



# MDDA NEWS

Newsletter of Metabolic Dietary Disorders Association

Issue 62

Our office will close from the 22<sup>nd</sup> December - 10<sup>th</sup> January 2017. For the remainder of January the office will operate with reduced hours.



*Merry Christmas and a Happy New Year!*



## 2016 A Year of Celebrations

As the end of 2016 approaches the MDDA reflect on a year that has been packed with events, rewarding activities and wonderful celebrations of **50 years plus of Newborn Screening**. Public awareness of IEMs throughout Australia has increased through "Our Miracles of Newborn Screening" educational and awareness campaign and our major 2016 fundraising event "Ride with the Acton's" which to date has raised over \$50,000! Thank you to Philip & Sarah Acton for spearheading this outstanding event.

The MDDA initiated new educational programs, discussion forums and workshops to empower and inform people with IEMs, the general community, stakeholders and health professionals while continuing to build stronger IEM support networks.

We would like to take this opportunity to thank everyone who has

contributed in any way this year. The MDDA relies on the support and dedication from our members to further our support programs, educational programs and retreats. Thank you!

We also want to take this opportunity to acknowledge Monique Cooper – President and Louise Healy – Vice President. Both Monique and Louise find time to prioritise and schedule MDDA into their busy lives, between running their own businesses and family commitments. Their dedication, collaboration, strength, knowledge and direction enables MDDA to be effective, productive and valuable giving a **voice to the IEM community**. They consistently lead the MDDA in education, connecting, support and advocacy, working toward MDDA's mission, vision and goal.

From our families to yours, we wish you all a peaceful, safe, happy Christmas and New Year, filled with love and

laughter. We look forward to sharing 2017 with you all.

Jenny Briant and Kerry Tulloch  
MDDA National Office

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

# End of Year Events

## Queensland

The Queensland Christmas party was held on Sunday 20th November at Taylors Range Country Club, Ashgrove in Brisbane. Over 80 people attended, it was great to see familiar faces and also meet new families. The perfect weather set the scene for two great traditions - the Lolly Hunt, and the Water Bomb

fight! Dr Jim and Anita may need to invest in rain coats before next year's party... no one was holding back!

Thank you to Santa for making time in his busy schedule and stopping by with gifts. It's lovely to see the little ones faces light up.

Thank you to all who brought along a plate to share and new recipes to try. The Chocolate Christmas tree treats were a huge hit! Thank you to those who helped to set up and pack away afterwards, your help is appreciated.

Many thanks to Nutricia for supporting this event.



## Victoria

Sunday the 27th of November from 12pm at Bundoora park saw the Victorian members get together and kick off their end of year picnic.

While jumpers may have been needed, the Melbourne weather held off for the kids to be able to have a great time catching up and with plenty of room to run around



there were a few tired little faces by the end of the day. Thanks to Katy Drewitt for organising the day.

*"The food was nice. I liked trying the new foods and meeting new people, it's interesting to hear how they have dealt with PKU" Brooke.*

## South Australia

South Australia MDDA members and friends gathered at Rymil Park, East Terrace on Saturday December the 3rd for a lovely afternoon. Thank you to Sasha for organising and for the delicious low protein catering.

Many thanks to Nutricia for supporting this event.





# Virtual Round Table Discussions

MDDA new initiative offering education, support, experience from the comfort of your home.

Recently the MDDA has held three meetings via Webinar using our exciting new Webex technology including: the Annual General Meeting, PKU National Protein Counting Guidelines informational webinar and a session focused on Tyrosinaemia Type 1. The online video conferencing allows you to participate in the meeting via a login through your computer, tablet, laptop or mobile phone by downloading a free small plugin or app. We hope that this new initiative will assist with isolation, location, remoteness and financial barriers that often prevent people from attending events such as social gatherings and conferences. It is certainly worth becoming familiar with this technology and installing the app as the MDDA sees this as great way to have more members become actively involved where your location is no boundary.

We are currently planning further on-line events including a Maternal PKU support group session to be held early 2017 and a Urea Cycle Disorder seminar in the first 6 months of 2017. We would like to hear any ideas you have for Virtual discussions you would like to participate in. You can email [office@mdda.org.au](mailto:office@mdda.org.au) with your ideas.

### Annual General Meeting

We held our first virtual AGM on 16 November 2016. Hosting the virtual meeting meant adhering to all the rules and procedures of a traditional AGM, while in a virtual environment. Webex technology allowed all the participants to communicate as effectively as if they were attending in person. Our Executive Director and President both attended in person and our Treasurer presented her report remotely. The AGM was successful with members participating actively in the meeting. Many attendees shared positive comments via the 'chat' function.

### PKU National Protein Counting Guidelines

On Wednesday the 23rd November Annabel Sweeney, BSc G DipNutDiet Adv APD dietician from the SA Women and Children's Hospital joined MDDA members and committee for an online Webinar. Annabel provides dietetic care to the patients of the metabolic clinic and has many years of experience, looking after patients with metabolic disorders.

Annabel presented and responded to a wide variety of questions about the new national protein counting guidelines – their purpose, why they are different to previous guidelines, advice for people who wish to continue to use the existing guidelines, and advice for people wishing to transition to the new ones. Questions about phe and tyrosine content in foods, and questions about why both phe and tyrosine are important in the management of PKU were discussed. Annabel also explained the history of the original PKU counting guidelines and the reason behind developing the new guidelines. A copy of the webinar will be added in 2017 to a "member only" section of the MDDA website.

### Tyrosinaemia Type 1

On Thursday 24th November the MDDA facilitated an online session for Tyrosinaemia Type 1 families. We are grateful and appreciative that Dr Jim McGill and Dr Shanti Balasubramaniam agreed to present on latest research, management and take questions from our families. The webinar was successful with encouraging feedback from all attendees. The allocated hour went so quickly and could have continued on as the questions kept coming through. One member's experience:

*'Thank you MDDA also heaps for organising the WebEx conf today that just focused on Tyro type 1 ! It was great to learn from two experts sharing their experiences with us and flexibly asking questions during the event via typing them in. So much interesting information was exchanged in just an hour because it was the only subject we were focusing on. I can't wait for the next WebEx conference and I very much hope that other Tyro families will join as well so I can learn from their questions and the experts responses to them as well. Thank you so much! This is a very clever way to get expert advice beyond the immediate doctor team, a special treat given the rarity of this condition and lack of access to other sources of insights and latest learnings.'*

We sincerely thank the health professionals for their enthusiastic participation in our webinars and are most grateful for their time and effort to share their experience, knowledge and research with the MDDA community. MDDA hopes that this technology will allow us to offer more on-line services to our members giving them greater access and opportunity to participate in educational sessions for the purpose of keeping our members educated, informed and connected.

## Cook @ Home Low Protein Master Classes!

These cook at home events are a wonderful opportunity to experience what the MDDA community is all about to; **educate, connect and enable**. The cooking days encourage sharing of dietary information, meal planning and invention, in a relaxed social home environment.

In December member Sonia Hellings from Victoria opened her home for two days of low protein cooking led by Kathy Madefferi, Chef & PKU mum. Both days Kathy & Sonia demonstrated how to make "Chicken" nuggets, Arrancini balls, "Sausage" rolls & Sushi. This was a hands on opportunity to get involved and try out new recipes, flavours and ideas. Everyone left with a 'goodie' pack to stock up the freezer for a few easy meals for over the holidays.

Future dates for early 2017 are being planned for:  
QLD (Brisbane) Gordon Park  
NSW (North) Blue Mountains  
WA (North) Wanneroo  
Keep an eye on our website and Facebook group for confirmations of dates.

Thank you to all those who have kindly offered to open up their homes to all members looking for new recipes and tips on cooking delicious low protein foods.

If you are interested in hosting a cook@home day in the future please contact the [office@mdda.org.au](mailto:office@mdda.org.au)

Thank you to Nutricia for sponsorship of these cooking days .



# NSW FAMILY RETREAT 2016

**A**nother successful family retreat was held this year at Ingleside NSW on the 30 September – 2 October. Our retreats provide invaluable opportunities for people with all IEM's and their families to meet in a social environment and build positive relationships with other members of the MDDA and IEM community.

Fairy Floss, bubble machine, slushies and music set the scene for a fun 'Friday Carnival' evening. DIY wood fired low protein pizzas were a hit with savoury and dessert pizzas, YUM! Jacket potatoes, sushi and finger food proved to be winners with all ages too! Full tummies all round.

Saturday the younger kids were kept busy with loads of activities provided for them in our childcare room. For those a little older Laser Tag was arranged on the beautiful grounds. The kids were well catered for in activities, tennis, basketball, volleyball, swimming pool and a games room kept everyone busy. Saturday afternoon was a "Masterchef" low protein cooking challenge. There were delicious meals made with loads of flavour and some interesting inventions too. Those who didn't participate in the cooking workshop enthusiastically supported the "Doggies" in the AFL grand final. Saturday evening Philip & Sarah Acton shared their journey from the beginning of 'Ride with the Acton's' fundraising and awareness campaign. A video of Philip's bike ride and his passion, emotion and dedication for our cause left most of us reaching for our tissues. Thank you Philip & Sarah!

The weekend program included a variety of sessions for attendees including:

- Practical tools for Stress & Anxiety Management
- Adult wellness group
- Practical and organisation tips & discussion including;
  - quick meals for the whole family
  - Dealing with school lunches, treats, school camps

- Partners discussion group for partners of adults with IEM's - support strategies, challenges and ideas
- Specific IEM group discussions – sharing challenges and strategies
- Advocacy: optimal care in managing an IEM
- IEM Management & Wellbeing – Patient Perspectives on 'Being the best You'
- MDDA Future Initiatives

## Educating

**Dr Sharon Cunningham** BSc (Hons) PhD Research Fellow, Gene Therapy Research Unit, Children's Medical Research Institute and the Children's Hospital at Westmead.

An informative session opened the retreat on Friday afternoon on 'The Future of Treatments for Inborn Errors of Protein metabolism – Liver Targeted Gene Therapy'. The presentation included discussion of research on Urea Cycle Disorders and liver targeted gene therapy - time frames, challenges and applications to other IEMs.

**Dr Avihu Boneh** MD, PhD, FRACP Department of Metabolic Medicine, Royal Children's Hospital Melbourne Metabolic Research, Murdoch Children's Research Institute, Department of Paediatrics, University of Melbourne

Dr Boneh presented on the latest research for PKU and other IEMs and what it means. He reported from the SSIEM (metabolic) and ISNS (newborn screening) meetings he had recently attended. Dr Boneh also discussed the topic of guidelines for the management of diseases.

**Mary Westbrook** Dietitian – retired Genetic Medicine, Westmead Hospital

Mary presented a comprehensive report

on formulas/supplements. What is in PKU & other IEM formulas and a comparison of different formulas available.

**Professor Bridget Wilcken** Clinical Director, NSW Biochemical Genetics and Newborn Screening Services, Children's Hospital at Westmead.

Professor Wilcken is recognised worldwide for her contributions to improve and enhance newborn screening efforts for metabolic disorders. She has made significant contribution to the development of high quality assays for detection of these disorders and frequently pioneered the implementation of new and better laboratory test procedures. She is recognised as a leader in the field of newborn screening.

We were delighted and honoured to have Prof Wilcken at our retreat. The Professor presented 'Celebrating the Past – 50 years of Newborn Screening - What it means and what is next'

Further information and slides of the health professional's presentations can be found on the MDDA website; <http://www.mdda.org.au/educational-resources/literature-presentations/>

Thank you to Prof Wilcken, Dr Boneh, Dr Cunningham and Ms Westbrook for participating in our retreat. We appreciate their efforts in preparing appropriate information for their presentations. We cannot thank them enough for being so generous with their time and expertise to attend our retreat for us all to expand our knowledge of IEMs. We thank them for being so willing to answer our questions and help in furthering our understanding.

Thank you to all those who come up to us over the duration of the retreat and offer their assistance throughout the weekend, it is very much appreciated!

Thank you also to our sponsors, your generous support enables us to continue to provide events such as these to the IEM community.

MDDA are committed and work very hard to ensure we deliver quality venues, food choices, educational programs and opportunities for socialising and educating to enable as many individuals and families attend our events as possible. From the feedback we receive all comment that they benefit from the weekends and find the sessions very informative as well as enjoying the social side of meeting other IEM families and sharing stories and experiences.

Expressions of Interest for the Victorian retreat are open, if you would like to attend please register as soon as possible.



## NSW Family Retreat - Member Feedback

Thank you to the incredible MDDA team. For such a small amount of people who do so much & do it so well for the benefit of their members. Thoroughly enjoyed the weekend. Always leave feeling connected & re-energised to better manage my sons PKU.

I love the retreats, we get to meet so many people and it makes it easier for the kids to understand.

What a wonderful opportunity to meet and discuss your experiences, challenges and successes with other families with similar circumstances.

A great way for children to meet other children with the same condition and develop lifelong friends.

I love connecting, meeting and catching up with everyone & learning more about IEM's. Tasting new LP products and dishes is always great too.

This retreat was my first and it didn't disappoint. The information was informative and interactive. I enjoyed hearing other people's IEM stories and also sharing my own experience. It was a blast! Definitely go again!

## Thank you to our Sponsors for the NSW Retreat 2016

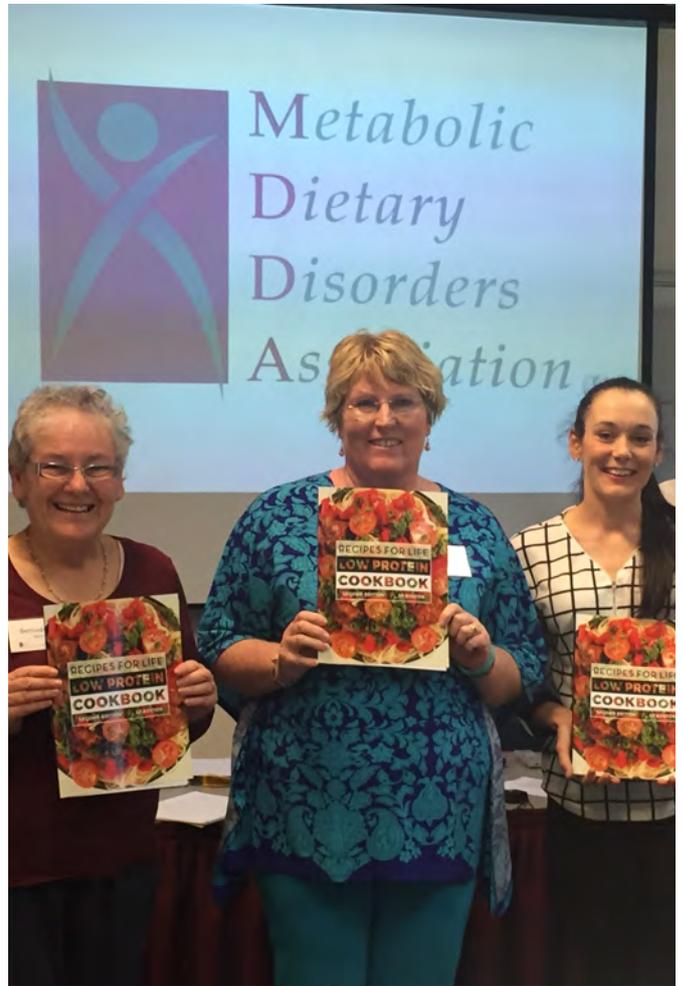


### 2017 MDDA FAMILY RETREAT - Victoria

The retreat for 2017 will be held in Victoria at Countryplace, Kalorama October 6<sup>th</sup> – 8<sup>th</sup> (tbc). Planning for an informative, interactive and integrative weekend has begun. Details will be announced shortly.







# Fundraising Updates



## Ride with the Acton's

In our last newsletter we told you of Philip and Sarah's story and the amazing, enduring ride that Philip went on covering over 1512km in 18 days. Philip's ride may have finished on the 19th of July but donations have still been pouring in. Recently Philip was lucky enough to be invited to a charity golf day organised by the 'HOO HOO Club 265' and Rob Spiller at The Willows Golf Club in Townsville. These golf days are held every year and they donate to rare causes within the community. This golf club is a small club of only 5 men!

We thank Rob Spiller and the Willows Golf Club Townsville and all that donated. The HOO HOO Club donated \$3000 to the MDDA and were more than happy to add in the extra to bring the Ride with the Acton's fundraising total to **\$50,000**. It has been an amazing effort and the MDDA community are overwhelmed by the support, and generosity that people have shown whilst most importantly raising the awareness of IEM's in the community.



THE GRAND



WARRANDYTE

Thank you to the Grand Hotel Warrandyte, management, staff and patrons whose fundraising efforts raised \$1727 for the MDDA.

President, Monique Cooper and Jenny Briant were there to accept the cheque and talk about what this means to the MDDA.

These funds will assist with the programs and events MDDA provide to our IEM Community.



## Market Day Sausage Sizzle Lions Club of Park Orchards

The Lions Club of Park Orchards recently held their sausage sizzle at the Park Orchards Market and kindly donated all funds raised to the MDDA, they raised \$405.80. The Lions Club is a community based club that support many local and international causes. Thank you to all those that went along and bought a sausage and to the Lions Club for thinking of us!

Please contact [office@mdda.org.au](mailto:office@mdda.org.au) for an information sheet if you would like to get your local community club involved in supporting us.



## Fundraising Ideas

Keep a look out early January for an exciting new fundraising /awareness initiative being launched by our member, Nicholla. The idea is to get your family and friends involved and take a "Protein Challenge". They can pledge \$ per gram or plan to eat for a day on 10g protein. More details will be shared early next year with the event to take place on 1 May 2017.

If you have an idea about raising funds for MDDA ...contact [office@mdda.org.au](mailto:office@mdda.org.au)

# ITEM Food Grant Information 2017

The ITEM food grant is to help people with an ITEM and their families maintain dietary compliance by providing financial support to purchase **specialised low protein medical foods**. Other specialist products such as medications and supplements cannot be purchased with money provided under the Programme. Using the grant for its intended purpose helps demonstrate to the government the ongoing need for the grant.

Further information can be found at;

<http://www.mdda.org.au/educational-resources/item-food-grant/>

## Payment schedule 2017

The table below outlines the due dates for the ITEM food grant payment for 2017. **The payment is due on or before the Friday of the first full week of each month.** If the payment has not arrived by the date listed please contact the department.

### Dates for Food Grant Payments 2017

Department of Health  
contact details:

6 January  
10 February  
10 March  
7 April  
12 May  
9 June

7 July  
11 August  
8 September  
6 October  
10 November  
8 December

ITEM Programme Officer  
Grant Services Division  
Department of Health  
MDP 205, GPO Box 9848  
CANBERRA ACT 2601  
Phone: (02) 6289 8980  
[iemprogramofficer@health.gov.au](mailto:iemprogramofficer@health.gov.au)

Any questions please contact the Department directly on (02) 6289 8980.

## Low Protein Food Suppliers

[www.vitaflo.com.au](http://www.vitaflo.com.au)  
[www.pkuconnect.com.au](http://www.pkuconnect.com.au)

[www.cortexhealth.com.au](http://www.cortexhealth.com.au)  
[www.platypusfoods.com.au](http://www.platypusfoods.com.au)



## What we love about our facebook group.

We love members who inspire us. This month Taylah Shier motivated us all when she posted about her weekly meal planning and big low protein cookup! We love your enthusiasm, organisation and creativeness Tay. Keep it coming!

If you would like to join our private facebook group go to;

<https://www.facebook.com/groups/metabolicdietarydisordersassociation/>  
and request to be added.



## New Arrival....a baby boy!!

Congratulations to  
**Carly and Brett**  
on the arrival of their first child  
**Leonardo Snow Allen**  
Born 3 November 2016.

Enjoy your first Christmas together!



# Christmas Recipes

## Cranberry & Orange Muffins

### Ingredients: (makes 10 large muffins)

100g soft margarine  
100g caster sugar  
200g low protein baking mix  
2 teaspoons egg replacer  
2 teaspoons baking powder  
150ml milk replacer  
1 tablespoon grated rind 1 small orange  
100g (1 cup) fresh cranberries, halved

### Method

1. Preheat oven to 200°C.
2. Place the margarine and sugar in a large bowl, beat well until light in texture and creamy coloured.
3. Combine the low protein mix, egg replacer and baking powder. Beat into the creamed mixture, alternatively with the milk replacer until a soft smooth batter is achieved.
4. Stir in the orange rind and cranberries.
5. Divide the mixture between 10 muffin cases in a large muffin tin. If desired, sprinkle a little granulated sugar over each muffin.
6. Bake the muffins for 20-25 minutes, until well risen and firm to touch.
7. Cool on a wire rack and enjoy.



*\*Calculate as guided by your dietitian*



## Carrot & Tarragon Spread

### Ingredients:

200g carrots, peeled and sliced  
50g onion, finely chopped  
25g butter, melted  
1/2 teaspoon dried tarragon  
1 tablespoon finely chopped fresh parsley  
4 tablespoons mayonnaise#

### Method

1. Place the carrot and onion in a pan, cover with water and bring to the boil. Reduce the heat, cover, and simmer for 5 minutes.
2. Drain the vegetables and rinse in cold water. Drain very thoroughly and transfer to a food processor.
3. Add remaining ingredients to the food processor and process until required consistency (rough or smooth).
4. Transfer the spread to a sealed container and chill until required.
5. Serve in a bowl or spread on low protein bread, rolls or crackers, with extra garnish of your choice if desired.



*\*Calculate as guided by your dietitian*

#low protein brands include Kewpi & Praise



# PKUNSW UPDATES

## Youth Camp

Point Wolstoncroft Sport & Recreation Centre, New South Wales, was the venue for this years youth camp. It was held on the 28th September to 2nd of October.

The camp was a great success with plenty of outdoor activities, cooking, information session and of course great friendships being formed. Read the day to day account on PKUNSW facebook page or on [www.pkunsw.org.au](http://www.pkunsw.org.au)

## End of Year Picnic

This was held on the 27th November at Western Sydney Parklands and lived up to past years expectations of a relaxing family fun day out. It was great to see so many families and friends coming together.



## Adult get together

It was great to see that our Adult NSW members had a night out on the town at Bondi Pizza in Sydney. Well done to Debbie for getting everyone together.



## Information Update

Review outcome recommendation 17,  
- Removal of 'per serve' details on Australian Nutrition Information Panels

Food Standards Australia New Zealand (FSANZ) received 78 submissions, including MDDA's and 19 campaign submissions from those with (or caring for family members with) metabolic disorders such as phenylketonuria. The review outcome noted "In particular, submitters emphasised the importance of per serving information in the management of lifelong diseases such as phenylketonuria, diabetes, and kidney diseases."

In conclusion the key findings from the analysis of Recommendation 17:

"The vast majority of the 78 submitters to the public consultation did not support the recommendation to remove the mandatory requirement for per serving

information in the NIP. This view was expressed by consumers, health professionals, food businesses and government agencies."

"Should recommendation 17 be considered further, the impact of implementing the recommendation on a number of standards in the Code would need to be assessed. Situations where per serving information might be mandated would also need to be investigated, for example, when a daily intake claim or nutrition content or health claim is made."

# Product Updates



**Majans**  
**Infuzions Potato mix**  
**Protein per100g:** 3.9g  
**Serving/Pkt size:** 110g  
**Suitable for:** All  
**Available from:**  
 Woolworths



**Dr. Oetker — Edible**  
**Wafer Cupcake Cases**  
**Protein per100g:** 0.2g  
**Serving size:** 1.1g  
**Protein per serve:**0.0g  
**Suitable for:** All  
**Available from:** Coles



**Weis Sorbet**  
**Dark Choc & Coconut**  
**Protein per100g:** 1.3  
**Serving size:** 73g  
**Protein per serve:**0.9  
**Suitable for:** All  
**Available from:**  
 Coles & Woolworths



**Dole**  
**Fruit & Custard — Peach**  
**Protein per100g:** <1g  
**Serving size:** 123g  
**Protein per serve:**1.0  
**Suitable for:** All  
**Available from:**  
 Woolworths



**Belmont**  
**Skidoos — Buttonbix**  
**Protein per100g:** 4.8  
**Serving size:** 27g  
**Protein per**  
**serve:**1.3g  
**Suitable for:** All  
**Available from:** Aldi



**Golden Palm**  
**Date Rolls with coconut**  
**Protein per100g:** 1.8g  
**Serving size:** 45g  
**Protein per serve:** 0.8g  
**Suitable for:** All  
**Available from:**  
 Woolworths



**Old El Paso**  
**Mini stuff'n'stand**  
**Protein per100g:** 8.5  
**Serving size:** 12g  
**Protein per serve:**1.03g  
**Suitable for:** All  
**Available from:**  
 Coles & Woolworths



**BFree**  
**Sweet potato wraps**  
**Protein per100g:** 4.6g  
**Serving size:** 42g  
**Protein per serve:**1.9g  
**Suitable for:** All  
**Available from:**  
 Woolworths



**Kettle—Sweet potato**  
**Sea Salt Chips**  
**Protein per100g:** 4.0g  
**Serving size:** 25g  
**Protein per serve:**1.0g  
**Suitable for:** All  
**Available from:**  
 Coles & Woolworths

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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.

Email to: office@mdda.org.au

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