Metabolic Dietary Disorders Association

The Hon Greg Hunt MP- Minister for Health. with MDDA members

Annual Report

2017 -2018

President's Message

Building support and moving forward was the major focus of the MDDA this financial year.

The 2017-18 year proved to be another year of evolution for the Metabolic Dietary Disorders Association. Continued growth and progress has strengthened our position as the national peak body and has enabled us to provide leadership and support in the areas of advocacy, education, connecting and providing a strong voice for the IEM community. MDDA is now well-positioned representing patients with Inborn Errors of Metabolism (IEM's) to the public, the media, industry and government. Working on our organisational structure and member relationships and communications has enabled us to move forward with new initiatives and support programs assisting in accomplishing our mission to improve the lives of people with IEMS.

The past 12 months have seen the MDDA Executive Committee, volunteers, staff, programs, and support services continue to adapt and evolve, presenting opportunities for growth. With an ongoing focus on achieving positive health outcomes for people living with IEMs, the MDDA has successfully delivered on several initiatives and growth strategies. This is a testament to the hard work of the whole organisation, all whom are helping MDDA build on the quality of the support we provide to our community.

For people with IEMs, their families and carers, it can be challenging to find good information about the condition and to connect with others in the same circumstance. By the strengthening of our communications strategy we have been able to reach a much larger audience through our website, our e-news and Facebook page and group member forum. With the website in place, it is now much easier to find good quality information about the condition, management and the latest news and research.

Contents

MDDA is endorsed as a Deductible Gift Recipient (DGR) and donations over $2 are tax deductible.

www.mdda.org.au/help/donate/

Our largest attended National Family Retreat was held 6-8 October 2017 in Victoria. This weekend bought an intensive two days of workshops, discussion, education and opportunity to develop personal support networks and ongoing friendships. I would like to express my gratitude to the health professionals who attended and presented at the retreat. I am incredibly grateful that they see value in participating in the workshops and see them to be informative and worthwhile to our attendees. The theme of the conference, 'Choose your own adventure", reflected the need for us to continue on our path and understand the many possibilities and benefits that can result by being responsive and empowered to take charge of your own health and wellbeing.

The Great Protein Challenge initiative commenced in February 2018 which exceeded our expectations in broadening our awareness and reach into the community. 'The Great Protein Challenge: How Low Pro Can You Go?' encouraged 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. The Challenge ran from 1 February and concluded on Rare Disease Day, 28 February. All funds raised through the Challenge will help to raise ongoing awareness and provide much needed funds to further many research and support programs underway. A BIG thank you to all of our Pledgers and Players who took part in the challenge, we raised over $17,000.00, gave a massive boost to our online marketing reach and received excellent feedback from the many participants involved! We intend on improving and upscaling the Challenge for 2019.

A big supporter MDDA and our challenge is The Grand Hotel Warrandyte - who continue to offer a dedicated low protein menu to IEM customers in Melbourne. The Grand encouraged their whole team and customer base to participate in the challenge at their hotel. They also provide in kind support with recipe consultation and cooking resources at our retreats and their ongoing support is most appreciated.

On 15 February, at Parliament House in Canberra, MDDA partnered with Rare Voices Australia on 'A Hunger for Support' – a special lunch event to highlight the importance of supporting Australians living with the rare genetic metabolic disorder – Phenylketonuria (PKU). It was a great honour to represent the MDDA as President and stand as a parent of a child diagnosed with the rare disease. I only know too well the importance of advocacy in this space. MDDA members, Taylah Shier and Bek Mills also shared their personal experiences of living with PKU. We welcomed the attendance of The Hon Greg Hunt MP, Minister for Health, and many other politicians and policy makers who joined us for lunch, and gained an appreciation of the many challenges PKU presents on a day to day basis. A display table showing the protein levels of everyday food was particularly eye-opening for them. As the national peak support group, we 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.

MDDA, with the support of our PKU community, has been actively campaigning for a number of years to secure access to KUVAN® (sapropterin dihydrochloride) 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. MDDA welcomed the decision in April by the Pharmaceutical Benefits Advisory Committee (PBAC) to defer the listing of Kuvan 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. We were thrilled 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 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.

In July 2017, MDDA joined regional and several country-based PKU patient organisations from around the world and made history by agreeing to form the first international association for PKU – the Global Association for Phenylketonuria (GAP). This global entity will serve as a supportive umbrella organisation to regional and national patient organisations and groups in bridging the gaps in care for PKU worldwide. In addition to advocating for universal access to newborn screening and care, other GAP priorities include, mentoring like-minded patient associations through offering best practices and support; increasing collaboration among PKU researchers, scientists, clinicians and patient groups, and ultimately working for a cure. GAP will work to make PKU a global health priority, ensuring all people living with PKU, despite their origin, will be able to reach their full potential. Myself and Louise Healy are proud to be founding trustees of the association representing Australia and the South Asia Pacific region and special acknowledgement goes to Debbie Colyer for her early engagement representation of the MDDA on this important initiative.

A project under my management that we have been planning for some time now is a PKU/IEM Dietary Management and Wellbeing App called "My Low Pro PAL". This app is intended to become an integral support resource for an individual's day to day management of their IEM and all related clinical, dietary and holistic health priorities. The app will deliver a comprehensive management tool for daily IEM management, diet/menu planning, nutritional monitoring, protein counting, milestone recording, healthy wellbeing goal setting and tracking. One of MDDA's strengths has been the provision of high quality information and resources to our members and consumers. In the digital age, the potential to reach those who need these resources has expanded tremendously. We are adapting and taking the opportunities that technology provides as we engage with the new technological era. We intend to launch phase 1 of the app and wellbeing program in 2019.

During the year our partnerships with other stakeholders, organisations, businesses, governments and the IEM community have strengthened and grown and present many exciting opportunities for the future of our association, and to our members. I am extremely grateful to the Australian Government under the Health Peak and Advisory Bodies Program for their financial support as well as to all of our individual and organisational financial donors particularly in this current challenging financial climate. Ongoing funding for small not-for-profit organisations such as ours is an on-going issue and often a source of uncertainty, however we remain focused on delivering high quality responsive services within our existing resources and capability.

Our partners include; Menarini, Orpharma, Biomarin, Nutricia, Cortex Health and Vitaflo.

We are most grateful of the support all these organisations provide to MDDA and without them so many of our programs and events including our retreats just would not be possible. It is inspiring to us as a patient group to see the genuine dedication, and commitment of the many individuals we work with across these organisations share, and it is through these relationships and collaborations that we continue to find new ways to develop and deliver new programs and resources that support our members and help to achieve our shared vision.

It was with incredible sadness 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.

The MDDA wellbeing program was a key passion of Robyn's from its very early conception, and with Vitaflo's unwavering commitment and support of this program, we are thrilled to know we will be in a position to launch our brand new program next year - something we know she would have been extremely proud of.

Thank you to the members who continue to use their voices and stories to raise awareness to the wider community and provide a detailed picture of living with an IEM and the challenges that affect people's health, wellbeing, income and quality of life. Thank you to those members who fundraise and donate to the MDDA. Your gifts are one of our most important sources of future planning and strength to our association. Thank you for caring about the wide IEM community in such a generous and thoughtful way.

We are fortunate to have a forward thinking, hard working and skilled Committee of Management who put in many unpaid hours steering and supporting the organisation and advocating for more resources and better recognition for people with inborn errors of metabolism. It's been a busy year and without any doubt whatsoever, we would not have been able to achieve any of our successes without an incredible team of dedicated volunteers and supporters. I thank every volunteer in all areas of the organisation who have worked incredibly hard over the last 12 months to deliver and provide meaningful support to our community - through your hard work, people with IEMs are better informed and supported.

I would like to thank our small, hard-working office team who have been steady and productive and managed a lot with limited resources once again this year.

I am looking forward to building on the work we've completed and continuing to work with, and for, the community of people in Australia living with IEMs.

Monique Cooper,
President MDDA

Our Charter

The MDDA supports families and individuals affected by an Inborn Error of Metabolism whereby treatment involves a medically controlled diet.

What is an Inborn Error of Metabolism?

An Inborn error of metabolism is a genetic disease usually inherited from both parents which carry a defective gene. Generally metabolism is a process that involves complex reactions that change food we eat into a form which the body can use for growth or energy. Each chemical reaction is controlled by an individual special protein called an enzyme. Inborn errors of metabolism result when a particular enzyme does not work properly.

Failure or deficiency of the particular enzyme can lead to symptoms ranging from mild to severe neurological damage and physical disablement or death. These conditions are normally managed by medically prescribed diets; in many cases supplements and medication are also needed to maintain normal growth and development. Failure to adhere to the diet and/or supplements usually results in neurological and/or physical damage. With many metabolic disorders this damage is irreversible.

How is it normally detected?

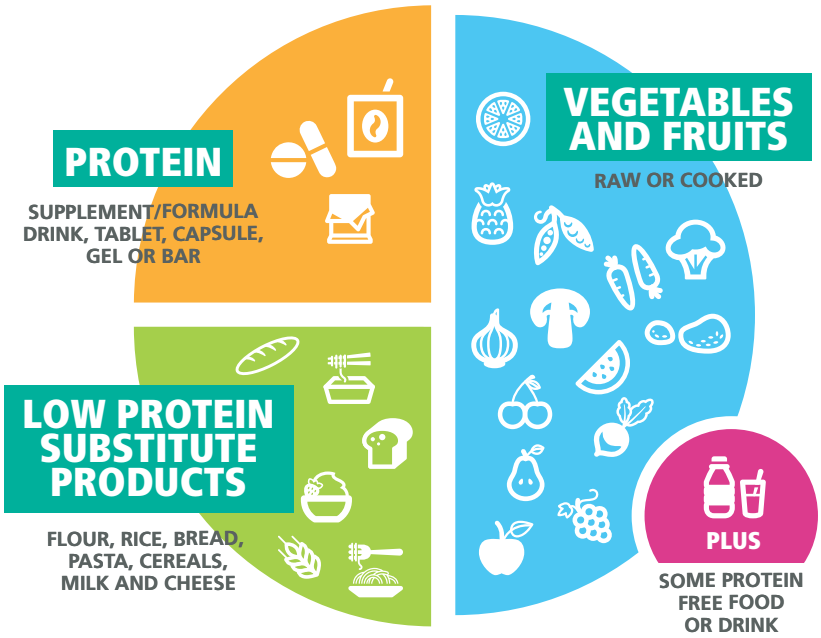
All newborn babies are tested by a blood test (known as the Guthrie/heel prick test) taken with the first few days – usually between the 2nd and 5th day after birth, for several conditions.

How is it treated?

Early detection and better treatment has meant that many people with IEM's are able to live normal, healthy lives so long as they maintain diet and treatment. Some affected individuals may need assistance with feeding including tube feeding. However, it must be remembered some metabolic disorders and some forms or mutations of metabolic disorders have higher morbidity and mortality despite early intervention and treatment. Late detection or non-adherence to diet and treatment often has catastrophic results including permanent brain damage, disability and death.

These disorders are rare and extremely complex to treat and as such due to genetic differences each has an individual management plan. This normally requires a medically prescribed diet in order to reduce the risk of mental and behavioural problems in individuals diagnosed with an IEM.

WHAT MAKES UP A LOW PROTEIN DIET?



What types of Metabolic Disorders exist?

Metabolic disorders are commonly known as;

> carbohydrate metabolism,

> amino acid metabolism and

> organic acid metabolism.

However there are hundreds of disorders involving metabolism. MDDA's support services and charter focuses on those IEM's which require metabolic dietary management which pose particular challenges for those Amino Acid IEMs (which are estimated to currently represent around 1,500 individuals in Australia)

The following disorders are represented by MDDA.

Amino Acid Disorders
- Maple Syrup Urine Disease,
- Phenylketonuria,
- Tyrosinaemia Type 1 & 2,
- Homocystinuria

Urea Cycle Disorders
- Ornithine Transcarbamylase,
- Citrullinaemia,
- Arginase Deficiency,
- Argininosuccinic Acidemia

Organic Acidaemias
- Methylmalonic Acidaemia,
- Glutaric Acidaemia type 1 & 2,
- Propionic Acidaemia,
- 3-Methylcrotonyl CoA Carboxylase Deficiency

How many are affected by these disorders?

Approximately one person in 15,000 has an Inborn Error of Metabolism. The extent of newborn screening varies from State to State, and thus some babies/children are not diagnosed until they present in hospital (usually during infancy) in metabolic crisis.

2017/2018 Key Achievements

24 NEW MEMBERS

550+ MDDA SUBSCRIBERS

613 FACEBOOK GROUP MEMBERS

3500+ VOLUNTARY HOURS

965 RECORD SUBMISSIONS FOR PBAC KUVAN LISTING

REACHED MORE THAN **55%** OF THOSE DIAGNOSED WITH IEM's

gap GLOBAL ASSOCIATION FOR PKU

Bridging the gap for PKU worldwide

MORE MEMBER DRIVEN **FUNDRAISERS**

INCREASED GOVERNMENT RELATIONS & PARLIAMENTARY ENGAGEMENT

NATIONAL FAMILY RETREAT

INCREASED AWARENESS OF IEMS

DEVELOPMENT OF **DIETARY & WELLBEING APP**

OVER **3500** SUPPORT EMAILS & PHONE CALLS

FIRST EVER AUSSIE LOW PRO RESTAURANT MENU HERE TO STAY!

THE GREAT PROTEIN CHALLENGE FEB 2018

9 Reviewed Australian Government health policies and programmes

85 Australian Government health policies and programmes resources and materials developed

9 Advice provided to the Department with regard to Australian Government health policy and programme matters

1210 Requests from members, the wider health sector and the community for information on Australian Government health policy matters

95 Medical practitioners attending MDDA education and training sessions

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

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

COMMUNITYNEWS.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.

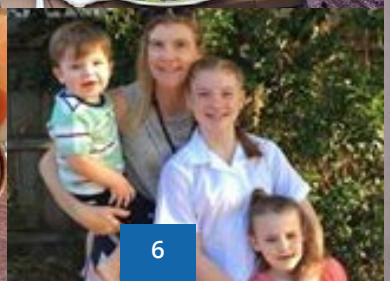
KIDSPOT.COM.AU

THE GRAND WARRANDYTE

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



THE AUSTRALIAN

Why little Elaynah can't have more peas

BRAD CROUCH
MEDICAL REPORTER

Our Purpose

The long term purpose and objectives of the association are to provide a credible, supportive service to all people affected by, and living with a dietary managed (Amino Acid) Inborn Error of Metabolism in Australia.

Policy

- Educate and advise government on Health policies and decisions effecting people with IEMs.
- Consult with health professionals to influence improved care and clinical resources for IEMs.
- Promote cooperation and consistency of care between state based IEM clinics, and facilitate a national framework of care.
- Provide well-informed support and advice relevant to the needs of people with an inborn error of metabolism and to the needs of interested parties.
- Assist consumers to improve their understanding of government policy and the availability of Inborn Errors of Metabolism grants and support resources and services.
- Promote national consistency in the treatment, care and management guidelines for IEMs.
- Represent the needs of people with an IEM dietary condition and their families with governments and other organisations.
- Promote and encourage individuals to self-advocate in matters related to their condition.

Consultation, Representation and Networking

- Consult with and represent members on all matters relating to IEM health care policy and programs, and advise Government and key stakeholders accordingly.
- Represent the national IEM community through participation in health policy discussion papers and national advisory and consultation forums.
- Maintain strong links with health care professionals, IEM clinicians and research communities.
- Build relationships and share information with other health and support organisations with similar or complementary objectives.
- Encourage community service and health/wellbeing groups to be interested in the incidence of metabolic dietary disorders in the community.
- Collaborate with International alliances for achievement of greater global IEM care.
- Liaise with medical food suppliers within Australia to ensure variety and continuity of specialised IEM food options.

Information Dissemination and Education

- Disseminate accurate information and provide education for members regarding the management of inborn errors of metabolism, government policy and relevant healthcare information.
- Provide tools, resources and programmes to assist with dietary compliance, greater health and overall wellbeing.
- Share information and improve the knowledge and understanding of specialist IEM health professionals and clinicians regarding the care and management of inborn errors of metabolism.
- Provide regular networking opportunities and forums for the Australian IEM community to connect, share, support, develop and contribute together as a community.
- Contribute to broader community awareness and education regarding the needs of people with inborn errors of metabolism and the needs of their families and carers.
- Play a role educating the greater Australian community on the importance of the newborn screening programme and consult with advisory groups on its further development.

Governance

- Maintain our position as an effective national body representing the consumers and the carers of people with an inborn error of metabolism.
- Operate as a well-managed and accountable community based organisation.
- Continue to involve the IEM community in all aspects of planning and coordination of IEM support programmes, and encourage personal participation and contribution.
- Continue to maintain a diverse and active executive committee and office personnel team, seeking continuous training and development opportunities.

The year in review

The MDDA continues to contribute to the IEM community through a consistent commitment from volunteers and office staff alike. The 2017/2018 year saw several outcomes achieved.

2017/2018 Key Outcomes

How Low Pro can you Go?

February 2018 marked the inaugural launch of The Great Protein Challenge, an important MDDA health initiative to raise awareness and support of IEM's. The 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. The aim was to encourage everyday Australian to experience a typical day in the life of a person living with PKU by significantly reducing their protein intake for 24 hours.

As well as funds, the awareness raised through various media such as radio, newspaper and TV interviews was beyond expectation and very encouraging for future years.

The MDDA are extremely thankful to the 275 pledges and 70 players. This is a great result for our first year and we look forward to seeing this grow in future years.

Funds raised will enable the MDDA to continue offering support, education and services to help all IEM members lead a life at full potential. Over $17,000 was raised.

Parliamentary Visit

In February MDDA Executive Committee members and representatives attended the Parliamentary luncheon in collaboration with Rare Voices, ahead of Rare Disease Day. MDDA President Monique Cooper, spoke on MDDA's role as a support group, her experience as a mother of a PKU child and the launch of The Great Protein Challenge. The lunch focused on educating parliamentarians about PKU and the reality of lifelong treatment.

The Grand Hotel Warrandyte - Australian first permanent low protein menu options -

The Grand Hotel Warrandyte released a permanent Grand low protein Menu and became the first Australian restaurant to offer this. The low protein menu has been created with the dedicated commitment and support of Executive Chef, Brad Hawker, The Grand Manager Peter Appleby, and MDDA president Monique Cooper. The Grand team led by their manager has continued to offer support to the MDDA and assisted at the 2017 retreat, running low protein cooking workshops.

Global Association for PKU (GAP)

In July 2017 representatives from regional and national PKU support organisations from Europe, North America, South America, Middle East and Australia met to discuss the formation of an international PKU association. A constitution was finalised in February 2018 with the full unveiling of priorities and objectives scheduled for later 2018. GAP will work to make PKU a global health priority, ensuring all people living with PKU, despite their origin, will be able to reach their full potential.

Kuvan Advocacy

2018 commenced with MDDA's consumer submission to the Pharmaceutical Benefits Committee. PBAC received 965 consumer comments in support of listing Kuvan. A testament to the passion and commitment of our community and supporters. While the decision at present is to defer the listing of Kuvan onto the Pharmaceutical Benefits Scheme the deferral means that PBAC recognises the benefit of Kuvan for some PKU patients and remains open to listing the treatment on the PBS in the future.

MDDA will continue to work hard to advocate on behalf of Australians with PKU and other IEM's for access to available treatments with the Australian Government.

National Policies

MDDA continues to work with Rare Voices Australia to advocate for a consistent national framework for the management of rare diseases and for rare disease policy.

MDDA also remain in close communication to the nationally recognised Australian Society of Inborn Errors of Metabolism (ASIEM) for clarification of national guidelines and for the management and treatment of IEM's.

Discussions held with stakeholders regarding the implementation of an Australian patient registry for IEM's and rare diseases.

PKU/IEM Dietary Management & Wellbeing APP

After comprehensive research and planning, development is underway for a management tool for day to day IEM management. This APP will aid diet/menu planning, nutritional monitoring, protein counting, milestone recording, healthy wellbeing goal setting and tracking.

THANK YOU ...

to the following member driven fundraising initiatives...

Matilda Dean - Laurimar Primary School (VIC)

Tracey Scott - Entertainment Books (VIC)

Sonia Hellings & Yarra Flats Bakery - Yarra Glen charity bowls tournament (VIC)

Felicity Simmons - Ironbody Crossfit Gym (WA)

Lauren & Justin Penneyston - PKU T20 Smash (TAS)

Lauren & Justin Penneyston - "Eggs" weight loss Challenge (TAS)

McGill family - Cut for Cure - (VIC)

Kaitlyn Greer - Forest Crescent Primary School (WA)

July

MDDA president and vice president participate in the founding of the first global association for PKU.

August

New look MDDA logo and branding.

September

President attends the International Congress of Inborn Errors of Metabolism in Rio, Brazil.

UCD members made aware of submission to have Pheburane added to the PBS and to submit comments.

October

VIC Family Retreat - CountryPlace Conference Centre, Kalorama.

AGM held.

Vice President attends & presents at the ESPKU Conference, Hell, Norway.

Virtual round table ran on emerging treatment/ research.

November

Vic, PKUNSW and Queensland end of year functions held.

New National Guidelines for PKU Management in Australia announced.

MDDA collaborated with the Grand Hotel, Warrandyte, Vic, creating an Australian first by providing a permanent menu for people with low protein dietary needs.

Discussion group established for PKU Adults - online sessions held.

Executive Officer & President attend workshop on Building your Advocacy capacity.

December

Other State end of year gatherings.

January

Consumer submission to Pharmaceutical Benefits Advisory Committee submitted.

Meetings with consumer representatives from the PBAC committee were convened.

Media articles and cases studies prepared to raise awareness.

February

Vice President meets with MPs & Senators & Minister for Health raising awareness about IEM's and needs.

Inaugural launch of The Great Protein Challenge.

In collaboration Rare Voices Australia & MDDA held a parliamentary Lunch.

Rare diseases day celebrations.

News articles and interviews on TV & Radio promoting awareness.

Vice President attends meeting of Global PKU in Amsterdam to finalise the structure and sign constitution.

March

Record 965 submissions made to PBAC for Kuvan listing.

Committee members attend a consumer hearing with the Pharmaceutical Benefits Advisory Committee regarding Kuvan

President & Vice President attend and present at Vitaflo National IEM dietitians conference

PKU T20 Smash fundraiser (TAS)

April

Research commences on development of PKU/IEM Dietary Management and Wellbeing APP.

May

International PKU/IEM Awareness month.

Member fundraising activities:

- Cut for Cure (Vic)
- "Eggs" weight loss pledge (Tas)

Far North Queensland Clinic

June

Newly Diagnosed IEM 'new parent' & 'infant' kits being developed.

PKU webinar held for maternal women.

Private facebook group established for MDDA members with Fatty Oxidation disorders.

International PKU Day - June 28.

Presented at Newborn Bloodspot Screening to over 50 Maternal Health Nurses in Vic.

GAP launch preparations finalised.

Member Services

The MDDA continues to contribute to the IEM community through a consistent commitment from volunteers and office staff alike. The 2017/2018 year saw several outcomes achieved.

Core Member Services

Newsletters

MDDA Matters is a printed newsletter that is posted to all members and through specialist metabolic units throughout Australia. It provides useful dietary information as well as patient stories, event information, Govt support services etc. Newsletters often include inserted product information sheets and order forms, as well as event invitations and surveys etc.

MDDA e-news is a more frequent email newsletter sent to subscribers providing direct links to key online resources and information, including surveys, research studies, Government discussion papers and consultation forums etc.

Brochures & Kits

Information brochures are used to develop awareness and provide support and advice.

Factsheets are used to focus on particular topics / or interest groups. New parent/member kits are provided to all new members.

Dietary Resources

Dietary management resources include:

> Online recipe catalogues
> Online product catalogue
> Printed Recipe book
> Cooking days

Future plans are underway for additional resources including a dietary app and meal planner tool.

Telephone Support

Telephone contact for parents and individuals which provides a first place empathetic contact with people with similar experiences to the caller.

A toll-free number is available for members use.

Website

The website allows MDDA to share information from:

Professionals; provide technical information in 'layman-terms' to enable ease of access by individuals and newly diagnosed families.

Commercial providers: provide information about food products and how they may be obtained.

Governments; provide accurate information about benefits, support and services provided.

Members; share stories and experiences and provide peer support and mentoring.

MDDA; provide information on upcoming events, activities, and discussion forums and coordinated volunteer projects.

LINK Referral Network and Personal Visits

The MDDA LINK Network provides individuals an opportunity to obtain one on one support, information and advice.

This is particularly important when parents, teens, adults and those a family, experience feelings of uncertainty and being overwhelmed with information and emotions.

Personal visits to families and individuals are sometimes used in a time of need, and the MDDA national LINK network provides a co-ordinated approach to this – ensuring suitably selected and briefed outreach persons are involved.

MDDA LINK representatives are informed on latest Government policy and available healthcare services, to be able to assist and advise newly diagnosed families on available services and resources.

News & Groups

MDDA's social media channels and online news feeds keep members and key stakeholders informed about latest information, news and resources. The MDDA member only forums are facilitated via the MDDA Facebook Groups. MDDA keeps media and all stakeholders informed of any breaking news.

Social Functions and Cooking days

Social functions are used to establish friendships and build informal networks to allow members to share and learn from other members. Cooking days are also encouraged to enable cross sharing of dietary information and meal planning and ideas.

National Events

Educational and networking events are held in different locations around Australia on a regular basis. These provide forums for information exchange for all involved and interested in the treatment of inborn errors of metabolism usually related to specific or general diagnostic issues.

> Seminars relating to health and family issues.
> Conferences for health professionals to consider specific issues.
> A forum to exchange information and address specific issues relevant.
> Discuss and provide input on latest Government policies.
> Educate and update the skills of individuals and their families affected by an inborn error of metabolism for greater health and wellbeing outcomes.
> Develop and strengthen peer mentoring relationships.








Peer Mentoring Program

The MDDA Peer Mentoring program provides psychosocial support to patient cohorts that are particularly vulnerable to compliance issues due to the nature of their circumstances. The targeted groups are:

Adolescents (ages from 10 to 21 years): research shows that this group is particularly vulnerable to compliance due to the restrictive nature of the dietary treatment program and the impact this has on their psycho-social functioning.

Maternal PKU: due to the detrimental impact of increased levels of phenylalanine to the unborn child of a mother with PKU, females who are contemplating having a child, or are expectant of a child require extra support to ensure they maintain a particularly restrictive dietary program.

Parents of newly diagnosed children: due to the unfamiliarity of the restrictive treatment program, and the severe negative implications of non-compliance on the newborn's development in their early years, peer support is highly valuable for optimal health outcomes for both parent and child.

Individuals and families affected by a rare form of an inborn error of metabolism: due to the rarity of some disorders, and the geographical spread of the patient group, psychosocial support can be difficult to obtain.

Trained and experienced volunteers who are living with an inborn error of metabolism deliver the Program. Referrals are made to the Peer Mentoring Program Supervisor via the Metabolic Clinics in each State. The Peer Mentoring Program Supervisor monitors and provides support to all Peer Mentors, to ensure the strict guidelines are adhered to, and additional professional support is provided as required.

Member Service Benefits

The trigger for individuals to use the services of MDDA is often linked with a recent diagnosis or awareness of a metabolic dietary disorder.

Frequently people come to the organisation in desperation having developed a disjointed or extreme view of the potential outcome and consequence of a metabolic dietary disorder, and there is a need to rationalise this with a balance of experience and realism.

MDDA provides the support network along with linkages to important resources and information to support all members on their journey.

Our Members

Who are our members?

> Individuals who have a metabolic dietary disorder.
> Parents of children diagnosed with a metabolic dietary disorder.
> Families and supporters of individuals with a metabolic dietary disorder.
> Teachers of children with a metabolic dietary disorder.
> Members of the medical profession in various roles from treatment through research.
> Consumer advocates who may represent people affected by IEMs.
> Other organisations or individuals who may have an interest.
> Educational institutions, government bodies, and students.

What is our membership base?

This financial year has seen 24 new members join. Additional national subscribers include more than 12,000 wider community supporters via our social media sites (IEM family members, friends, teachers, carers, allied health carers etc.)

Affiliated groups (regularly share MDDA information with their members and constituents), including; State based Metabolic clinics, Product/Food suppliers, Affiliated groups including; Rare Voices Australia, ASIEM, GSNV, Genetic Alliance of Australia and National Dietitians Association, Foster care networks providing support to families who are fostering a child with an IEM.

Where are they located?

MDDA IEM members are geographically spread across both metropolitan and regional Australia. Based on the location of incidences and general population trends, a higher portion of members come from the main cities of Melbourne, Brisbane and Sydney.

Minority groups such as Aboriginal and Torres Strait Islanders, people from non-English Speaking backgrounds and people with disabilities access MDDA support services to assist in the effective management of their IEM in order to protect their long term health.

How are they grouped?

Families & Individuals

> Babies
> Children
> Adolescents
> Adults
> Parents
> Families & other supporter

Organisations & Professionals

> ASIEM clinicians
> Other Health Professionals
> Teachers
> Counsellors / Social Workers
> Researchers
> Genetic Counsellors





Looking forward

In order to fulfil our goal of achieving positive health outcomes for individuals living with metabolic dietary disorders, key objectives of the MDDA moving forward include:

- **To strengthen** the role and function of the MDDA as the national peak support body consulting with, representing and supporting individuals who are diagnosed with an inborn error of metabolism and the families, carers and supporters of those individuals.
- **To expand** the reach and membership of the MDDA to ensure all diagnosed individuals are aware of the MDDA and connected with the greater IEM community and peer support network in Australia.
- **To embrace** and provide a support structure for individuals and people who are connected with individuals with rare or isolated inborn errors of metabolism to achieve greater recognition and acknowledgement of their condition and access to available resources throughout all levels of the Australian community.
- **To provide** an umbrella organisation for other more specific and "niche" IEM groups whom represent individuals and their families affected by inborn errors of metabolism.
- **To raise** the conscious awareness and educate the broader community of Australia including governments, health professionals, scientists, educationalists, food suppliers, and the general community of the extent and diversity of IEM conditions and the positive prognosis with effective dietary compliance and treatment.
- **Advise government** on specific needs for IEM individuals relevant to government services, resources and policy.
- **To develop** stronger and more durable links with the research communities, health professionals and universities with a view to creating ethical and sustainable health outcomes for people with various inborn errors of metabolism.
- **To develop** links with other related community based organisations and educationalists throughout Australia to enable them to be aware of the needs of individuals with inborn error of metabolism and to promote greater acceptance, acknowledgement and understanding of individuals, their families, carers and supporters.

Strategic Drivers

The Metabolic Dietary Disorders Association (MDDA), a national self-help group, was founded in 1996 by parents to support other families and individuals affected by Inborn Errors of Metabolism (IEMs) which are rare genetic disorders.

The MDDA supports and represents families and individuals affected by a genetic Inborn Error of Metabolism whereby treatment involves a medically controlled diet.

VISION

All individuals living with an IEM are leading a life at full potential, not limited by choice.

MISSION

The MDDA educates, connects and enables individuals and families living with an Inborn Error of Metabolism (IEM) – ensuring more informed choices and a better quality of life.

GOAL

Achieving positive health outcomes for individuals living with inborn errors of metabolism (IEMs), and requiring life-long metabolic dietary management skills, resources and support.

Financials 2017-2018

The Financial Year of 2018 has been another eventful and exciting year for the MDDA. Many events have been held and many more are in the pipework for this year and years to come.

I would like to thank our members for their ongoing support and contributions to the MDDA. We have had many donations this year that came along with membership renewals. A big thank you to you all. Alone our individual member donations was around $20K. I would like to thank the Mitter's, Laurence Herst, MKG Partners and Yarra Glen Bowling Club for their generous contributions.

In relation to fundraising we had a number of initiatives that were organised by members and their friends. These included:

- Cut for Cure – the McGill Family
- T20 Hobart & Eggs Challenge - the Penneyston Family
- Forest Crescent & Laurimar Primary Schools
- Felicity Simmons and Ironbody Crossfit Gym

This year was also the inaugural year for The Great Protein Challenge. This was a huge success and we received a lot of coverage and support as well as raising over $17K from the initiative. Our members really took this on and it was great to see all the enthusiasm shared. Special acknowledgement goes to the team at Lady Cilento Children's Hospital, The Grand Hotel Warrandyte and MP Michael Sukkar (our local federal member) who all actively supported our challenge in a public arena. We look forward to holding this each year and creating awareness around IEM's.

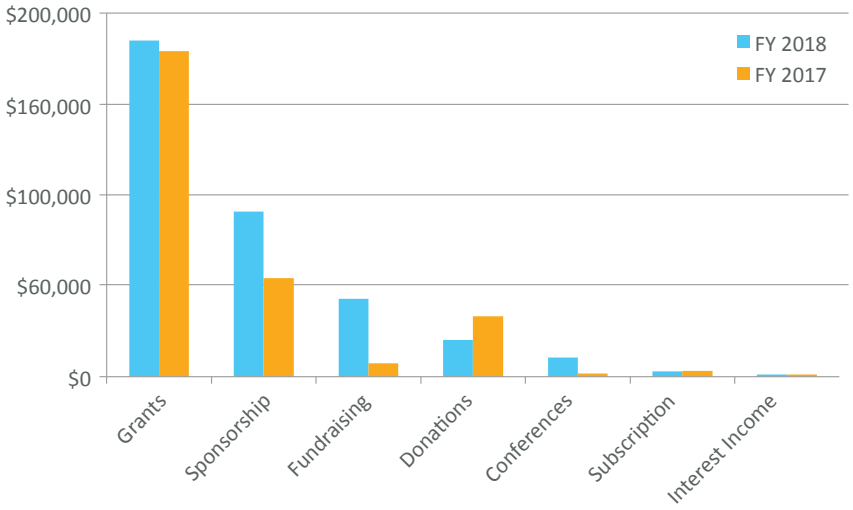
I also must thank the Australian Government who support us with the National Secretariat grant. Without this funding we would not be able to function in the capacity we do. These grants cover 100% of our wage and salary costs and the majority of our National Office expenses.

I also need to thank the NDCI who provide financial assistance to get members to our annual retreats. The MDDA would also like to thank our product sponsors for their ongoing support. Our product sponsors help us in many of our ongoing projects and retreats. Their contributions assist greatly in making our events and projects a success such a major success. Our sponsors include , in no particular order, Vitaflo, Nutricia, Cortex Health, Menarini, Biomarin and Orpharma.

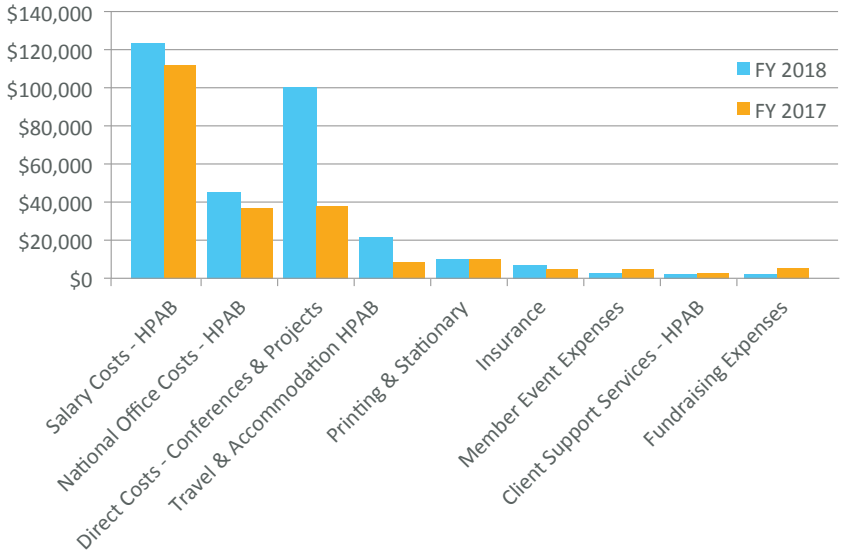
Again, a big thank you for the ongoing support of everyone.

Paige Moore,
Treasurer MDDA

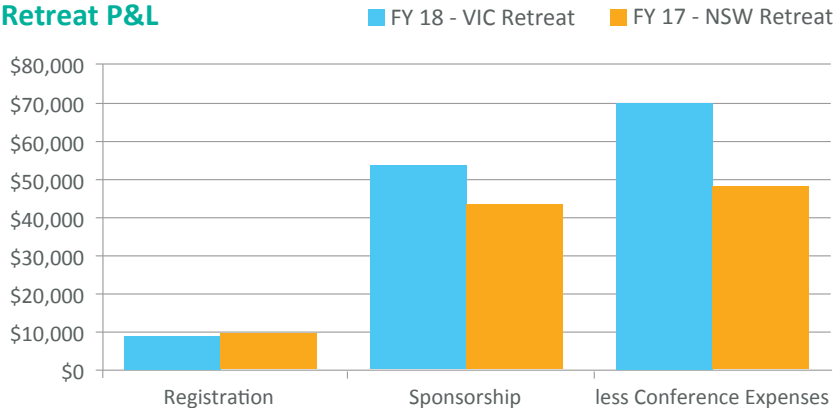
FY 18 Income Comparison



FY 18 Expense Comparison



Retreat P&L



Any financial member may request a full set of Metabolic Dietary Disorders Association audited financial statements.

How you can help

Sponsor a program, initiative or event

MDDA has a number of programs and events looking for financial support, some examples include;

- Low Pro Pop Up Kitchen & Hamper Drive
- IEM Family Assist - retreats & remote clinics
- My Low Pro PAL
- PKU Pathways - outreach support, mentoring
- National PKU & IEM Research & Clinical Care Fund

Make a donation

Donations made to MDDA can go towards a number of different initiatives or research projects;

- MDDA is a regular supporter of Professor John Christodoulou's PKU research project who has made considerable progress in recent years with his PKU probiotic initiative.
- MDDA is seeking funding to support a number of research initiatives in the area of progressing knowledge and potential new treatments/cures for PKU and other IEMs.

Volunteer

Join MDDA. Become involved with the committee or project team and be a part of making a difference for all individuals with IEMs whilst making new friends.

Join #teamMDDA

Become a #teamMDDA supporter and raise funds for MDDA as your chosen charity through participating in an activity of your choice, and raising awareness and funds for MDDA whilst doing something you love.

Host a Fundraising Event

Hosting a fundraising event can be a fun and rewarding experience, and provide a good mechanism for raising awareness and money for IEMs in our community.

Who we are

Executive Committee

President
Monique Cooper, PKU Parent VIC

Vice-President
Louise Healy, PKU Parent QLD

Treasurer
Paige Moore, PKU Parent VIC

Secretary
Bianca Albanese, PKU Adult NSW

General Committee

Peer Support Programs:
Susi Hendricks, PKU Parent VIC

Wellbeing:
Carmen Esparon, PKU Adult QLD

Adult Programs:
Katy Drewitt, PKU Adult VIC

PKU Maternal:
Nicholla Kinscher, PKU Adult NSW

Special Interest Representatives

Transitional Team

QLD
Brooke Dwan, Sarah Acton, PKU Parents

SA
Sasha Cranwell, PKU Parent

State LINK Representatives

NSW
Andrew McDonald, PKU Parent

QLD
Zoe Mitter, Brooke Dwan, Sarah Acton, PKU Parents

VIC
Wendi Emmerson, Susi Hendricks, PKU Parents

SA
Sasha Cranwell, PKU Parent

WA
Maria Contera, Fiona Greer, PKU Parents

IEM Specific LINK Representatives

MSUD
Faith Hill, MSUD Parent

HT1
Shanna Driussi, HT1 Parent

HCU
Tara Bowman, HCU Parent

UCD
Beth Engwirda, UCD Parent

GA1
Janine Hafey, GA1 Parent

PKU (Adults)
Debbie Colyer, PKU Adult

OUR SPONSORS

Vitaflo
Innovation in Nutrition

NUTRICIA
Advanced Medical Nutrition

cortexhealth

MENARINI

Orpharma
A ray of hope

BIOMARIN

OUR SUPPORTERS

Yarra Valley CRUMBS Gourmet Biscuits

GLUTEN FREE Genius

PLATYPUS FOODS

siPahh

Cobs

THE GRAND WARRANDYTE

VeganPerfection
pure indulgence for healthy living

MONSTER

PKU Direct Oceania

YOUR ONE STOP LOW PROTEIN FOOD SHOP!

ACKNOWLEDGEMENTS

The MDDA recognises its state based partner and strategic alliance PKUNSW, and the contribution both organisations together have made to the IEM community of Australia working hand in hand to benefit all PKU and IEM individuals.

MDDA Metabolic Dietary Disorders Association

NSW PKU Association

CONNECTING | EMPOWERING | ENABLING ALL IEM AUSTRALIANS

CONTACT US

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