholarship committee will review all applications. The committee consists of well-known PKU professionals and Guthrie family members.

Scholarship awards:

Academic excellence and financial need of the applicant will be among factors considered, but financial need is NOT a prerequisite for being awarded a scholarship or merit award (it is only considered when the committee decides on the amount of the award). We are looking for excellent students, no matter what their financial need.

More information can be found at <https://pkunews.org/guthrie-koch-scholarship/>

NATIONAL
PKU News

Product Updates



Veggie Crisps
Protein per 100g: 3.3g
Protein per serve: 1.7g
Serving size: 50g
Suitable for: All
Available from: Costco



Kez's Kitchen Free
Melting moments
Protein per 100g: 1.3g
Protein per serve: 0.4
Serving size: 32g
Suitable for: All
Available from: Coles



Jumpy's—original
Protein per 100g: 4.1g
Protein per serve: 0.7
Serving size: 18g
Suitable for: All
Available from: Coles, Woolworths



Slendier
Spaghetti & Fettuccine
Protein per 100g: 0g
Protein per serve: 0g
Serving size: 125g
Suitable for: All
Available from: Woolworths



Has No
Macaroni & Cheese
Protein per 100g: 6.0g
Protein per serve: 1.9g
Serving size—dry mix: 31g
Suitable for: All
Available from: Aldi



Casalare
Macaroni Twists
Protein per 100g: 4.0g
Serving size: calculate as required
Suitable for: All
Available from: Coles



The Cake Stall
Apple Rounds
Protein per 100g: 3.1g
Protein per serve: 1.5g
Serving size: 47g
Suitable for: All
Available from: Aldi



Fruit Wise—Different varieties
Apple & Cherry Fruit Straps
Protein per 100g: 2.0
Protein per serve: 0.28g
Serving size: 14g
Suitable for: All
Available from: Coles, Woolworths

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MDDA News

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