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MDDA News

Newsletter of Metabolic Dietary Disorders Association

Issue 60
2016

2016 - A Reason to Celebrate

2016 marks 50 years of newborn screening in Australia, and at MDDA **we celebrate!** 50 years of early detection of PKU in our babies has meant life changing outcomes for every single baby that has been picked up during this time - many now thriving as adults, and who faced a very different future if born prior to testing.

MDDA is involved in a number of celebrations and activities throughout the year to honour the 50 years. Kick starting with the recent Victorian Royal Children's Hospital event, where hundreds of health professionals, scientist, government representatives and media all joined together to celebrate the program and discuss current successes and advancements. At this event, MDDA provided an uplifting presentation **expressing our gratitude** as a community – for our babies to have been given the chance to live a life free from disability. It was certainly nice to be able to share our stories and achievements with the many people involved in the newborn screening program, and celebrate the triumph that it has been for our families.

Members wishing to be involved in our newborn screening campaign and celebrations this year are encouraged to keep an eye on our website and facebook forum, as further details on how you can be involved will be coming soon.

If you haven't already done so, I also encourage you all to put the dates for our upcoming **family retreat** and **youth camp** in your diaries taking place end of September this year in NSW. Registrations will open shortly for these events, and we recommend you make every effort to get there as it will be a great experience for the entire family.

This news edition celebrates and shares back to **school stories** from some of our members, introduces the **2016 committee** and also reveals a new '**adults only**' section (don't worry it is not *sealed* and is certainly for the most part PG rated).

You will also read about how this July Philip Acton father of 3 adorable boys will take on the epic feat of cycling from Townsville to Brisbane to raise awareness of all IEMs and fundraise for the MDDA. Information will follow soon as to how you can support Philip in his valiant challenge.

Happy Reading!

Monique Cooper, President MDDA

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Donations over $2.00 are Tax Deductible

Meet your MDDA Executive committee 2016

Monique Cooper: - President

Monique has been involved with the MDDA since 2010 when her son Charlie was diagnosed with PKU. In 2012 Monique became the president of the association and since this time has led the executive team. Like many new parents, Monique and her husband Dean reached out to the MDDA when Charlie was born to meet other families faced with the same diagnosis, developing a personal network of support and ensuring the best possible path was taken for a positive future for Charlie. Monique and Dean also have an older daughter, Chloe (10). Monique runs her own business as a marketing and events management professional and also gets involved in a number of school committees and kids sporting club activities.

Louise Healy: - Vice President

Louise has been involved with the MDDA since the 2008 conference that was held in Brisbane. She has held roles of committee member, Link network contact, Wellbeing and Advocacy co-ordinator for the MDDA. Louise is married to Brett and they have two children Evie (8) and Sam (5). Evie has PKU . Louise has post graduate qualifications in psychology and runs her own business providing executive and leadership coaching to businesses and individuals. She has a particular interest in neuroscience and mindfulness and how these can help people to thrive in challenging situations. Louise is also active at her children's school including convening a Chair at the biannual fair. Both the children love coming to the MDDA events and the Brisbane Christmas party each year is a highlight for them. Evie is currently planning to work for the MDDA when she grows up!

Melinda Mcginley: - Secretary

Melinda's interest in the MDDA started upon attending the retreat in Victoria 3 years ago, in which she was initially reluctant to attend! Melinda found the MDDA committee to be so welcoming and passionate with a great vision of how to help everyone with an Inborn Error of Metabolism, that she started to do a bit of voluntary work in the office, becoming secretary in November 2015. Melinda is married to Nick and has two boys Charlie (9) and Darcy (7). She has been lucky enough to be a stay at home mum, but now that the boys are older, has returned to study to pursue a social work career. Darcy has PKU, which she finds can be challenging at times, so she is hoping her life experience can help in dealing with others.

Paige Moore: - Treasurer

Paige became involved with the MDDA when her daughter Sophia (6) was diagnosed with PKU in 2010. Paige volunteered for the MDDA and then became Treasurer in 2012, following the conference in Brisbane. Paige now is partnered with John and they have a second child, Michael who is 4 months old. Paige works as a Finance Manager for a boutique law firm in Melbourne's CBD and is currently on maternity leave. Paige has a passion for sailing and races regularly out of Williamstown, The MDDA has become part of Paige and her families daily lives as they have made many new friends who they rely on for support and have become a "Second Family". Their, daughter Sophia, has also made many friends with IEM's and without the MDDA this would have never been possible.

Susanne Hendricks: - Health & Wellbeing, Peer Support Programs

Susi has been involved with the MDDA within various roles on the Executive Committee since 2002 when her family returned to Melbourne from England. Finlay, their second child, was diagnosed with classic PKU at birth in 2000. They also have an older daughter, Isabella(18) and a younger son, Sebastian(5). As a mother of a child living with PKU (now 15) and a Psychologist, Susi is passionate about ensuring those born with an inborn error of metabolism are able to live life to their full potential and experience no difference in opportunities and experiences compared to those without the condition.

Richard Drewitt: - IT Operations & **Katy Drewitt:** - Adult Program

Katy and Richard have been involved with the MDDA for the last 5 years. They have held positions of Secretary, Vice President and general committee members. Katy currently leads our Adult program and Richard head our IT Operations. Katy has classical PKU which was diagnosed at birth. She was treated on diet up until the age of 10 and then returned to diet when she turned 30. Katy's personal experience has led to her volunteering for this role in supporting other adults. They live in the northern suburbs of Melbourne with their almost 2 year old daughter, Eden.

50 year Anniversary of Newborn Screening in Victoria

On the 10th February this year the MDDA and members attended The Royal Children's Hospital to celebrate 50 years of Newborn Screening in Victoria. The MDDA president Monique Cooper was invited to present to researchers, doctors and nurses from across the State involved in the NBS program. Monique's heartfelt presentation began from the moment they got 'that call' that most parents can tell you exactly where and what they were doing through to how PKU is now part of their everyday life. Monique's presentation included a celebration video focusing on the positiveness and gratefulness felt by many families who without diagnosis via the heel prick test their lives would have very different outcomes. The reaction to this presentation has been overwhelming with Monique now being requested to present at hospital maternity wards around Melbourne to help show the importance of the heel prick test. Well done Monique we are proud of you!

Murdoch Children's Research Institute media release following;

"Newborn screening is a vital health program that tests more than 99% of the State's infants for serious, treatable conditions. Victoria's newborn screening program is operated by Victorian Clinical Genetics Service, which is based at the Murdoch Children's Research Institute, and is fully funded by the Victorian Government.

The voluntary heel prick test is performed within 48 to 72 hours after birth, with almost all parents choosing to participate. With 220 babies born in Victoria each day, approximately 79,000 newborn screening tests were performed during 2015.

The newborn screening program commenced in 1966, initially screening for one condition, phenylketonuria (PKU), a genetic disorder that prevents the normal breakdown of protein. Today, the heel prick test screens for 25 rare, but serious medical conditions, including PKU, hypothyroidism and cystic fibrosis. The blood is taken by pricking the baby's heel and most babies have a normal screening test result. Samples are spotted on to cards, which are commonly known as the 'Guthrie card' after the test's inventor Dr Robert Guthrie, and analysed at the Newborn Screening Laboratory at VCGS.

According to Dr Damien Bruno, Laboratory Director at VCGS, newborn screening is an extremely successful public health program that can make a huge difference in the lives of young families.

"Many parents can't recall their child's heel prick test, but for the few who do receive a diagnosis as a result of newborn screening, it can make an incredible difference in the future of their child," said Dr Bruno.

Dr Bruno said that in many cases, simple treatments or lifestyles changes, such as diet changes for children with PKU, can be started early to prevent permanent damage that would otherwise have occurred had the test not been performed.

The VCGS hosted a special one-day event to mark the Anniversary, welcoming researchers, doctors and nurses from across the State who had worked on the program since its inception. On hand to mark the occasion were families whose children were diagnosed with conditions as a result of newborn screening, including Monique Cooper and her son Charlie, diagnosed with PKU via newborn screening.

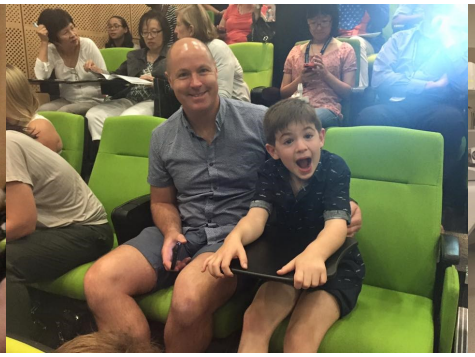
"Like many new parents, it was a shock for us to receive a diagnosis, but because newborn screening was able to pick up Charlie's condition early, we have been able to ensure the best possible path was taken for a positive future for our son," said the mother of two, who is also President of the national support group Metabolic Dietary Disorders Association (MDDA)". End.

Laboratory tours were conducted to see what happens with the new born screening cards sent to the hospital for processing. MDDA will request tours for later in the year for those interested, we will let you know dates once confirmed.

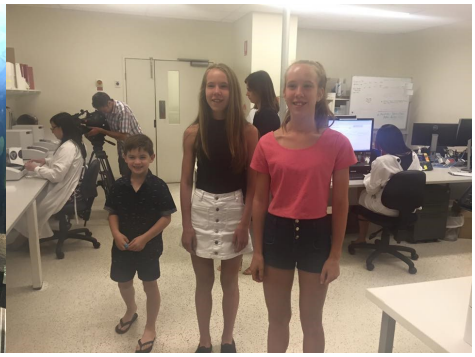
Thank you and congratulations to Sally Morrissy Newborn Screening Nurse from the Victorian Clinical Genetics Services for all the organising and the success of the day. Thank you to Charlie for being our little "super star" ambassador. Charlie Cooper, Brooke and Nat Hellings appeared on the news that night helping to continue our campaign of raising awareness of rare inborn errors of metabolism in the community.

The MDDA will celebrate nationally 50 years+ of newborn screening throughout 2016. There will be opportunities for you to be involved in the celebrations. Keep a look out on our website for upcoming details.

Monique presenting



Dean and Charlie Cooper at the symposium



Charlie with Brooke & Natalie Hellings on a lab tour

To: Monique Cooper,
President MDDA

Dear Monique

Please thank your team for regularly sending me the MDDA news & updates over the years, even though I retired from RCH Melbourne 30th Sept 2005.

The impressive News-letter and current annual report show a thriving support group. It is marvellous to see the developments and growth of the state support groups and the wide spectrum & aspects of IEM covered these days. I am very proud of your team and the huge input you all gave to change the Government's decision over the food grant withdrawal. This you rightly did for the wellbeing of those with an IEM; **WELL DONE.** It brought back many memories especially re the food grant application and campaign to get it accepted both times by the Australian Government. I was involved in the original submissions for a food grant or more support foods on PBS for PKU and similar disorders. I did much of the costing comparing PKU alternative to the cost of a normal food & the diet for different age groups so I know the amount of work such things require; but they do make a difference as witnessed in 2015 .

You may be interested to hear some of the other early IEM dietary struggles both in Australia & UK. It all comes to memory as I was invited to the New Born Screening (NBS) meeting at RCH on 10th February 2016 celebrating 50 years of NBS in Victoria.

I was briefly involved in the NBS campaign in 1960-3 at RCH Melbourne when mostly toddler PKU's were being diagnosed & the diet made little difference to their development. As a new graduate dietitian at RCH I was given the task of researching & organizing the PKU diet using a horrible formula for these children called Cymogran or Lofenalac. It was a challenge as the American and English diet versions seemed so different, but it was a fantastic privilege to be involved and to see the early diagnosed younger siblings of known PKU's initially, then those diagnosed by NBS who started the diet at an earlier age doing well.

Indeed it was because no one seemed to know what the PKU diet should be that at Easter 1963 I sailed for England to work for a year in London at Great Ormond Street Children's Hospital (GOSH) as England was the 1st country closely followed by USA to start dietary treatment for PKU. My aim was to get experience in these rare diseases and there dietary treatments.

I was 1 of just 2 dietitians working at GOSH in those days. After a year I was asked to stay on and ended up as Chief Dietitian. An amino acid formulae was 1st made at GOSH when a child diagnosed with MSUD was admitted to GOSH and this was adapted for children with PKU. One of the 3 then GOSH dietitians had to put aside 1-2 afternoons each month to make each child's formulae, weighing each ingredient with ≥1g accuracy. Some ingredients required even more accurate Pharmacy scales.

The Clinical Biochemist Professor Barbara Clayton advised and supported our work. After much research published in Medical journals these amino acid formulae to treat patients with Inborn Errors of Metabolism (IEM) were marketed as the Aminogran & Neocate formulae ranges. The parents often had to weigh measure & add 5-6 additional ingredients each day when making the formula such as special minerals and vitamins to ensure adequate nutrition for the child's needs. Gradually new formulae were invented many by the GOSH team and then mostly Pharmaceutical companies took over the manufacture of these special products used to treat patients diagnosed with IEM. What a contrast to these days with multiple choices of formulae, different ones for each IEM disorder and age group.

I ended up working @ GOSH for 24 years returning to RCH Melbourne in June 1987 initially as Chief Dietitian and later moved to Victorian Clinical Genetic (& Metabolic) Services until 2005 when I retired. Thereafter I continued a private practice for children with less complex dietary problems than IEM such as food allergies and continued this till I finally retired at the end of 2015.

Keep up the good work as a 'truly national support group.' I wish you well for the future.

Yours
Dorothy Francis
Paediatric Dietitian

NB: At the 50 year anniversary celebrations our president caught up with Dorothy Francis, **Paediatric Dietitian** who had recently sent this email reminding us all of how far we have come. She has kindly agreed to the publication of this email.

IEM Food Grant Information for 2016

Purpose of the Grant

The Department of Health information page regarding the IEM grant states: "The Inborn Error of Metabolism (IEM) Programme provides monthly financial assistance to approved grantees with protein metabolic disorders to assist with the purchasing of low protein foods.

The purpose of the IEM grant is to enable people with IEM to stay on strict diets and ensure long term health is maintained. Non-food items, such as medications and supplements, cannot be purchased with money provided under the Programme." When discussing any aspect of the grant on various forums please be mindful of its purpose.

Compliance with the diet and using the grant for its intended purpose is one of the ways we as a community can demonstrate to the government the ongoing need for the grant.

Compliance

The Department of Health information clearly states that "dietary compliance" is a condition of receiving the IEM food grant. Patients diagnosed with Dihydropteridine Reductase (DHPR) deficiency, Hyperphenylalaninemia and Phenylketonuria (PKU) must reapply for the IEM grant every twelve months. This is to help monitor compliance.

To ensure that you meet the reapplication criteria and can have your reapplication signed by your clinician we recommend the following:

- Attending clinic appointments as recommended by your clinician.
- Submitting regular blood samples as recommended by your clinician.
- Maintaining your diet and taking your supplement as suggested by your metabolic team. The recipe and product resources on our website can help you with ideas for keeping your diet interesting a varied.
- Attending MDDA functions such as cooking days, social functions and retreats can provide support, ideas and motivation if you are struggling with your diet.
- Contacting any of the people listed in the Link network on our website to get support and encouragement.

Payment Schedule 2016

The due dates for the IEM food grant payment for the remainder of 2016 are listed in the column below.

The payment is due on the Friday of the first full week of each month. If the payment has not arrived by the date listed please contact the Department of Health using the contact details listed.

This FAQ page from the Department of Health website provides useful information about the grant including what do to if you have not been paid and how to lodge an application.

http://www.health.gov.au/internet/main/publishing.nsf/Content/Inborn+Error+of+Metabolism+Programme

IEM Food Grant Indexation

The payment is increased each year based on CPI to reflect increases in costs of living.

Costs of Low Protein Products

As suppliers do not increase the price of their products every year the costs of imported products are affected by both CPI and non CPI factors such as exchange rates some years may see a larger than CPI increase in the price of products as we have seen this year.

We are fortunate that there are now several suppliers so we have a choice of products if any aspect of a product does not suit our needs. Please see list of suppliers in the column below.

Dates for IEM payments 2016

11 March
8 April
6 May
10 June
8 July
5 August
9 September
7 October
11 November
9 December

Department of Health contact details:

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

Low Protein suppliers

www.vitaflo.com.au

www.pkuconnect.com.au

www.cortexhealth.com.au

www.platypusfoods.com.au

If you have any general questions please contact the MDDA Office freecall: 1800 288 460

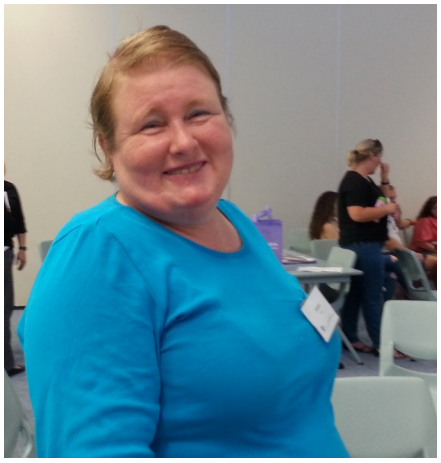
IEM ADULT NEWS - Debbie's Story

I was diagnosed with PKU at the beginning of 1961 at 2 years 4 months in Sydney, NSW. I have two sisters and one brother all non PKU. Life with PKU was treated so very differently back then, there was very little knowledge known in the world at this time. My mother fought hard for a diagnosis for me during my first two years of life literally living on our local doctors door step until one day I was convulsing and banging my head on the floor. The interesting thing about my hitting my head on the floor was that I placed my hands down on the wooden floors to protect my head. Quite intelligent really!

Mum took me out to The Royal Alexandra Children's hospital in Sydney where they did all the usual testing which all proved negative. They thought that I was deaf or autistic but soon ruled that out as well. The doctor told mum to put me in an institution and concentrate on my sister. There was no way she was going to give up on me and asked the doctor if there was any new conditions in the world that he had heard of. His reply was a medical journal from the LA Children's Hospital landed on his desk last night. "There is a condition in the newsletter but if your daughter tests positive to it she will have to be put in an institution". Mum wouldn't hear of this and said that she wanted me tested.

Mum was given impregnated paper to take home to place it in my nappy to test my urine and had to return it by post. If the paper turned green I tested positive for PKU which of course it did. I was put into hospital for a month the medical professionals tested me on different foods to see my reaction. One day I was given protein the next day I didn't have much to eat only raw carrot. Back then they believed that if you cooked food you would be adding protein. Mum came out to the hospital to take care of me every day. On the last day mum was handed a sheet of paper with three or four foods that I could eat. She did everything she could to give me a good start in life!

After going on a holiday with my parents to Lake Macquarie I got really sick so my father was sent by my mother out to find the local doctor. Fortunately for me this doctor had just had a meeting with Mead Johnston who were the makers of Lofenalac. My parents cut our holiday short as the doctor was able to put them in touch with medical professionals in Sydney that could help with my PKU treatment and soon after our return home I was put on Lofenalac.



My parents raised me as just one of the family with an active childhood participating in everything! We just had to visit the dietician fortnightly and of course went for fasting early morning blood test at the Children's Hospital when required. I remember on the way to the hospital we had to drive past the Arnott's biscuit factory. The aroma of the biscuits was amazing I wished I could eat one as I remember being so hungry and the smell of the biscuits made my hunger worse.

Mum was passionate about lobbying for the screening for PKU to be brought in to hospitals around Australia to prevent lives being affected by this disorder and to help others have the best quality of life possible. In 1962 screening for PKU was beginning to be introduced into hospitals and baby clinics all around Australia.

During the 60's families kept ailments and sicknesses their kids had behind closed doors. There was no awareness for disorders back then so here we were informing kindergartens and schools about PKU, what was known at that time and the fact that I had to live on a special diet which certainly drew so much negative attention. Mum came up to the kindergarten and school for every recess and lunch break to make sure I didn't swap my food with anybody as the teachers weren't there to monitor what I was eating.

Lofenalac wasn't a great tasting formula and had a really bad smell but I grew to like it and soon it was just a part of my life. I was changed to another formula which was Calorine the sweet, glucose powder. We had to mix PKU Aide 2 which was the tyrosine mixture, ketovite tablets, ketovite liquid, fergon tablets and liquid then a calcium tablet with 1/4 pint of cream every day. They thought that since I couldn't have milk that adding cream everyday would help with my development throughout the early teenage years. I never could stomach this formula. When I was in my teens I was approached by the medical professionals who then believed that teens with PKU could come off diet. I did which was such a bad decision on my behalf.

Over the 18 years I was off diet my symptoms grew worse overtime, even though I was working full time I was lucky to be working with such a great team of people who put up with my temper tantrums, mood swings, tremors, eczema, exhaustion, etc which all led to other health problems. I almost lost my job. My family were concerned at how badly I was coping so mum made an appointment with the dietitians at The Children's Hospital at Westmead for me to get back on diet which I did. I was put onto Maximum XP unflavored which took

Continued page 7

Debbie's Tips

Diet & Lifestyle

- I like to refer to my PKU diet as a ***lifestyle*** not a diet. These days many people are on some sort of diet. When I hear the word diet it usually suggests that you have the choice of maintaining it for any length of time you choose. As we know the PKU diet is "diet for life".
- For me, I feel at my best when I am active! Did you know being active can help with reducing phenylalanine levels.
- Eating a range of vegetables and fruits supplies us with extra vitamins and minerals.

IEM Adult Tips & Tricks

- Drink your formula as it is the most important thing.
- When eating out in restaurants/cafes try to choose the healthy options from the menu. Discuss with the waiter/ waitress other menu options if you are finding it hard to order something suitable. Sometimes you only need to ask.
- Have a rough idea how much protein/phe you are getting during the day.
- Allocate a cooking day and cook up your favourite food/ snacks particularly if you work as it will make life easier.
- If you need support just know that help is only a phone call/ email away. We are all here to support each other.
- Always check with your metabolic clinic if you are unsure.

IEM ADULT NEWS - Debbie's Story cont

my body a long time to adjust to. I needed to as my blood test was 2,500 micro moles before I was put back on the low phenylalanine diet.

The medical professionals back then also told me that there was no way that I could have children which was so hard to hear. As time went on treatment and knowledge of PKU improved which was great.

In 2012 I was awarded the Order of Australia Medal for my work over the years to the health community through The PKU Association of Australia Inc. My mother was also awarded an OAM in 2015. I have managed to achieve quite a lot in my life such as carrying on my father's legacy of being on the Committee of The PKU Association of NSW Inc. in various roles. My parents helped to start up the association with a couple of other parents in 1968 when it was known as NSW PKU Society. Some of my passions are: helping people by my contributions to the community through the association, MDDA, traveling, attending PKU events, conferences when possible, softball, tennis, swimming, socialising etc.

The PKU Association Of NSW Inc. host camps for kids from 8 - 18 years I have been fortunate enough to work on the first PKU camp in 2000 with Mal Hayden and the staff from The Children's Hospital At Westmead,. The vision was to give children and teens an experience of being on their own, learning to deal with their diet without their parents around with PKU adult supervisors who are good role models. I enjoy being involved with these camps, being able to make their lives better and making PKU buddies which is so valuable throughout life.

I will be attending the 4th NPKUA conference in Indianapolis 28th to 31st July 2016. I have been to all four conferences that have been held by the NPKUA and they are truly an amazing experience.

My future goal is to live life to the fullest and to continue to live the PKU lifestyle!

Debra Colyer OAM

The MDDA welcome any adult with an IEM to contribute their Tips & Tricks 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. Next edition "Jill's story".

WA Members picnic

On Sunday 28th of February, WA members gathered at Heathcote Reserve for a picnic. Our Christmas party which was planned in early December had to be abandoned due to very bad weather, so we thought it would be a good idea for a get together on Rare Diseases Day.

This time round we had a bright and sunny day (albeit a bit windy) . The older kids got together with some parents to play games of cricket, soccer and boules. Most of the time though, they disappeared to the Pirate ship playground to leave the adults to talk.

It was great meeting and welcoming several new members to our IEM family. All of the new faces were parents and

family members with babies and toddlers with IEM's, and we look forward to getting to know them, on what will hopefully be a life-long journey together.

Conversing with people who understand what our IEM experience is about always makes for a nice afternoon.

Everyone got to taste bread and cupcakes made from Platypus Foods Bread Mix and Baking Mix and all were impressed with the results . We also had a variety of fruits, veggies and veggie chips for the kids to share.

At the end of this lovely day, several of the new members expressed their wish that get togethers like this would occur more often, so we hope to organise meetings on a more regular basis for our WA based members.

Fiona and Scott Greer

Rare Disease Day - 29th February 2016

The Genetic Support Network Victoria in collaboration with Murdoch Children's Research Institute celebrated Rare Disease Day on the 29th February by holding a seminar where the latest Researchers presented and outlined the importance of all countries and researchers sharing of data, in helping identify rare diseases. Dr Kym Boycott a leading investigator of Rare Disease Genes in Canada, Prof Kathryn North, the Director of MCRI and A/Prof Tiong Tan, Clinical Geneticist all presented on the benefits and exciting direction research into rare disease is heading into the future.

The MDDA was represented by President Monique Cooper, Jenny Briant and Kerry Tulloch.

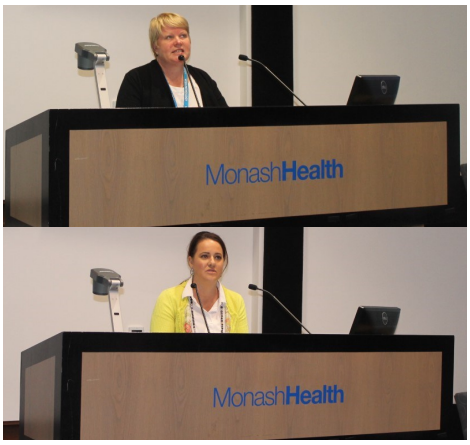
genetic support network of victoria

Murdoch Childrens Research Institute
Healthier Kids. Healthier Future.

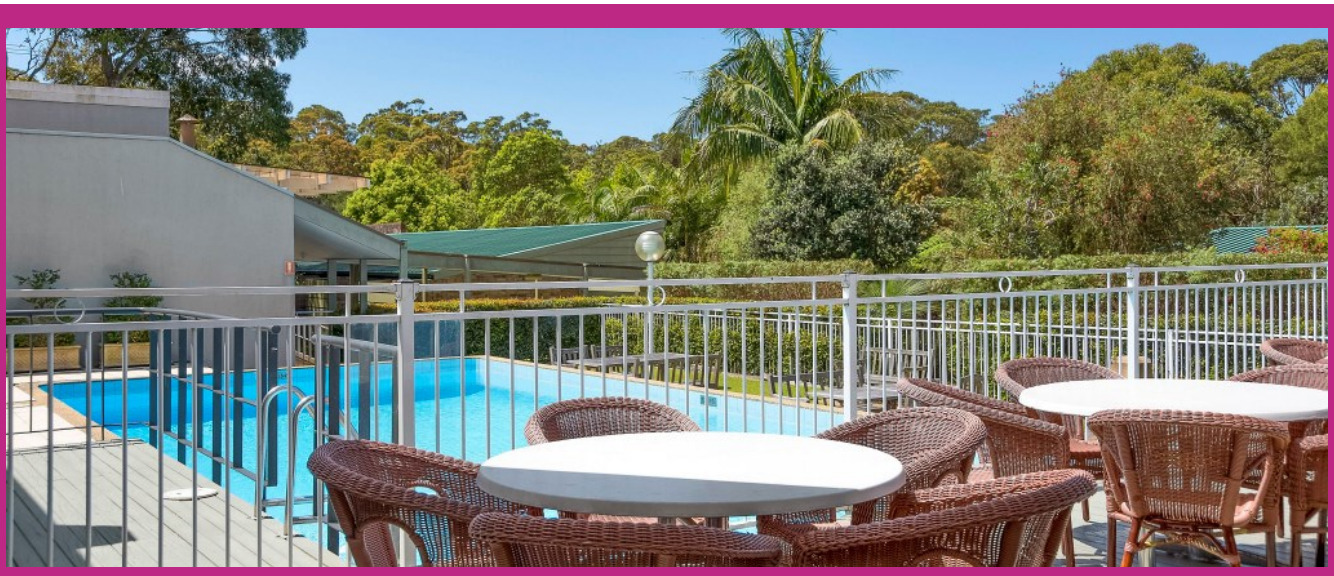
Newborn Screening Education

After the successful and moving presentation Monique Cooper gave at the Victorian NBS 50 year Celebrations, the MDDA were approached by Monash Medical Centre, Clayton Victoria and requested Monique repeat her presentation at an educational in-service over two days to enable as many midwives as possible to attend.

Monique presented alongside Victoria's newborn screening nurse Sally Morrissy. Monique gave a personal experience of Charlie's diagnosis of PKU by newborn screening to the management of their every life. Monique told how she remembered the words "no news is good news" when the midwife came to collect those few drops of precious blood from her newborn Charlie and then the phone call received to advise Charlie's diagnosis of PKU.



The midwives appreciated the insight Monique gave to the immeasurable difference the newborn screening program has made to their family and others diagnosed through the newborn screening program.



NSW MDDA Family Retreat 30 Sept –2 Oct 2016

Sydney Conference & Training Centre, Ingleside
Register your interest NOW!

MDDA retreats are designed to be relaxing weekends away to enjoy the company of other families and members of the MDDA, to make new friends, learn new ways of coping, learn new food ideas and leave with a sense of wellbeing and empowerment. They are also highly educational and provide all attendees with direct access to selected IEM healthcare professionals and other specialist presenters.

Some of the many activities to be enjoyed are:

- Social activities, fun team activities
- Cooking Challenge - all involved
- Specialist breakout groups by transitional stage ie. kids/teens, adults, maternal, parents/families
- Special Other/Rare IEMs Program
- Clinic updates & latest research insights

For further information and registration refer to our website or call our office on 1800 288 460

Community Education

Podcast

Our President, Monique Cooper and Secretary, Melinda Mcginley also took our message to the airwaves recently on 3WBC, 94.1 FM community radio. Here is the podcast link
http://www.spreaker.com/user/musicmatters/mdda-metabolic-deficiency-disorders
MDDA would like to thank Melinda for organising and also a huge thanks to Wonderful World Media Network, SwitchOn Radio and those involved at the station for helping us educated the community and also for donating their time to produce this podcast.

Back to school 2016

Back to school with MSUD
Student: Riley Fryer (age 11)

Year 6 - Ellison Public School,

What were you most looking forward to about going back to school?
Seeing my friends and awesome teachers. I'm finally in the biggest year of Primary, but sadly I will be the little kid again going into high school!

Describe your first day back
I got to use my first opal card. We went to the same classrooms as last year, after recess we were put in our new 2016 classroom - I got the best teacher.

How did you go about educating the school/teacher/ classmates about MSUD?
My mum had a meeting with the principal and teachers about MUSD when I started school. I don't really talk about it, I answer questions if people ask me.

How do you explain what MSUD is?
I can't have much protein, I have formula 3 times a day to help me grow, I also have extra Amino acids on a daily basis. I have to be very strict with what i eat.

Are there any major difficulties you have experienced at school?
I was bullied at school because of my MSUD, it is better now cause I stood up for myself.

What is generally in your lunch box?
2 pieces of fruit, popped chips, rice cake, popper and my formula.

What is your favourite food?
Fruit and Sushi.

How do you deal with class parties and excursions?
I take my own food.

What is your favourite part of school/Why?
Sport is my favourite , also seeing my friends. In year 6 there is cool things to do like ice cream day, fundraisers and you get given good jobs.

What would you like to learn this year?
I would like to get better at Maths.

What kind of books/movies do you like?
I love books. I love action and adventure books. I love all types of movies.

What do you do for fun?
Soccer, cricket and basketball.

Has having MSUD made participating in any sports/ activities difficult?
No not at all, I have heaps of energy. I just need to make sure I eat more.

What do you want to be when you grow up?
I want to play Soccer professionally. I want to also do a trade.

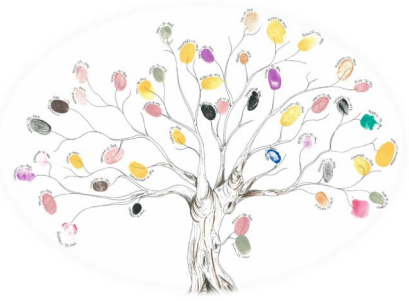
What is one think that you would like everyone to know about MSUD and school life
MSUD doesn't have an effect on my school life because I'm able to do sports. I can read and write and participate in school activities.

Any tips for future parents in making the school experience as easy as possible for a child with an IEM?
Have a meeting with the school to make sure they understand the condition. Try not to make them feel any different, my condition is a small part of me.

National Volunteer Week 9-15 May

MDDA value all our volunteers whether it's one hour of your time or an ongoing commitment. We have been fortunate to have very dedicated volunteers over the past 20 years. In 2015 over 6000+ hours was volunteered by Executive Committee alone. Thank you all for sharing your time, skills and interests to assist all living with an inborn error of metabolism.

If you would like information on how you can assist please contact the MDDA office.



The IEM Fingerprint 'Tree of Opportunity'

Back to School with Tyrosinaemia Type 1 Student: Charlie McGrath (age 7)

Grade 2 - Scarborough State School

What were you most looking forward to about going back to school?
Meeting my new teacher.

Describe your first day back
Really fun! I played with my friends.

How did you go about educating the school/teacher/ classmates about Tyrosinaemia?
Emma (mum): I discussed it with Charlie's new teacher and gave her the folder about Tyrosinaemia. I didn't go into too much information about it myself because I didn't want to overwhelm her. Just as long as she knew how important it is for Charlie not to eat any extra food/protein other than what is in his lunch box unless I am informed of it prior. Then I can either count it into his daily quota or if it is too high he will have to miss out or give an alternative for him.

How do you explain what Tyrosinaemia is?
Tyrosinaemia is a metabolic disorder where Charlie's liver can't break down the tyrosine in protein. Therefore he is required to have special formula and medication to help block the tyrosine being filtered through the liver.

Are there any major difficulties you have experienced at school?
A few of times we have had difficulties regarding Charlie drinking his formula, or rather not drinking his formula, and the teachers forgetting to remind him to have it. I think because Charlie looks and acts normal on the outside the teachers sometime don't take his condition very seriously.

What is generally in your lunch box?
Two pieces of fruit, mini taco wrap with mayo, cucumber, grated carrot and lettuce. Rice crackers, low protein carrot cake or mini banana & Choc muffins also carrot & cucumber sticks.

What is your favourite food?
Tacos.

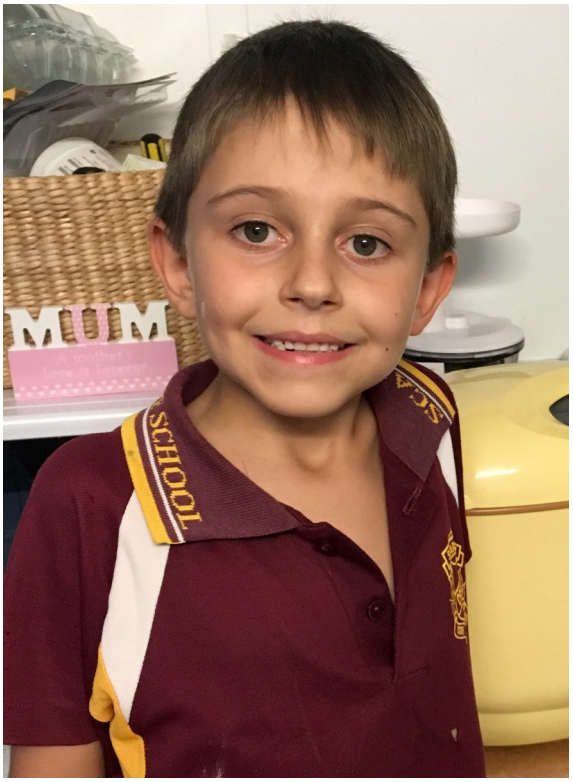
How do you deal with class parties and excursions?
Pack my own food unless I know there will be fruit and vegetable platters.

What is your favourite part of school/Why?
Playing, because I like to play with my friends.

What would you like to learn this year?
Handwriting.

What kind of books/movies do you like?
Goosebumps and Avengers.

What do you do for fun?
Find crabs; play with my Pokémon cards and playing with my friends.



Has having Tyrosinaemia made participating in any sports/activities difficult?
No not really, I can do most things everyone else can do. The only thing I have to be careful about is my belly because my liver is delicate.

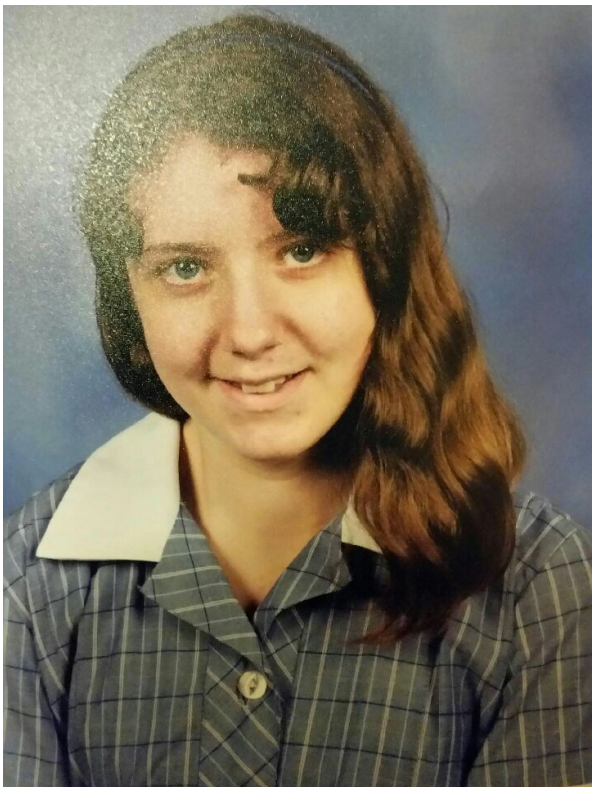
What do you want to be when you grow up?
Hairdresser (well that's a new one, I've never heard him talk about that one. More like a super hero!)

What is one thing that you would like everyone to know about Tyrosinaemia and school life?
Its fine, I don't really know what it is like not to have Tyrosinaemia at school. School is school and Tyrosinaemia is Tyrosinaemia. I just do them both together.

Any tips for future parents in making the school experience as easy as possible for a child with an IEM?
It can be stressful before they start but by that stage you already know what to feed your child so that just goes into their lunch box. They aren't allowed to share food at school anyway and your child will know the importance of their diet by then so most likely want touch anyone else's food. Let the school know the important bits about your child's disorder. Keep the lines of communication between their teacher and yourself open. But mainly educate your child about how important their diet its so they aren't likely to make wrong decisions. Apart from that try to relax all your hard work that you've put into keeping your little one healthy leading up to their first day at school will pay off. Their condition isn't any different at school as it is at home.

Starting Secondary College with PKU
Student: Jasmine Dawson (age 12)

Year 7, Epping Secondary College



What were you most looking forward to about starting Secondary College?
I was looking forward to meeting new friends and teachers.

How did you go about educating the school/teacher/ classmates about PKU?
Most of my friends have known about my condition since primary school, and I am lucky most are going to the same secondary school as me. This has made my transition easy. My teachers know because mum wrote a note explaining my condition.

Are there any major difficulties you have experienced at school?
No.

What is generally in your lunch box?
Sandwich, fruit, vegie chips, my formula and a muffin.

What is your favourite food?
Pasta with mushroom sauce, vegies and sometimes hot chips!

What is your favourite part of school/Why?
My favourite subject is art. I like being creative. I also like writing stories.

What would you like to learn this year?
Everything! I just want to do my best in learning.

What kind of books/movies do you like?
I love reading anything I can get my hands on. I love horror movies!

Has having PKU made participating in any sports/activities difficult?
No. I love swimming and dancing.

What do you want to be when you grow up?
I hope to become a famous DJ.

What is one thing that you would like everyone to know about PKU and school life?
Just be yourself and everything works out really well.

New Arrivals ….boys….boys….boys!!

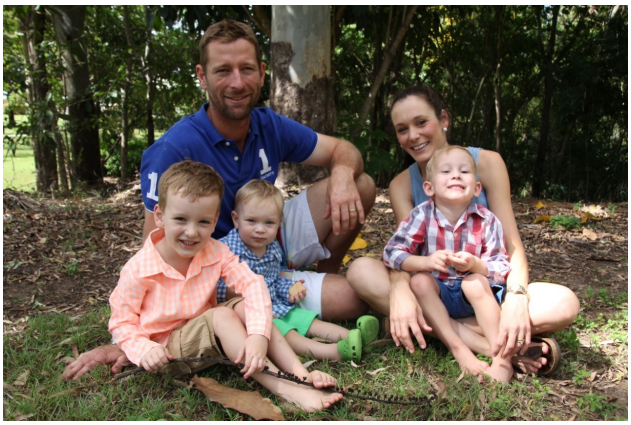
Congratulations to
Nicholla & Jo Kinscher
on the arrival of
Maximus Donald
Born 8 Jan 2016

Congratulations to
Paige, John and Sophia
on the arrival of
Michael
Born 4 Dec 2015

Congratulations to
Alison, Geoff, Molly & Genevieve
on the arrival of
Finnian James Robert
Born 20 April 2016

Fundraising Activities

Townsville to Brisbane 1500kms on a Bicycle in 3 weeks!

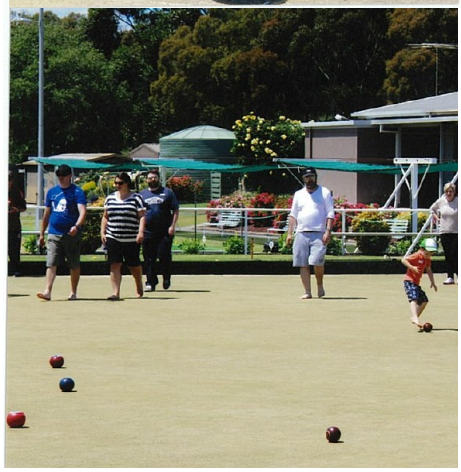


Philip Acton father of 3 gorgeous boys Thomas 5, William 3 (PKU) & Harry 1 (PKU) has set himself a goal to ride **1500kms on a bicycle from Townsville Hospital to Lady Cilento Children's Hospital in July 2016.**

Philip's inspiration is to raise awareness of PKU/IEMs, fundraise along the way for the MDDA and to teach his boys nothing is impossible!

There will be opportunities to support and follow Philip on the lead up and during his challenge. Further information will be made available soon. If you can help Philip let us know and we will put you in touch.

Family Fun day - A day on the green



On the 15th of November 2015, Mia Aitken and her parents Alison and Steve and family and friends held a family fun day at the Yallourn Bowls Club in the Latrobe Valley.

The intention of the day was to raise money for research into PKU, plus also to thank others who are in their lives and try to enlighten people to the condition in a friendly non frightening way. As we all know a day in the life with PKU is not easy but with family and friends on the journey, family gatherings and friends functions can become pleasurable and less complicated for all.

The day included novelty bare foot bowls and a bocce rink for all, then for the tiny tots there was a fishing game, quoits game, pin the tail on the donkey and a hooky boards to everyone could get involved in some form of activity and have a good time.

Fundraising was achieved by a cover charge/entry fee, hamper raffle, lucky number draw, drinks sales and a donation tin.

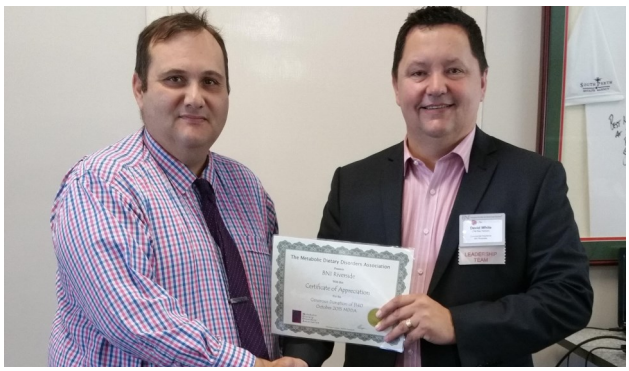
We have thanked the Yallourn Bowling Club for their generous support as they supplied the amenities of a BBQ area and club facilities for free plus a generous sponsorship. We have also thanked Woolworths for their fantastic support as they supplied the necessary catering products for free which enabled us to raise more money towards PKU research.

The day was a fantastic success with beautiful weather and great fun had by all. From the family Fun Day we were fortunate enough to send to Westmead Hospital the sum $1335. The day was devised from a general conversation about lawn bowls. That started the ball rolling and other ideas we need to make the day a success flowered from there.

We were amazed at the generosity businesses have to fundraising events and we encourage everyone to look around your local area to gain sponsorships or venues to conduct such events as it is very rewarding as the cause is so special to us all.

Rita and Anthony Knipping
(Grandparents of Mia)

BNI Riverside Supports the MDDA



Scott Greer presented the MDDA's Certificate of Appreciation to BNI Riverside President David White. A big thank you to BNI Riverside business group who have supported MDDA continuously over the last few years.

Autumn Recipes

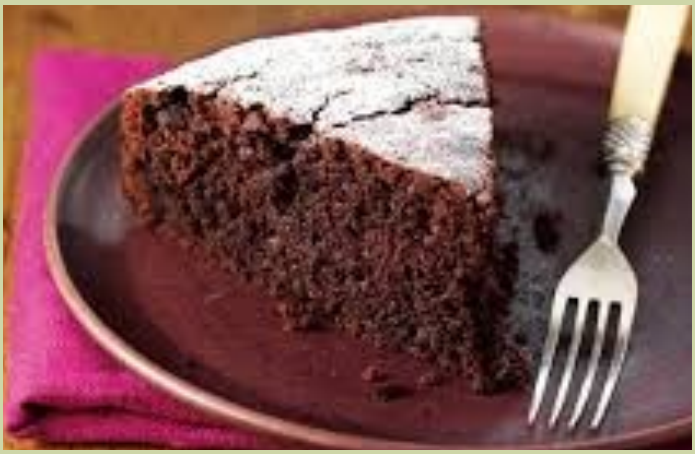
Warm Broccoli Salad

Makes 6 cups
(1/2 cup per serving)
Adapted from Apples to Zucchinis Cookbook

Ingredients
1 large head broccoli, about 8 cups
1 teaspoon canola oil
1 large spring onion, chopped finely
2 cups mushrooms, thinly sliced
1/3 cup balsamic vinaigrette
1/4 teaspoon salt
pepper

Method
1. Cut broccoli into small florets. Add to boiling water and cook for 3 minutes. Drain well and set aside.
2. Gently fry the shallots for 30 seconds then add the mushrooms until softened .
3. Then add the broccoli with the vinaigrette and salt to the mushroom and shallot mix.
4. Toss all the vegetables together to mix well. Add pepper to taste.

No Mess Chocolate Cake



Serves 10
Prep Time: 10 minutes
Total Time: 45 minutes

Ingredients
1½ cups lopro flour
3 tablespoons cocoa powder
1 cup sugar
1 teaspoon baking soda
½ teaspoon salt
1 teaspoon white vinegar
1 teaspoon pure vanilla extract
5 tablespoons vegetable oil
1 cup water

Method
1. Preheat the oven to 180 degrees. Grease an 8-inch square or 9-inch round cake pan.
2. Add all the dry ingredients directly to the pan and mix.
3. Make 3 little holes – 2 small and 1 large – in the mixed dry ingredients. Pour the vinegar in one of the small holes, the vanilla in the other small hole, and the vegetable oil in the large depression. Pour water over all, and mix with a fork until smooth.
4. Bake on the middle rack of the oven for 35 minutes, until a toothpick comes out clean.
5. Allow to cool and serve topped with your favourite fruit for a scrumptious dessert.

PKUNSW UPDATES

Rotary Charity Golf Day 2016

The Rotary Club of Pennant Hills recently hosted its 10th Annual Charity Golf Day at the prestigious Pennant Hills Golf Course. This was the 10th year in which all proceeds on the day were donated to PKU Research underway at the Children's Hospital at Westmead.

80 players participated in the event with the Pankhurst, Melham, Morris, Dovico and McDonald families all representing the PKU community.

A total of $20,000 was raised on the day. Many thanks to all the members of the Rotary Club of Pennant Hills and their sponsors for including the PKU Association in their fundraising activities.

City2Surf- Team PKU

Sunday 14th August
Join the PKUNSW team walking, skipping and creating awareness of PKU. This is a great public event to raise awareness of PKU. For more details www.pkunsw.org.au

Lab Coat Walk 2016

PKUNSW held its annual Lab Coat Walk of Fame on the 1st May for PKU Awareness Day.

As well as creating awareness for PKU they also used the event to raise funds for research currently underway at the Children's Hospital at Westmead. The event was held in Sydney's most popular harbour side walking tracks, the Iron Cove "Bay Run". You can still make a donation. For more information go to: www:pkunsw.org.au

PKU Gala Dinner

Saturday June 18th 2016
Ottimo House, Denham Court
Tickets: $250 per person
Tables can be secured prior to ticket release by emailing Mirella Nicomede: mnicomede@bigpond.com.au

PKUNSW 2016 Youth Camp 28 Sept - 2 Oct 2016

Calling all Youth's and Teen's between 8-17 years with an IEM!

Point Wolstoncroft Sport & Recreation Centre
Gwandalan NSW

This is a camp for you to meet other kids with IEMs, share stories, learn skills, enjoy a bunch of awesome activities and challenges, and best of all have a week away from mum & dad…oh and did we mention HAVE FUN!

Registrations will be open soon
The cost for the camp is $400

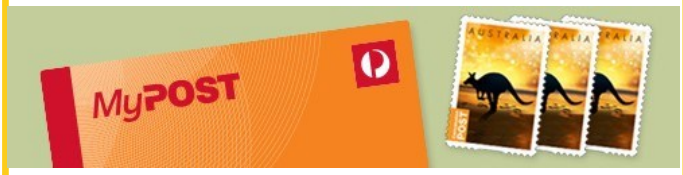
If you wish to receive updates and secure a spot
email: pkunsw.org.au or office@mdda.org.au

Information updates

Congratulations to Megan Fookes

Awarded the Medal of the Order (OAM) for service to the Rare Disease community.

Megan is co-founder of Rare Voices Australia



Postage

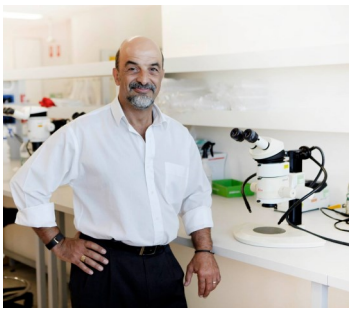
The cost of postage has recently increased. Australia Post do have some concessions available, you may be eligible to get a free MyPost Concession account. With this you pay 60c per stamp, instead of $1 and are entitled to buy up to 50 stamps per year at that price. You also get a free booklet of 5 concession stamps to get you started. If you have a Health Care Card or Pensioner Concession Card you may be eligible.

For more information pop in to your local post office or copy and paste this link into your browser http://auspost.com.au/parcels-mail/concession-stamps.html

Moved or changed your email—don't forget to notify MDDA! email office@mdda.org.au

GiveNow.com.au
Give more, give smarter, give better, give now!

Please consider supporting the MDDA by making a contribution
www.givenow.com.au/mdda



Professor John Christodoulou

Has moved to the Murdoch Children's Research Institute. He takes on the role as their new Chair in Genomic Medicine. MDDA thanks him for the exceptional care and compassion over the last 18 years to all his IEM patients. Professor Christodoulou has supported the MDDA, presented at our retreats, conferences and contributed to many other activities for which we will be forever grateful. We wish Professor Christodoulou all the very best with his new appointment at MCRI.

Entertainment Books

Tracey Scott is once again co-ordinating the sale of the Entertainment books for 2016. Get in NOW to make use of the full year of offers.

Go to: www.entertainmentbook.com.au/orderbooks/91531w0

PLATYPUS FOODS

Platypus Foods is an Australian company that has just started manufacturing low protein bread and baking mixes for metabolic disorders like Phenylketonuria (PKU).

Platypus Foods was created by Dr Kelly Hamill after her daughter, Olive, was diagnosed with PKU at birth just over 2 years ago. The baking mixes have almost no phenylalanine and no added sugar.

More information can be found at:
www.platypusfoods.com.au

Platypus Foods
PO Box 307
Bellingen NSW 2454
Email: platypusfoods@gmail.com
Tel 02 6655 2626

Product Updates

Alpine Coconut Milk yoghurt
Protein per 100g:1.9g
Protein per serve:1.9g
Serving size:100g
Suitable for: All
Available from:
Coles & Woolworths

Nudie Coconut Yoghurt - Blueberry
Protein per 100g:1.4g
Protein per serve:2.4
Serving size: 170g
Suitable for: All
Available from:
Coles

So Good Coconut Icecream
Protein per 100g:0.5g
Protein per serve:0.3
Serving size: 67g
Suitable for: All
Available from:
Coles

Syndian Vege Boost Burger
Protein per 100g:2.85g
Protein per serve:2.85g
Serving size:100g
Suitable for: All
Available from: Coles, Woolworths & IGA

Freedom XO crunchers & Rainbow crunchers
Protein per 100g:7.1g
Protein per serve:1.4g
Serving size:20g
Suitable for: All
Available from:
Coles & Woolworths

Sunbeam Date & Cacao Energy Bites
Protein per 100g:3.7g
Protein per serve:1.1g
Serving size:30g
Suitable for: All
Availvable from:
Coles & IGA

Tropical Fields Coconut rolls
Protein per 100g:1.5g
Protein per serve:<1.0g
Serving size:33g
Suitable for: All
Available from:
Costco

BirdsEye Potato Waffles
Protein per 100g:2.2g
Protein per serve:1.2g
Serving size:56g
Suitable for: All
Available from:
Coles & Woolworths

Majans Prawn Crackers
Protein per 100g:0.7
Protein per serve:20g
Serving size:0.1g
Suitable for: All
Available from:
Aldi

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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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