



PBAC Kuvan Deferral = Making Progress!

MDDA welcomes the decision by the Pharmaceutical Benefits Advisory Committee (PBAC) to defer the listing of Kuvan (sapropterin hydrochloride) on the Pharmaceutical Benefits Scheme (PBS) for Australians living with phenylketonuria (PKU). Whilst it is disappointing not to have received a positive recommendation, the deferral means the PBAC recognises the benefit of Kuvan for some PKU patients and remains open to listing the treatment on the PBS.

The deferral also ensures the PBAC can now work with the sponsor company (BioMarin) to seek further evidence and determine the best pathway forward to make Kuvan available on the PBS.

MDDA, with the support of our PKU community, has been actively campaigning for a number of years to secure access to this treatment for all Australians with PKU who are responsive to therapy. This has included extensive political, media and public advocacy by our PKU and broader metabolic dietary disorders communities. Although the

outcome has not been a straightforward recommendation, there is still hope to secure subsidised access to Kuvan – which is the first and only treatment available for PKU – through the PBS for some patients.

We were heartened to see the PBAC acknowledge the input received from individuals, organisations and healthcare professionals in support of this listing. We would like to thank everyone who submitted a consumer comment to the PBAC about how important it was for our PKU community to get access to this treatment on the PBS.

We were blown away to be told by the PBAC that it received **965 consumer comments** in support of listing Kuvan on the PBS! This is not just extraordinary for a rare disease – but it is the first time the PBAC has ever received this volume of consumer comments for any treatment it has previously reviewed. This is a testament to the passion and commitment of our community and supporters and we can't thank you enough.

We also want to thank each and every one of our supporters that helped to achieve this outcome. Whether it was raising the issue with your Federal Member of Parliament, sharing your story of living with PKU with media, or talking about the issue with your family and friends to raise awareness of PKU, this has been an enormous effort and we are very grateful and proud of the role everyone has played.

We will continue to work hard to advocate on behalf of Australians with PKU for access to available treatments with the Australian Government. We look forward to keeping you updated of any developments, as we keep pushing for reimbursement of Kuvan on the PBS.

***Yours Sincerely
Louise & Monique
MDDA Kuvan Advocacy Team***



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Advocacy



2018 certainly started off with a bang for PKU advocacy both here and overseas. Key priorities have been around preparing the Global Association for PKU for launch and Government advocacy and awareness for Kuvan.

JANUARY

MDDA President, Monique Cooper and Vice President, Louise Healy met to finalise plans for the “How Low Can You Go” challenge and the International Rare Disease Day parliamentary event.

MDDA's consumer submission to Pharmaceutical Benefits Advisory Committee was submitted and meetings with the consumer representatives from the PBAC committee were convened.

Media articles and case studies were prepared to raise awareness about PKU with the public and key stakeholders.

FEBRUARY

Feb 1 - Saw the inaugural launch of MDDA's “Great Protein Challenge”, an initiative designed to educate and appeal to everyday Australians on the dietary challenges faced by those living with a protein restrictive IEM.

PKU was the particular focus for 2017 due to the coinciding government attention desired for the Kuvan submission under consideration by the PBAC. Future years will embrace and educate on all IEM's.

February 11 - 15th Louise was in Canberra meeting with a MPs and senators and/or their advisors including Bruce Lehmann, adviser to Senator Bridget McKenzie, Mr. Steve Georganas,

member for Hindmarsh, Mr. Trent Zimmerman, member for North Sydney, Ms. Catherine King Shadow Minister for Health and Medicare, Mr. John Alexander, member for Bennelong, Senator Slade Brockman and Minister for Health Mr. Greg Hunt. This series of meetings allowed MDDA to raise awareness about Inborn Errors of Metabolism, challenges for our community and the need for access to additional tools and treatments to help manage these disorders.

February 15 - MDDA and Rare Voices Australia collaborated to hold a parliamentary lunch ahead of Rare Disease Day. This lunch highlighted the inequities in the health system experienced by people with rare conditions and focused in particular on educating parliamentarians about PKU and

the reality of lifelong treatment. There were presentations from Nicole Millis from Rare Voices Australia, Dr. Kaustuv Bhattacharya and our president Monique Cooper spoke passionately and brilliantly, as did member Tay Shier from Western Australia, representing the needs of young people and adults. Bek Mills from Canberra also shared her families experience with Kuvan. MDDA members Charlie Cooper, Sarah

Mokbel, Tay Shier and Evie Duce all spent time discussing the management of their condition with many different politicians. The lunch was a great success and Minister Hunt even unexpectedly spoke about his plans for supporting the rare disease community. You can read an extract from Monique's speech on page 4.





February 20 – Louise headed to Amsterdam to meet with the international team and finalise the organisational structure, constitution, management arrangements for an international PKU advocacy organisation. Over 2.5 days we worked extremely hard to finalise all agreements, and meeting outcomes included; signing a constitution, choosing a board of founding trustees, officially registering the organisation and making final preparations to officially launch the organisation in Atlanta in July 2018. At that time, we will have an organisation that; unites and supports PKU patient organisations from around the world, is an inclusive, transparent and democratic organisation and aims to make PKU a global health priority. It has been an enormous pleasure and privilege to work with this group of passionate and informed people and we are pleased to announce that both Monique and Louise will be founding trustees of the new Global organisation.

MARCH

March 6 - Monique, Bianca Albanese and Bek Mills attended a consumer hearing with the Pharmaceutical Benefits Advisory Committee regarding the submission for Kuvan. This meeting gave the PBAC members a chance to understand the practical, financial, social and quality of life impacts of managing PKU.

March 15 - Monique and Louise presented at the Vitaflo Live Life Well Metabolic Dietitians conference. This gave us a chance to share the MDDA's plans for specific wellbeing projects and gain dietitian's feedback on these plans. In addition, we discussed several possible collaborations to improve services for people with IEM's including possible research, transition planning and tools and resources to support people with IEM's in nursing homes and other care settings.

Acknowledgements

It has been both an exciting and busy start to 2018 with plenty more to come! None of this could have been achieved without the energy and drive of our President Monique Cooper whose vision and passion keeps pushing us forward. This coupled with the undying persistence and determination of our Vice President Louise Healy who has brought us to the forefront of minds of key government decision makers and politicians, ensuring effective health policy for Australians living with an IEM is a priority. MDDA also thanks office staff Jenny and Kerry whose organisation, attention to detail and flexibility mean we are where we need to be, when we need to be and with the resources we need.

Thank you to all of you who participated in providing consumer comments or speaking to your local members about living with an IEM. Once again, for a very small community, we have been very effective in making our voices heard and we look forward to updating you further on progress being made in this space.

(Extract from)

Speech: Monique Cooper Feb 2018 Parliamentary Luncheon

MDDA President, Monique Cooper presented at Parliament House, Canberra, on the 15th February 2018 with Nicole Millis from Rare Voices Australia. Here is Monique's speech.

The MDDA educates, connects and enables all Australians living with rare inborn errors of metabolism. We support them to achieve positive outcomes and live a life of full potential.

As the national support group, we also play an important role in informing government on policy and we work closely with the Department of Health on the administration of the IEM food grant – which many of you will be familiar with after we lobbied hard for its reinstatement back in 2015.

8 years ago I knew nothing about PKU! That was until my second child Charlie was one of the 25 babies to be born in Australia that year. Just days after he was born we received a phone call that changed our lives and his forever.

What we learnt then and soon after was this...PKU occurs when liver cells are unable to break down an amino acid called phenylalanine (Phe), which is found in most foods.

Possibly the one thing that stands out the most were the two simple words – Brain damage! Not that I didn't know what that was – but rather until then I had never associated those words with anyone in my life let alone my 5 day old brand new baby boy that was cradled in my arms.

After some time and adjustment, the education continued, and we then started to learn ...

How fortunate we were to receive that phone call – had Charlie not been born in Australia or had he been born 50 years earlier – he likely would have been missed and most certainly would not be sitting here like he is today enjoying a lunch at Parliament house as a capable, happy and healthy young boy.

How fortunate we are to have access to world class care, our supplements and foods to be able to manage our condition and prevent harm.

But we also learnt that with all this would come a heavy burden...

In order to protect Charlie's brain from damage he had to adhere to a strict lifelong medically controlled diet. Severely reducing almost eliminating all forms of natural proteins from his diet.

The amount of protein a person with PKU can consume daily varies. It is calculated through blood Phe levels, age and growth.

- In infancy and earlier years the focus is around preventing irreversible damage to the growing brain.
- In adolescence and adulthood, the importance is on maintaining optimal brain health and preventing neurological damage.
- PKU Maternal women – Metabolise for their unborn baby so the most strictest of controls must be put in place in order to protect the developing brain of their child.

PKU sits in a category of its own...Research states it is one of the hardest diets to comply with and data shows 70% of people struggle with compliance.

Even with the best of intentions it is an extremely difficult diet to manage and there are lots of elements outside of our control. Stress and Sickness are just two common ones to mention – with a small head cold or virus being enough to have levels skyrocket.

Even with proper care and treatment, emerging clinical research is showing, many adults are showing white and grey matter deficits in their brain. Mental health issues such as depression and anxiety are common in people with PKU. They are also 50 per cent more likely to develop psychiatric disorders.

With the lack of natural proteins in the PKU diet, other health concerns are apparent. These include; bone density issues, poor body mass composition and other nutrient deficiencies. Obesity is also a big one - due to high sugar content in many supplements and allowed foods.

Whilst guidelines exist around what is considered to be safe and effective PKU management, it is still apparent that there is much more to be learnt about achieving optimal health outcomes and further tools are needed.

... Monique goes on to talk about the effectiveness of Kuvan in the treatment of PKU and also launches the Great Protein Challenge to members of parliament. For a full copy of her speech please contact the MDDA or visit www.mdda.org.au.

In Memory of Robyn Walker

It is with great sadness that we inform you that Robyn Walker, General Manager of Vitaflo Australia, passed away on the 29th of January after a long illness. Robyn was a generous and enthusiastic supporter of our community providing expert advice, care and concern to us, as well as being a significant financial supporter of MDDA initiatives through Vitaflo Australia. Robyn initiated the Vitaflo Australia international travel grant, giving our members a chance to further their understanding of PKU on a global scale. She supported and attended many a family retreat and Christmas party and was passionate about patient wellbeing - contributing valuable insight and advice that inspired and strengthened MDDA's member programs in this area. Her care often extended to personally going above and beyond in the service and support she provided individually to many families through Vitaflo Australia. Apart from all this, those who met her know that she was warm, wise, caring, and had the highest of concern for our patient group. She was appreciated and admired and will be deeply missed by us all. Our sincere condolences to her family. Vale Robyn Walker.



ICIEM - International Congress of Inborn Errors of Metabolism

On 5-8 September 2017, MDDA President Monique Cooper attended the 13th International Congress of Inborn Errors of Metabolism in Rio De Janeiro, Brazil.

This meeting provided a chance for Australia to be represented at the SAFE Associação Amiga dos Fenilcetonúricos do Brasil exhibitor stand, and also participate in the global PKU association poster sessions where we spoke to many medical professionals and researchers about our plans for the launch of our global association for PKU.

Other PKU patient organisations represented included; National PKU Alliance (USA), Grupos de Padres PKU Asociación Civil de Fenilcetonuria de Argentina and Canadian PKU and Allied Disorders.

MDDA along with patient groups from Brazil, Argentina, North America and Canada convened a meeting with key industry stakeholders from supporting organisations fostering further collaboration on our goals and objectives, and to help



to secure ongoing support of the global organisation as we lead up to its launch this coming July in Atlanta.

Attending this congress was an excellent opportunity to meet with international leaders in IEM research and development. It is exciting to hear of many research projects underway, some in their infancy and others close to completion of clinical trials (such as pegvaliase for PKU). The MDDA continues to keep informed of these upcoming treatments and looking into ways to create pathways for access into Australia.

It also provided a chance to share with others the many great initiative MDDA has underway here in Australia and look at ways to help and also leverage from experiences of other International support organisations.

The MDDA is excited to announce that Australia will be the home of the 14th ICIEM, taking place in Sydney 27-31 August 2021. Further information will follow on how patient families can get involved.

Congratulations!

New Arrival – Baby Boy



Rory David Large
Born on 17 March 2018
8lb 8oz

Congratulations to Dannielle & Ryan and some very excited Grandparents!

New Arrival – Baby Boy



Charles (Charlie) Jack Allen
Born on 10th February 2018
7lb 11oz

Congratulations to Carly and Brett. A big brother for Leonardo.

RE COUNTING OF AVOCADO

MDDA Vice president followed up with ASIEM dietetics group about avocados after the UK announced they were not counting them anymore. The response is that, based on the original research done from Royal Children's Hospital Adelaide and due to the volume usually consumed, it is strongly recommended that we count avocado as directed in the nationally endorsed PKU protein counting guideline (for PKU) and the ASIEM food counting guideline for other IEMs. Links to both these tools can be found on the MDDA website www.mdda.org.au in the resources section under guidelines (PKU) and handbooks (other IEM).



How Low Pro Go? can you

thegreatproteinchallenge.com.au

THE GREAT
PROTEIN
CHALLENGE

FEB
2018

SBS NEWS

Australia

Australians urged to cut protein for a day



MDDA Executive Office, Jenny Briant, Michael Sukkah MP, MDDA President, Monique Cooper and son Charlie.

1 in 15,000: Dangerous disorder a battle for this family

WARWICKDAILYNEWS.COM.AU

2018 marked the inaugural launch of The Great Protein Challenge, an important MDDA health initiative to raise awareness and support of IEMs.

This year we focused on PKU with the plan for future years being all IEM's. The aim was to encourage everyday Australians to experience a typical day in the life of a person living with PKU by significantly reducing their protein intake for 24 hours. By limiting intake to just 10g of protein for a day, the challenge provided insight into some of the complex dietary challenges faced everyday by those living with inborn errors of protein metabolism such as PKU.

The Challenge ran during the month of February with the last day being Rare Diseases Day - 28th February. Participation was either as a "Player" – where you played your protein for a day; or as a "Pledger" where you pledged your support for a player or team. We had an amazing 275 PLEDGERS and 70 PLAYERS. This is a great result for our first year and we look forward to seeing this grow in future years.

Over \$17,000 was raised via the campaign, and this money will go towards further research, support programs and resources to help enable every person living with PKU, live to their full potential and optimal health. As well as funds, the awareness we have raised through various media such as radio, newspaper and TV interviews has been beyond expectations and very encouraging.

We were grateful to have some politicians join the challenge - some played and others pledged. Member for Deakin, Michael Sukkah MP joined the MDDA President, office staff and local members for a low protein lunch (off their specialised low protein menu) at The Grand Warrandyte, on his play date

This idea has been in the pipeline for a number of years with input from various members during this time, and the MDDA is proud to have been able to finally bring it to life on behalf of the entire Australian IEM community.

It is expected this initiative will become an annual awareness and fundraising event for the MDDA, with other countries also expressing interest in its success and therefore future plans to take the initiative globally are on the cards.





When protein makes you sick – Wollongong woman's rare disorder

Bianca Albanese is part of a large Italian family, but a rare and restrictive genetic disorder doesn't allow her to tuck into family feasts.

ILLAWARRAMERCURY.COM.AU



Australians urged to cut protein for a day

Australians are being urged to give up protein-rich foods like meat, eggs and dairy for 24 hours to support those living with the rare yet debilitating genetic disease phenylketonuria or PKU.

NEWS.COM.AU



'I have to count every gram my kids eat'

For most parents, preparing a family meal is pretty simple. For Micaela and her boys, it's a lot more complex.

KIDSPOT.COM.AU



Mandurah student Taylah Shier raises awareness of PKU through Great Protein Challenge | Community News Group

COMMUNITYNEWS.COM.AU



Duncraig man tells of difficulties living with genetic disorder PKU | Community News Group

Duncraig resident Con Giannas has a rare genetic disorder that means he can only eat 15g of protein.

COMMUNITYNEWS.COM.AU



Meet the woman, 28, who can only eat SIX GRAMS of protein a day

Bianca Albanese, of Sydney, was diagnosed at birth with Phenylketonuria, a condition in which the body cannot break down an amino acid found in protein.

DAILYMAIL.CO.UK



THE AUSTRALIAN

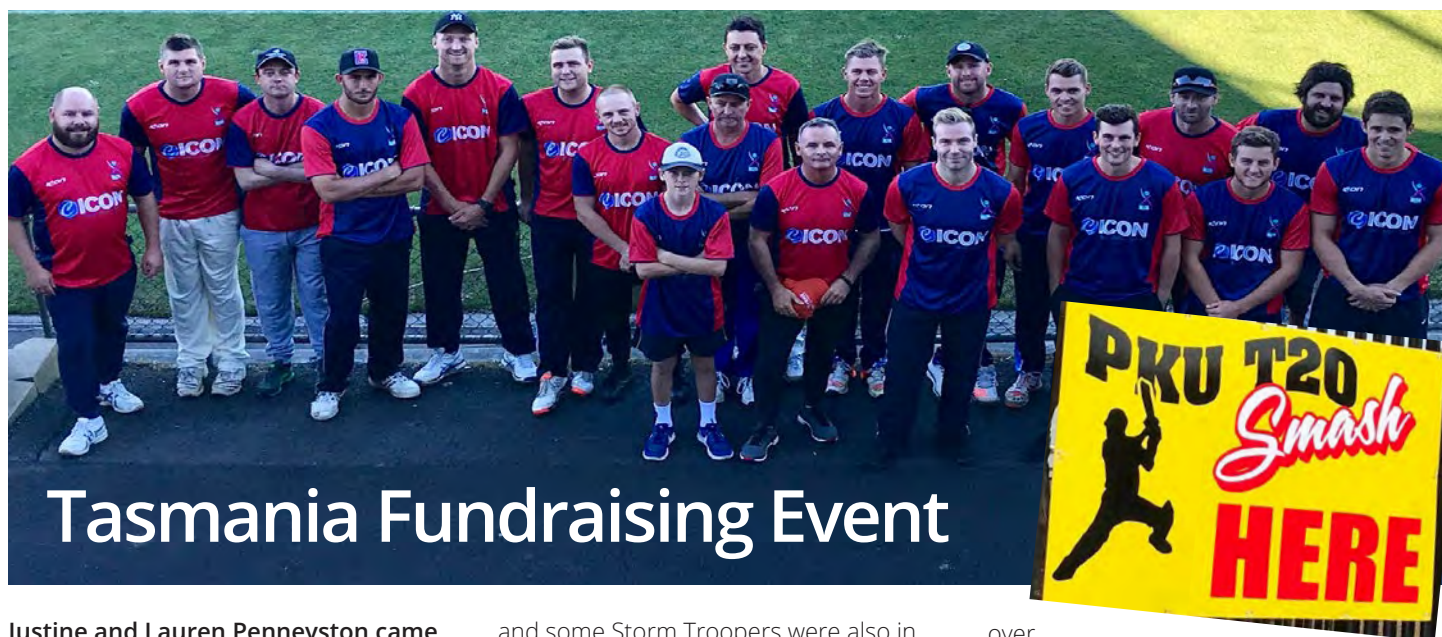
Why little Elaynah can't have more peas

BRAD CHUGH MEDICAL REPORTER

WHEN little Elaynah Chugh, four, was born, her parents, Brad and Sarah, knew they had a special little girl. But they also knew they had a special little girl with a special need. Elaynah has a rare genetic disorder called Phenylketonuria (PKU), which means she can only eat 15g of protein a day. That's about the same as a small pea. For most children, protein is a staple of their diet. But for Elaynah, it's a challenge. Her parents have to carefully monitor her diet, ensuring she gets the right amount of protein. It's a daily task, but they do it because they love their daughter. Elaynah is a happy, healthy child, and her parents are proud of her. They hope to raise awareness of PKU and help other families who are facing the same challenge.



FOOD RISK: Four-year-old Elaynah Chugh, centre, with mum Sarah, dad Steve and baby brother Max. Picture: MATT TURNER



Tasmania Fundraising Event

Justine and Lauren Penneyston came up with an idea and within weeks had the PKU T20 cricket match up and running. It was an amazing effort in coordinating sponsors, members and players. Thank you on behalf of the MDDA for raising awareness and funds and all your time and effort in making this event such a success.

Money raised will go towards assisting families in Tasmania coming to the National retreat in SA 2018. Current MDDA Tasmanian members should register their interest for the retreat and apply for funding by emailing office@mdda.org.au.

Here is Lauren's account of the event.....

What a HIT! Our first Tasmanian Fundraising Event was such a success it sure won't be our last!

On Friday 2nd of March we hosted the inaugural PKU T20 SMASH at KGV Oval, Glenorchy - Tasmania. We estimate around 500 people attended the game, which was an awesome turnout.

What started out to be just a game of Cricket turned out to be a much bigger Family Festival! Aside from the Cricket Match we also had Jumping Castles, Face Painting, Go-Karts and Food Vans. Batman

and some Storm Troopers were also in attendance.

We were extremely fortunate to have current and past International & Domestic Cricket Stars including Jackson Bird, Ben Dunk, Xavier Doherty, Brett Geeves, Tom Triffitt, Hamish Kingston & Aaron Summers. Also included in the line-up was current title holder of the WBA Oceania, WBO Oriental and Australian Featherweight titles and former Australian Commonwealth Games Boxing Team Captain - Luke Jackson, Current 'My Kitchen Rules' Star - Henry Terry, Win News Tasmania Presenter - Jake Keating, ABC Radio Presenter - Chris Rowbottom, ABC Radio AFL Commentator - David Lithgow and Politicians from the Tasmanian Liberal & Labor Parties and our very own 'PKU Kid' representative - Jordan Blyth. All funds raised will go towards the Tasmanian Families of children with PKU to help get them to this year's MDDA Retreat in Adelaide.

The night proved to be a huge success, raising over \$6000. It was so pleasing to see the community get behind the event. Winning Post Productions producing 2 x 30 second Television Commercials, one as a PKU General Awareness TVC and the other to promote our event. Channel 9 Tasmania playing both TVC's state wide,

over 300 times. Local Commercial Radio Station 7HO FM doing a Live interview and also running promo ads. ABC Radio featuring our event on various shows in the lead up. All of this was provided to us Free of Charge. We also had all of the Players shirts donated for both teams by Jon Wells at Icon Sports.

So much fun was had by everyone with some huge 6's being hit! A huge congratulations goes to Jordan Blyth who was awarded Man Of the Match for his hard hitting and 4 Wickets! All of the players requested to be involved again next year.

Following the match we auctioned items that were donated to us by various local business' and some of our star players. The Auction was a big success as far as raising money goes!

Also a big thank you to Monique Cooper and her family for making the trip down to help out on the night. Much appreciated!

If you have a fundraising idea please contact the office via office@mdda.org.au

GET INVOLVED TODAY!



Diet for Life

My story by Con Giannas

My mother used to tell me a story when I was growing up that when I was born she looked at my fingers and noticed they were long and she remembers telling my Dad that I will grow up to be a surgeon someday. However, this all came crashing down shortly after when the Doctor told my parents I had PKU and what that potentially meant.

I was born in April 1970 and the Guthrie test was new and treatment was still a hit and miss. After several months in hospital my parents got to bring me home however mum used to have to go back everyday and then every week and this later become monthly. For somebody who has never driven this was an enormous task.

In the 70s low protein food was limited and low protein bread had to be ordered from the children's hospital. The formula at the time was a horrible powder type which my parents used to add with jam to make it palatable, it was still horrible and they used to have chase me around the house and even down the street to take it.

Thankfully my mother was incredibly strict on my diet and would never allow me to have anything that could risk high protein levels. In 1976 I turned 6 and in October of that year my Doctor added one egg a day to my diet. After showing no obvious signs of affect this became two eggs and on the 2nd August 1977 I came off my diet, I was 7 and 4 months. **I remember my mum put on a little party for me with every type of food thinkable, popcorn, cheese, milk, chips, chocolate etc. but after trying everything all I wanted was a salad.**

After coming off diet I went in for 6 monthly and then annual checks and my Doctor told me and reassured my Mum that I was cured of PKU and that I never have to worry about it again. He even said that I could be prime minister one day. However the reality is that whilst off diet I would never really live up to my true potential.

Going through my later childhood and teen years, off diet, affected not only my social life but I know the my ability to concentrate greatly changed my ability to achieve higher grades at school and to ultimately go to University.

As a adult in my twenties, one of the major symptoms I suffered from was chronic tiredness which no doctor could ever diagnose. I would go out to dinner in Northbridge (Perth's main restaurant and night club area)) and would find myself doing laps around the street just to keep awake. Another trick to keep awake whilst out was to do star jumps in the toilets these sometimes worked but not always.

Working life was difficult, whilst I could do my job well I always struggled to concentrate and keep awake. I would regularly fall asleep in the afternoon whilst on hold to take a call and would come home and would be so tired I could not move or help around the house.



When I had children I would read them a bed time story and would fall a sleep after the second page, my daughter would often shout out "Mum, Dad has fallen asleep again!"

Mum didn't tell anybody what I had, as she puts it, she didn't want me to be treated different. It wasn't until I was about 18 that I found out what I had and the consequences of what could happened if my parents didn't enforce my diet.

Over the years I tried to learn a bit more about PKU and it wasn't until 2014 when I was 44 that I was having lunch and googled PKU, every site I went on said "Diet for Life". Reading the symptoms I had most of them. I remember going to my wife that night and saying that I think I should get checked.

Of course my GP really didn't know what PKU was and looked up in a medical book and found the testing that needed to be done. After having my blood test my GP reported my levels to be over 2800. I was referred to the Adult clinic at Royal Perth Hospital.

My appointment with the clinic was on the 26th May 2014 at around 10.30am. I walked out of there just before noon that day and I have never touched meat again.

After 37 years off diet, I made the decision to stay on diet for life. I can honestly say that it is the best decision I have made.

PKU does not define me and no longer limits me. Being on diet I can now truly live up to my full potential and enjoy life to the fullest.

In life, I have no regrets, however I do regret going off my diet.

Living with an IEM

India Bruce

Age 11 IEM: MMA

My name is India Bruce. I am 11 years old and together with my family, love to spend time in the ocean going sailing, swimming, surfing and snorkelling.

I was born with a metabolic condition called Methylmalonic Acidemia (MMA), which means that I am only permitted to eat a small amount of protein each day.

Treatment.

To treat MMA I have two medicines, four times a day, count the protein in my diet everyday and do lots exercise so that I can keep fit and healthy. While my family have been helping me live with MMA since I was 4 days old, having MMA can be challenging. Mum and Dad work hard to try and make my meals similar to those eaten by other people around me. They cook the same type of meals without the high protein foods like meat and include low protein options to keep my protein count low. They also send lots of yummy food to parties so that I can join in the fun of eating, but I would love to go for 'seconds' and 'thirds' from the party food table, like everybody else!

I am very lucky to have my extended family and friends around me because when I go to their house they always check in with what I can eat beforehand so that I feel included too.

Starting Grade 6.

This year I began my final year of primary school. It has been easy starting Year 6 with MMA because my teacher works closely with Mum, who is also a teacher

at my school. She knows that I need to eat low protein food, which I make myself and she encourages me to manage my own medicine time around midday each day.

This year I have taken on a role as a Year 6 leader in the Learning Portfolio. In this role I help and encourage younger children to read, complete their homework and I also put forward bills in our Year 6 Parliament to support learning initiatives.

One of my favourite roles that I have taken on this year is the role of Arts Ambassador. In this role I get to help with the Arts and the organisation of the school musical groups. I am really looking forward to performing in our Wakakirri team because I enjoy being on stage and had a wonderful experience with this last year.

Camp Experience.

At my school we go on camp for the first time in Year 6. I have really been looking forward to this for many years, but I've also been worried about organising my food at camp. I didn't have to worry so much because Dad was invited to come along on our camp to help and he organised all my food while we were there. Camp was exciting, fun and focused on teamwork and mateship. It challenged us to give everything a go and believe in ourselves. Most of my meals were very similar to those provided by the camp because Dad had found out about meals that would be served in advance and the camp chefs were great at working with Dad to help cook my food.

MMA



It was the best experience ever and even Dad took on the challenge of walking through gooey, shoulder-high mud!

The future.

Through this experience I have learnt that I don't need to worry so much about living with MMA in the future because the people around me, like my family and teachers are always looking out for me too. They talk to me about the events that are coming up, foods that I like to take on excursions and camps and the ways that I can manage MMA in my everyday life. I am looking forward to the new challenges that lay ahead for me this year.

Why your membership matters

Membership ensures MDDA can continue to support all individuals living with an IEM and help them achieve positive health outcomes

- > provide more informed choices, resources and support
- > provide support by way of website, newsletters, recipe resources, Peer support, conferences, family retreats, social activities and many other programs.
- > enables MDDA to provide a voice to government and decision makers on all levels, to promote research into inborn errors of metabolism
- > to raise awareness to the greater community and to advocate for all individuals and families living with an IEM.

Please contact us office@mdda.org.au if you would like to check on the status of your annual subscription or would like to become a member of the MDDA.



Elaynah Cranwell Age 4 IEM: PKU

Protein allowance: 4g

Tell us about the first day of kinder – from a parents perspective – and Elaynahs

Starting Preschool is both an exciting and nerve racking time for any family let alone throwing PKU into the mix. For us trusting in strangers to take the responsibility of your child and trusting that they will follow everything you have told them was the biggest challenge to overcome.

Elaynah was so ready for preschool she was not going to let PKU get in her way. For her, PKU was not even in her thoughts. She just wanted to be the big kindy kid she had been hanging out for all Christmas.

What did the teachers know about PKU?

Nothing, they knew of the newborn screening but not what they tested for.

How were they in accommodating any special requests/requirements?

Very accomodating. After they realised the seriousness of the condition as well as how it will impact Elaynah they were quick to change weekly planned baking activities to better suit options which were easy for me to make a low protein alternative.

In preparing Elaynah for kinder what extra steps did you have to take?

Prior to Elaynah starting we made an appointment with the Principal of the school as well as the Preschool director. After explaining the condition as well as how it will impact her whilst at preschool a meeting was arranged with all teaching staff rostered on the days Elaynah would be attending. We went through and explained everything as well as answered any questions they had. Whist this is not always possible to do it is something we would highly recommend for piece of mind.

Are there any major difficulties you have experienced with starting kinder?

Day 1 we had a hick up. They forgot to check Elaynah had taken her supplement. I will admit I did send a very strongly worded email to the director expressing my concerns given our conversation with the staff was only the day prior. After this though they made signs up and put on the staff fridge so that when they go to get their own lunch out they are reminded to check if she had it.

Does she talk about PKU to new friends/teachers?

Yes she does. She explains she has PKU and that she can't eat protein. She came home from Preschool the other day saying her friend Eva asked why she couldn't eat some food and went on to explain that the teacher explained to the class about her PKU and why she is a little different. She said she felt happy and special when everyone started asking her if she could eat ice cream and other types of food.

What is generally in her snack/ lunch box?

2 serves of fruit as the have morning and afternoon fruit time. For lunch she normally has a Cooler 10 plus salad and either bread roll, half mini low protein pizza, zucchini slice or savoury muffin. As the weather starts to cool down I'll provide warm pasta or rice dishes in a snack size thermos.

What is her favourite food?

Either strawberries or stone fruit. She also loves popcorn and sorbet.

What activity does she love the most?

Craft and helping bake in the kitchen

How will you deal with class parties/excursions?

Speak with the staff and parents and try remain as involved as possible. For excursions I will try and have either myself or another family member attend in the early stages.



Any tips for future parents in making the transition to kinder easier?

Keep lines of communication open between yourself and the school. Try and be prepared for class baking or cooking days. Ask to have involvement of planning food based activities or obtain a copy of their plan for the term so you can pre plan meals around these activities.

Having a close relationship with the kindy will ensure if anything comes up you will usually be the first to know.

What is one thing that you would like everyone to know about PKU and kinder life?

It's easy once you get into the swing of things. Try relax and remember your child will be fine and PKU is really only a very small part of life at Preschool.

Fundraising Updates



Market Night - Laurimar Primary School

Laurimar Primary School hold a Market night each year with funds raised going to the grade 6 students nominated charities. This year we received a letter from Matilda Dean saying how much the MDDA meant to her family because her brother has PKU and that she had nominated MDDA as her charity. We would like to thank Matilda, and her fellow students, Bianca and Charlize, for choosing us and for all their hard work on the night. They raised an amazing \$174.50. Well done girls.



PKU Tasmania - 8 week weight loss challenge

Starting at 156.9kg Brett Smith "Egg" is going on a two month weight loss blitz. Follow his story and weight loss on the PKU Tasmania facebook page. You can pledge a donation per kilo with all monies raised helping families of children with PKU in Tasmania. There will be weekly updates on the site with the final weigh in being on the evening of the 8th June 2018.



Cut for a Cure... the dreads are going for PKU Awareness

After 11 years... Skip is parting with his dreads for PKU awareness... Skip's nephew & niece - have PKU. We are inviting you to join in the days festivities which will involve family fun activities for the little kids, 9 holes of golf for the big kids, wine & grazing platters for the ladies (and those not interested in the golf!) ... before the big C U T which will involve you donating to cut a dread...! Lock in the date - blow the cobwebs off the clubs - get your donations ready - this is gonna be HUGE!!

When: 27 May at 12:00-18:00
Where: Cardinia Beaconhills Golf Links
85-87 Stoney Creek Road, Beaconsfield
Upper, Victoria 3808

**Please contact office@mdda.org.au
for any further details.**

Entertainment Books 2018

Once again Tracey Scott is selling Entertainment Books for the MDDA. All money raised goes directly to the MDDA, with 50% going towards research. Please share this link with your family and friends. www.entbook.com.au/91531w0



Visit our website for the largest range of low protein foods

www.cortexhealth.com.au

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- ☐ Friendly, professional, personalised care
- ☐ New products added regularly



Check us out on Facebook

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NEW!!! WINTER WARMER BREAKFAST CEREAL



Great breakfast option

A staple to every low protein pantry



2 June - Gala Dinner

The PKU Gala Dinner is always a popular event and tickets sell fast. Come along and have a great evening while raising funds for Research into PKU. There are only a few tables left, if you would like to attend confirm asap by emailing info@pkunsw.org.au

PKU Gala Dinner 2018
Saturday 2 June
Ottimo House, Denham Court

Tickets \$250 per person



12 August - City2Surf

Another year has passed and the PKU Association of NSW Inc will again take part in one of Australia's most renowned road races - Sydney's City2Surf. The City2Surf is a 14km route from Sydney CBD to Bondi Beach with an estimated 80,000 competitors who participated. This year it will be on Sunday 12 August 2018.

As iconic as the City2Surf fun run is, 'Phen' the PKU Association platypus mascot, is always amongst the pack, whether it is smiling for a group photo, a high five from a spectator or television / media interview.

We always have a fun time, raising Awareness for PKU so if your keen to participate, no matter what your fitness level is please email info@pkunsw.org.au to register your interest.



2 to 6 October – PKU Youth Camp

Save the date

PKU Youth Camp Tues 2 Oct to Sat 6 Oct 2018

The aim of the National PKU Youth Camp is to have a fantastic time with other PKU children. Campers get to experience various outdoor activities that will test their confidence and encourage team building and problem solving skills. Just as importantly, campers will get the opportunity to make new friends and try new low protein foods. This amounts to a great deal of fun for all campers in a safe and well supervised environment.



National PKU Youth Camp

Tuesday 2 October to Saturday 6 October 2018

at Berry Sport and Recreation facility

A fun and enjoyable camp for children aged 8-17 years with PKU

AN EXPERIENCE OF A LIFETIME

Enjoy activities such as archery, abseiling, rock climbing and canoeing while getting to know other kids from around Australia who have PKU.

TRY DIFFERENT FOODS

Obtain new ideas and recipes and try different foods for the PKU diet.

REGISTER NOW

Registrations for 2018 are now open so secure your place and email info@pkunsw.org.au. If you would like to talk to a supervisor, contact James on 0439 977 502.



MEET SOME OF THE SUPERVISORS

BARBARA SLISKO

My name is Barbara and I'm a 21 year old university student living with PKU. I'm supervising this year, as I have for the two previous camps, because not only do I enjoy volunteering but I enjoy the environment where myself and the other supervisors and campers can discuss living our lives with PKU.



JAMES ROBERTSON

I live in Maroubra with my wife and three boys, two of whom have PKU. I have been a leader on the previous two PKU Youth camps. I enjoy spending time with family and friends (playing sport, camping, at the beach...) and cooking



PAUL MELHAM

I have two young daughters, 1 with PKU and have been supervising the past 3 camps. The reason why I volunteer to supervise at PKU camps is to gain a greater understanding of how families manage PKU and also to gain reassurance that Pippa, my daughter, would have every opportunity to thrive and not be held back by her PKU.



SARAH SLACK

I am the Nutrition Education Assistant at The Children's Hospital at Westmead and help families with the practicalities of low protein diets: providing ideas, resources and hands-on education. I was a supervisor at the last PKU camp and thoroughly enjoyed the week and am looking forward to being involved in the next one because I have seen how beneficial it has been for many of the patients who went to the last camp. The social interactions and friendships formed at camp are invaluable.





Recipes

**calculate all recipes as per guided by your dietitian*



Eggplant Savouries

Ingredients:

1 tablespoon olive oil
2 tablespoons chopped onion
2 cloves garlic minced
1 medium eggplant cubed
2 cups low protein bread crumbs
1 teaspoon dried oregano
1 teaspoon dried parsley
1 teaspoon egg replacer
Salt and pepper to taste

Portions Makes 24

Method:

Preheat oven to 180°C. Heat the oil in a fry pan and cook the onion until soft.

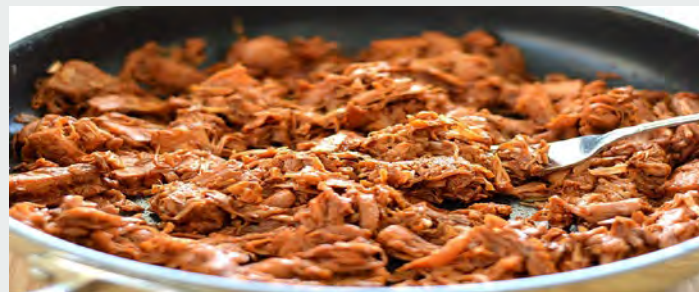
Add garlic and eggplant and cook for 15 minutes until the eggplant looks grey.

Transfer eggplant mixture to food processor and puree. Stir in crumbs, herbs, egg replacer, salt and pepper.

Roll 1 tablespoon of mixture into a ball and place on a lined baking tray. Repeat until all mixture is used.

Cook for 20-25 minutes turning halfway.

Serve with your favourite dipping sauce.



B-B-Q Pulled Jackfruit

Ingredients:

2 x 20g oz cans green Jackfruit in brine
1/2 tablespoon brown sugar
1 teaspoon smoked paprika
1/2 teaspoon garlic powder
1/2 teaspoon salt
2 tablespoons oil
1 cup BBQ sauce
1/4 cup water

Portions 6
Serving size 1 cup

Method

Rinse and drain the canned jackfruit and place in a bowl.

Mix in the sugar, paprika, garlic, chilli powder and salt with the jackfruit.

Add mixture to sizzling fry pan and cook for 3 minutes then add BBQ sauce and reduce heat to low.

Cover and simmer for 30 minutes. Stir occasionally and adding water to thin the sauce if needed.

Once the jackfruit has softened remove from heat and pull apart with 2 forks.

Serve with a salad or in a low protein bun.



Strawberry Icecream

Ingredients:

3/4 cup (175ml) aquafaba (liquid from a can of chickpeas)
225g fresh sliced strawberries
75g Powdered sugar

Portions 14
Serving size 1/2 cup

Method:

Place aquafaba in a large bowl and whisk until stiff peaks form (whisk for about 10-15 minutes).

Add the powdered sugar and lightly whisk to incorporate well. Set mixture aside.

Puree the strawberries then add to the bowl of aquafaba mixture. Mixing gently using a spatula.

Line a suitable container with parchment paper and pour mixture in.

Place in the freezer for 4-5 hours.

Scoop out as desired and enjoy!



Raisin & Cinnamon Cookies

Ingredients:

225g low protein flour
75g soft butter
1 teaspoon baking powder
35g soft dark brown sugar
85g raisins
3 teaspoons cinnamon
85g golden syrup

Portions Makes 12

Method:

Preheat oven to 170°C
Rub the butter into the low protein flour mix until it resembles breadcrumbs.

Mix in baking powder, sugar, cinnamon and raisins

Add in golden syrup. Mix well and bring together into a dough.

Turn out onto a work surface and knead lightly.

Divide the mixture into 12 even balls. Place on a greased baking tray 3cm apart. Use a fork to gently flatten tops of cookies.

Bake for 12 minutes or until golden but soft to touch. Let cool for 5 minutes.

Product update



Jimalie: Coconut Wraps

Protein per 100g: 3.1g
Protein per serve: 0.5g
Serving size: 14g - 1 wrap
Available from:
Health food stores



Field Day organic: Fruit Stars

Protein per 100g: 0g
Protein per serve: 0g
Serving size: 18g
Available from:
IGA, Health food stores



Upton: Barb-b-que Jackfruit

Protein per serve: 1g
Serving size: 75g
Available from:
Vegan Essentials &
Healthy Being stores



Nudie: brekkie

Protein per 100g: 0.4g
Protein per serve: 1.0g
Serving size: 250ml
Available from:
Coles & Woolworths



Old El Paso: Enchilada Sauce

Protein per 100g: 1.0g
Protein per serve: 0.4g
Serving size: 37g
Available from:
Coles & Woolworths



Jans: Jalapeno Cassava Chips

Protein per 100g: 3.6g
Protein per serve: 1g
Serving size: 28g
Available from:
Woolworths



Health attack: Crispy Fruits - pure strawberry

Protein per 100g: 8.3g
Protein per serve: 0.8g
Serving size: 10g
Available from: Woolworths



Mission: Gluten free wraps

Protein per 100g: 1.8g
Protein per serve: 0.9g
Serving size: 48g
Available from: Coles



Raw C: Coconut milk coffee

Protein per 100g: 0.6g
Protein per serve: 1.8g
Serving size: 300ml
Available from:
Woolworths

Special Medical Foods Suppliers



Nutricia / PKU Connect / Loprofin

[www.pkuconnect.com.au/
product-category/
low-protein-foods/](http://www.pkuconnect.com.au/product-category/low-protein-foods/)

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Ph: 1800 889 480



Vitaflo / V2U / Fate

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home-delivery](http://www.vitaflo.com.au/home-delivery)

Ph: (03) 5229 8222



Cortex Health / Cambrooke

[www.cortexhealth.com.au/
products/low-protein-foods](http://www.cortexhealth.com.au/products/low-protein-foods)

Ph: 1800 367 758

PKU Direct Oceania
www.pkudirect-oceania.com

Platypus Foods
www.platypusfoods.com.au

2018 National Family Retreat

South Australia

21-23 SEPTEMBER 2018
ADELAIDE HILLS CONVENTION CENTRE



MDDA retreats are designed to be relaxed weekends away to get to know and enjoy the company of other families and members of the MDDA. With plenty of activities to join including;

Cooking Demonstrations and Workshops

Discussion Forums

Doctor and Dietician Presentations

Team Building Exercise

Kids & Teens Club

and much more

Cost - MDDA Members

Accommodation options are available both onsite and offsite. Single accommodation onsite is extremely limited, so sharing is encouraged where possible

	Onsite: AHCC - Handorf Resort	Off site: The Manna of Handorf
Adults (Twin Share)	\$240 pp	\$240pp twin share offsite
Adults (Single)	\$375pp (<i>limited - share preferred</i>)	\$295pp single offsite
Teens (12-17)	\$115 pp (sharing with 2 adults)	\$165 (sharing 1 adult)
Kids (2-11)	\$95 pp (sharing with 2 adults)	\$135 (sharing 1 adult)
Kids (<2yo)	Free (Kids Club / Occasional care available at \$50pp)	

Costs are ALL INCLUSIVE and include 2 night's accommodation, all meals and activities from Friday Afternoon to Sunday lunch.

Includes low protein and special dietary meal requirements, some snacks included.

Alcoholic beverages at own cost.

No Accommodation Packages

Package includes all conference activities, meals and kids club but exclude accommodation and breakfast

	Fri-Sun	Sat Only
Adults	\$155	\$75
Teens	\$95	\$60
Kids	\$75	\$40

Limited spaces available. Day rates available.

BOOKINGS ESSENTIAL

Register today! www.mdda.org.au

This newsletter will only grow and get better with your input.

Please share your stories, ideas and tips, birthday celebrations and functions with us via office@mdda.org.au

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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.

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