



Metabolic  
Dietary  
Disorders  
Association



# Annual Report

2016 -2017

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[www.mdda.org.au/help/donate/](http://www.mdda.org.au/help/donate/)

## 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.

## President's Message

### What a year for reflection and celebration!

Every year I take great pride in reflecting on the work of the Metabolic Dietary Disorders Association (MDDA). This financial year just gone there were many major accomplishments for the MDDA and was another industrious year for us. Continuing to provide leadership and support in the areas of national advocacy, education, connecting and providing a voice for the IEM community.

We have continued to focus on improving our digital online presence, benefits to members, our internal infrastructure and managing ways to maximise our financial structure. MDDA is fortunate to have hardworking executive and general committees, enthusiastic volunteers, along with dedicated staff, all very committed and working steadfast toward the vision and goals of the MDDA. It is pleasing to report that a number of projects commenced this year and we look forward to seeing continued development in the coming year.

MDDA provided networking and forum opportunities for our community allowing members to connect, share and support one another. Our national family retreat was held in October, Ingleside NSW. Over 120 individuals and their families, health professionals and stakeholders were able to meet in a social environment and build positive relationships with other members of the MDDA and IEM community whilst also attending many educational presentations and discussion forums.

Our "Being your best You" innovative wellness program was launched and the 8 week pilot program was a great success. This program aims to provide psychological and social support to adults living with an IEM, providing 1on1 facilitation and access to a peer support network along with the tools and techniques to assist with the management of their IEM. The program is designed to instil confidence in participants to cope with the daily challenges they are confronted with and promote optimal outcomes. We are pursuing options for a funding framework to extend the development of this beneficial program.

The introduction of a new MDDA initiative "Virtual Round Table" discussion technology has allowed MDDA to offer online services to our members giving them greater access and opportunity to participate in educational sessions, keeping members informed, educated and connected. This initiative has assisted with the feelings of isolation and the barriers of location, remoteness and finances that often prevent people from attending MDDA's gatherings and conferences. Two online forums were held where we facilitated over 80 participants. The first forum "PKU – National Protein Counting Guidelines" and the second specific to Tyrosinaemia Type 1 presenting on research, management and participant questions on health and treatment topics.

In February of this year MDDA presented in partnership with Rare Voices Australia at the bipartisan Parliamentary launch of the "Fair for Rare" campaign. We presented to key government officials and members of parliament on newborn screening and the impact the positive diagnosis has on patients' lives, the importance of early diagnosis in relation to patient health outcomes. We spoke with ministers and senators regarding the importance of a national co-ordinated approach to equitable access to co-ordinated care,

services and treatments for all Australians who suffer from a rare disease. We also had the opportunity to meet with the IEM Grant program team and discuss ongoing program improvements around governance and communication and we continue to represent and keep our members informed on the program.

MDDA has initiated a Rare Disease patient data registry working party with key stakeholders including Rare Voices Australia and metabolic clinicians that will support the collection of data. Our main intention for the registry is to drive translational research, ensuring better outcomes for people with dietary metabolic conditions.

MDDA was represented at the annual Far North Queensland remote clinic offering support and social inclusion. We coordinated four cook@home low protein workshops, social events and opportunities throughout each state for members to connect, encouraging sharing of dietary information, meal planning and support. We networked and participated in forum opportunities with national and international groups for the purpose of sharing information on rare diseases, research, prevention and treatment, sharing of resources and best practices.

MDDA reported regularly to the Department of Health on matters of policy, education, consultation and provided advice to the department from communication and consultation with our members.

We have continued to actively promote awareness and incidence of IEMs. An Australian first was created with collaboration of the Grand Hotel in Warrandyte, an inclusive dining experience catering for the low protein diet. This fantastic event was promoted in local newspapers, radio station, online new articles and extensively throughout our members social media platform. It provided an exciting insight into how an establishment might be able to embrace low protein meals as a regular feature on their menu and is something we are now piloting with the Grand on an ongoing basis with intentions to expand the concept to other venues Australia wide in the future.

The greatest awareness and fundraising effort for this year was from our member Philip Acton who took on the challenge of a life time. Philip who had never ridden a road bike decided his journey would be a 1512km bike ride from Townsville to Lady Cilento Hospital, Brisbane. Philip and Sarah have 3 gorgeous boys, 2 with PKU. Philip's inspiration was to be a good role model for his three boys and show them that you can give anything a go. Philip and Sarah set a fundraising target of \$20,000 which they surpassed a week out from the departure date. "Ride with the Acton's" raised an amazing \$50,000+. We are extremely grateful to Philip & Sarah, the funds raised will enable MDDA to continue supporting members and developing our programs.

I would like to take this opportunity to thank everyone who has contributed in any way this year. The MDDA relies on the support and dedication from our members, stakeholders, friends and families to further our support programs, educational programs and social events. Thank you to the health professionals who willingly and generously support MDDA events. I thank our sponsors and donors for their generous support which enables MDDA to continue providing events and opportunities for our IEM community. Thank you to the executive committee, staff, volunteers, our members and all supporters of MDDA for their invaluable contribution they made over the past year.



Monique Cooper,  
President MDDA



## Who we are

### Executive Committee

<b>President:</b>	Monique Cooper	PKU Parent VIC
<b>Vice-President:</b>	Louise Healy	PKU Parent QLD
<b>Treasurer:</b>	Paige Moore	PKU Parent VIC
<b>Secretary:</b>	Melinda McGinley	PKU Parent VIC

### General Committee

<b>Peer Support Programs:</b>	Susi Hendricks	PKU Parent VIC
<b>Wellbeing:</b>	Carmen Esparon	PKU Adult QLD
<b>Adult Programs:</b>	Katy Drewitt	PKU Adult VIC
<b>IT Operations:</b>	Richard Drewitt	PKU Spouse VIC
<b>PKU Maternal:</b>	Nicholla Kinscher	PKU Adult NSW

### Special Interest Representatives:

#### State LINK Representatives

<b>NSW</b>	Andrew McDonald	PKU Parent
<b>QLD</b>	Zoe Mitter, Brooke Dwan, Sarah Acton	PKU Parents
<b>VIC</b>	Wendi Emmerson, Susi Hendricks	PKU Parent
<b>SA</b>	Cassie Graue	PKU Parent
<b>WA</b>	Maria Contera, Fiona Greer	PKU Parents

#### IEM Specific LINK Representatives

<b>MSUD</b>	Faith Hill	MSUD Parent
<b>HT1</b>	Shanna Driussi	HT1 Parent
<b>HCU</b>	Tara Bowman	HCU Parent
<b>UCD</b>	Beth Engwirda	UCD Parent
<b>GA1</b>	Janine Hafey	GA1 Parent
<b>PKU (Adults)</b>	Debbie Colyer	PKU Adult



# 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?

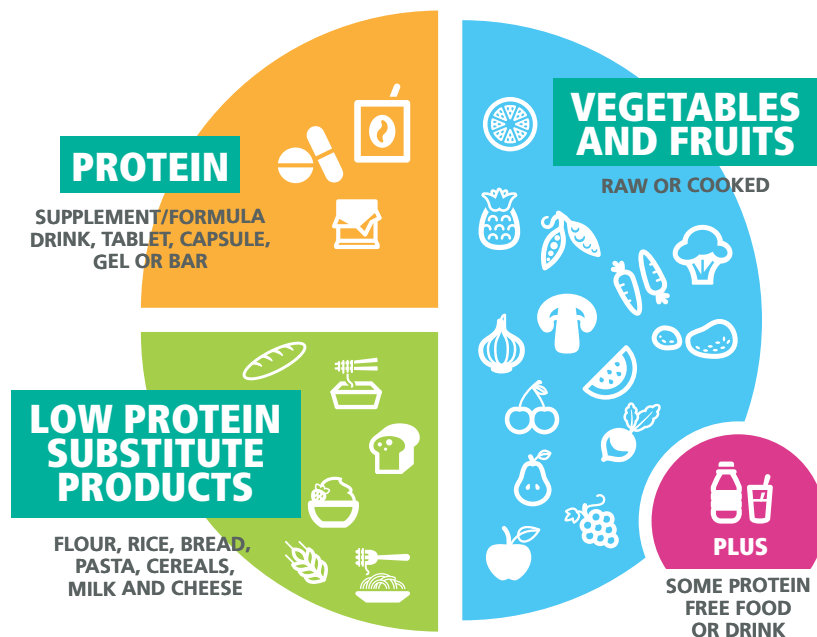
All newborn babies are tested by a blood test (known as the Guthrie Test) taken with the first few days – usually between the 2nd and 5th day after birth, for several conditions.

## 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

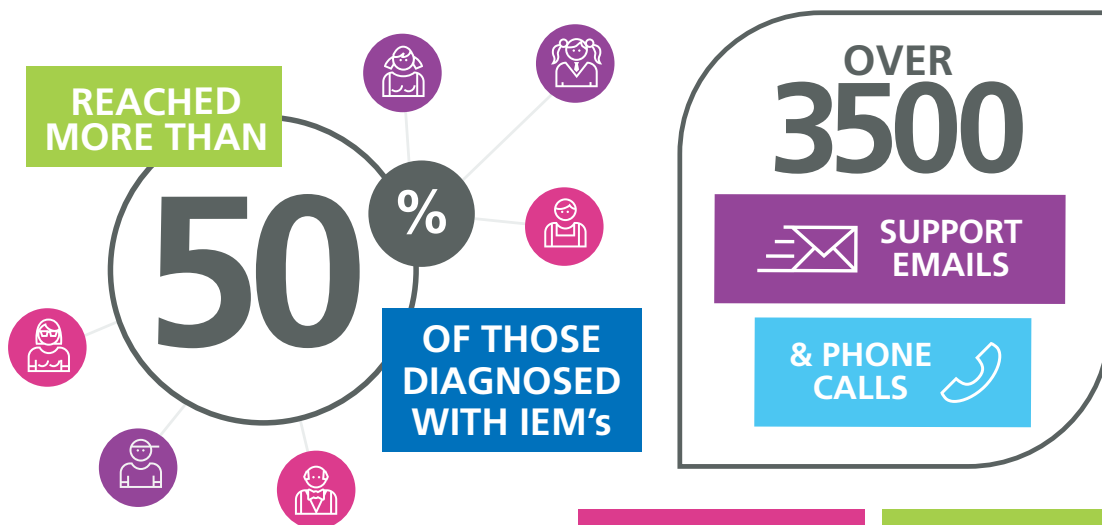
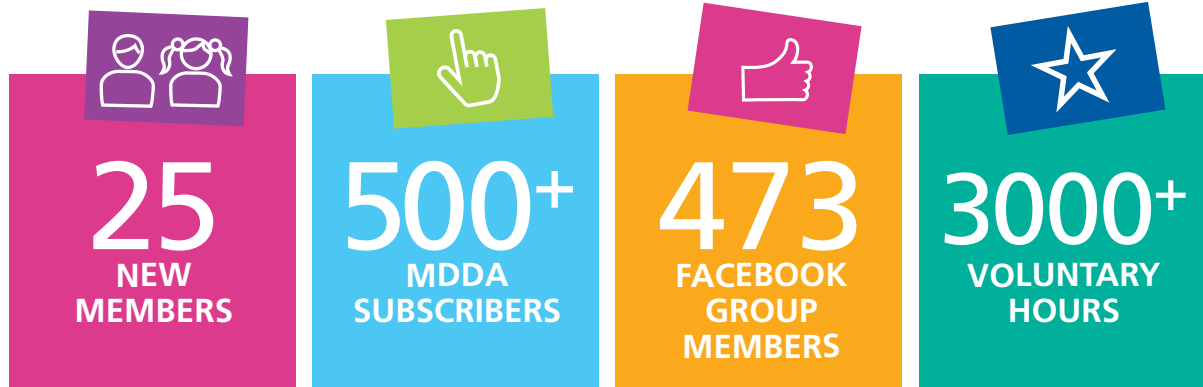
### Organic Acidaemias

- > 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.

# 2016 / 2017 Key Achievements



FIRST EVER

AUSSIE LOW PRO RESTAURANT MENU  
HERE TO STAY!





# Ride with the Actons



# 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 affecting 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 2016/2017 year saw several outcomes achieved.

## 2016/2017 Key Outcomes

### Ride with the Acton's

Philip, Sarah and their 3 boys embarked on a journey to help raise funds for the MDDA and most importantly to raise awareness for all IEM's. Philip rode over 1500km from Townsville to Brisbane from the 2 -19th July 2016.

Promotion of IEM's and newborn screening during this event included Channel 7 news report, radio interviews, publications in local newspapers, online news articles, social media and raising general public awareness during this event.

The MDDA are extremely thankful to the Acton's and all their supporters. 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 \$50,000 was raised.

### Parliamentary Visit

In February MDDA Executive Committee members and representatives attended the Parliamentary launch of the 'Fair for Rare' campaign to highlight the importance of supporting Australians living with rare diseases. MDDA Vice President Louise Healy, spoke on newborn screening the impact on patient lives and the importance of early diagnosis to patient outcomes.

MDDA member Faye delivered a powerful patient perspective 'Living with a child with a rare disease' and the impact that effective policy can have on a patient's life.

### PKU/IEM Awareness month - The Grand Dining experience

The Grand Hotel, Warrandyte Victoria, become the first Australian restaurant to create a unique dining experience for families with inborn errors of metabolism. It was a wonderful way to celebrate PKU/IEM awareness month.

President Monique Cooper and hotel manager, Peter Appleby along with The Grand's Executive Chef Brad Hawker got the idea of a low protein menu off the ground. The outcome of the month long program was truly inspirational and it's now proven that low protein can be catered for with the right level of creativity, and attitude.

### Increased Media coverage & greater public awareness

MDDA use a range of social media channels to provide opportunities for members to have input into MDDA direction, activities and support services. These social media channels also provide tools for keeping members informed of relevant issues and for promoting optimal health outcomes through a focus on treatment compliance and general wellbeing.

MDDA involved in an international consensus for the imminent need of a global association for PKU.

### Adult Wellness Program

MDDA implemented a pilot adult wellbeing program, focused on assisting PKU adults with total health and wellbeing strategies and an interactive peer support network. An 8 week e-coaching program designed to help educate & encourage members to improve vibrancy & energy. 'Being your best You!' commenced in September. The program was limited to 12 participants. Graduation of the program was celebrated at the MDDA family retreat. MDDA are currently reviewing the outcome of this program and if deemed successful will endeavour to secure funding to continue the program to further participants.

### 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 are represented at the National Life Savings Drug Program working group and the Newborn Bloodspot Screening committee.

MDDA also remain in close communication to the nationally recognised Australian Society of Inborn Errors of Metabolism (ASIM) 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.

## THANK YOU ...

to the following member driven fundraising initiatives...

Sarah and Philip Acton - Ride with the Acton's (QLD)

Charli Dean - LPS (VIC)

Tracey Scott - Entertainment Books (VIC)

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

Monique Cooper (VIC)

Grand Dining experience - PKU awareness month  
Lions Club of Park Orchards - Sausage sizzle

The Grand Hotel Warrandyte -- Raffle and  
PKU Awareness month fundraising (VIC)

Scott & Fiona Greer - MKG Partners fundraising (WA)

Nicholla Kinscher - Jamerry (NSW)



## 2016/2017 Member Highlights

### JULY

Major fundraising & awareness campaign "Ride with the Acton's" gets underway

Philip Acton rides 1500km from Townsville to Brisbane and raised over \$50,000

### AUGUST

MDDA President and Vice President attend the Human Genetics Society of Australasia 40th Annual Scientific meeting

### SEPTEMBER

MDDA implemented a pilot Wellness program for adults with IEM's

MDDA President & Executive Officer attend the 23rd Genetic Disorders Awareness week launch

### OCTOBER

NSW Family Retreat - Sydney Conference Centre

End of 8 week wellness program celebrated

First patient registry meeting

### NOVEMBER

Two national online - Virtual round table discussions were held via webex. The first, 'PKU - National Protein Counting Guidelines' and the second was specific to Tyrosinaemia Type 1 Families

MDDA Maternal PKU survey conducted to help determine what support, education & potential opportunities MDDA can provide

MDDA AGM and End of year Vic family Fun night

MDDA & PKUNSW end of year picnics

QLD Clinic and MDDA Christmas party

Outcome of Food Standards Australia Review on the removal of details on the nutrition information panel. MDDA submitted its concerns outlining the importance of this in the dietary management of IEMs

### DECEMBER

State end of year gatherings

Two Cook@home Low Protein Master Classes held in Victoria

Announcement of first global PKU association meeting to be held in Toronto July 2017

Second patient registry meeting held

### FEBRUARY

MDDA Parliamentary Visit - 'Fair for Rare' campaign launched - Vice President speaks on Newborn Screening

Cook@home Low Protein Master Class held in NSW

WA Members picnic

Rare Disease Day Celebrations

### MARCH

SA social function

VitaFlo National IEM dietitians conference attended by MDDA President & Vice President

Cook@home Low Protein Master Class day held in Victoria

### APRIL

First NBS Victorian Meeting held

International travel grant to ESPKU Conference in Norway, awarded to MDDA member

### MAY

PKU/IEM Awareness month

MDDA collaborated with The Grand Hotel, Warrandyte, Vic, creating an Australian first by providing an inclusive dining experience for people with low protein dietary needs

Far North Queensland Clinic

MDDA President took our message to the airways on Radio Eastern FM

### JUNE

Scheduled forums for members nationally living with UCD and members living in Far North Queensland

International PKU Day - June 28

# Member Services

The MDDA continues to contribute to the IEM community through a consistent commitment from volunteers and office staff alike. The 2015/2016 year saw several outcomes achieved.

## Core Member Services

### Newsletters

MDDA News 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?

MDDA subscription comprises of:

- > 410 IEM individuals (and/or their carers)
- > 110 health professionals, IEM clinicians, product providers and representatives from allied support groups

Financial members include 197 pre-existing members + 18 new members. 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.

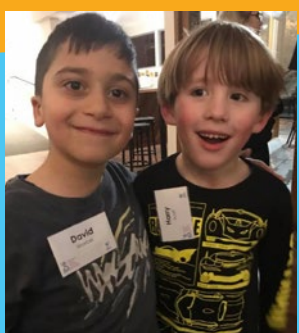
## How are they grouped?

### 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.





# 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;

Peer mentoring program for teens and maternal women

National IEM Wellbeing coaching and fitness program

Low protein menu planning resource



## 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.



## 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.



## 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.

# Financials 2016-2017

This financial year we have been able to sustain our financial stability, enabling us to deliver on our strategic drivers. We have kept our significant commitments set within our annual budget to achieve our strategic/operational plans, maintain business as usual expenditure within our available Commonwealth grant and external funding, whilst funding new projects and capability building from reserves where appropriate.

We have successfully submitted our annual Activity Performance indicators report including the income and expenditure financial reporting with the Australian Government Peak Body Healthcare Policy Input.

MDDA were successful in our application for the National Disability Conference Initiative funding. This Australian Government grant allows us to support people to participate in our nationally-focused conferences held annually throughout Australia.

We remain compliant with The Australian Charities and Not-for-profits Commission (ACNC) to maintain our accountability, transparency and regulatory obligations.

Our membership numbers have increased to 435 up from 390 in 2016.

The fundraising effort of "Ride with the Acton's" from our members Philip and Sarah Acton was formidable. The generosity and spirit that Philip and Sarah offered to support all those living with an IEM as he and his family took on a challenge of a life time raised much needed funds and spread awareness for all IEMs across Australia. Over \$50,000.00 was raised which will enable MDDA to continue to develop support programs and initiatives.

I would like to thank the Grand Hotel, Warrandyte who have been extremely supportive of the IEM community this year. The result of their amazing unique initiative of creating and offering low protein meals to provide an inclusive dining experience has been an exciting and inspiring concept. We are very appreciative of The Grand's support and their generous donation of over \$1820.00 to the MDDA this year.

We have also received many member donations and member driven fundraisers and we would like to thank you all for your support. I would like to make a special mention of the Acton and Mitter families' who have made generous donations to the MDDA. The MDDA is most grateful to all our donors and will continue to use these funds to further support our members.

The fundraising market has become increasingly competitive, with more competition for charitable donations and changing charitable giving trends. We extremely value the solid support of our perpetual and new supporters. Our fundraising plans for the remainder of 2017 into 2018 and beyond continue to be a long-term focus.



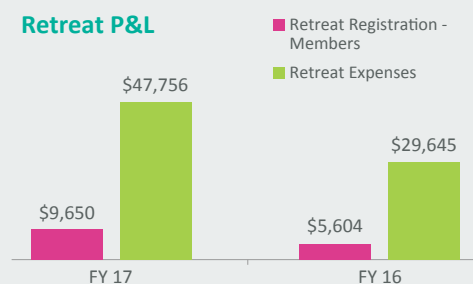
We aim to deliver a sustainable innovative fundraising platform focusing on keeping costs to a minimum to ensure that we can continue to provide increased organisation-wide service and support.

We would also like to take this opportunity to thank our members for their on-going support and our volunteer network including all our executive and general committee members. The executive committee continue to be on a pure volunteer basis and have contributed in excess of 1500 hours again this year.

Our sponsors and product suppliers: Nutricia, Vitaflo, Cortex Health, Menarini and Orpharma have all been instrumental in supporting the IEM community. They have assisted in enabling the MDDA to run successful programs, contribute to the retreats and other initiatives to benefit the MDDA members greatly.

The MDDA is focused on supporting our members and giving back to them where we can. The annual retreats have been very successful and we do our best to assist our members in getting to these events. These retreats are heavily subsidised by the MDDA through the efforts of our fundraising activities, donations, product sponsorships and government grants.

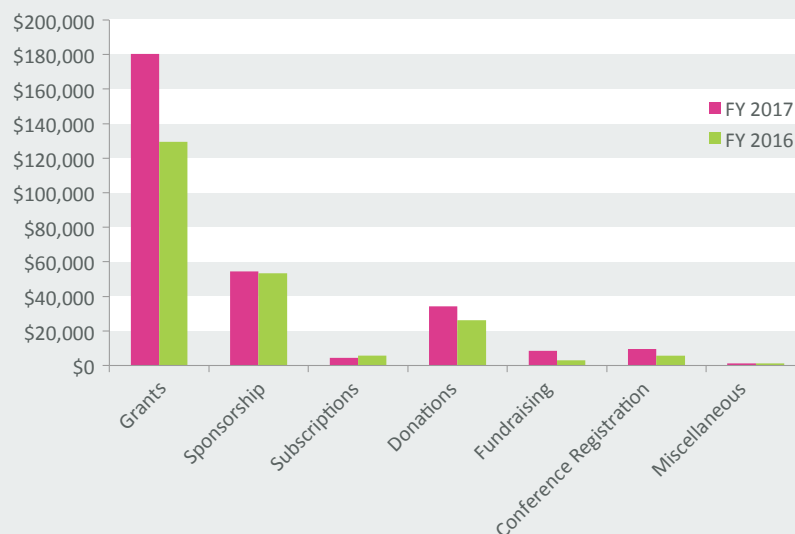
Below is a chart where you can see the cost of running these events far out ways the outlay that members have had to contribute.



#### Comparison financial highlights:

- The retreat expenditure has increased each year indicating the MDDA is offering more at these events and attendances are increasing.
- The members have only had to contribute 20% of the overall costs to attend the events each year.

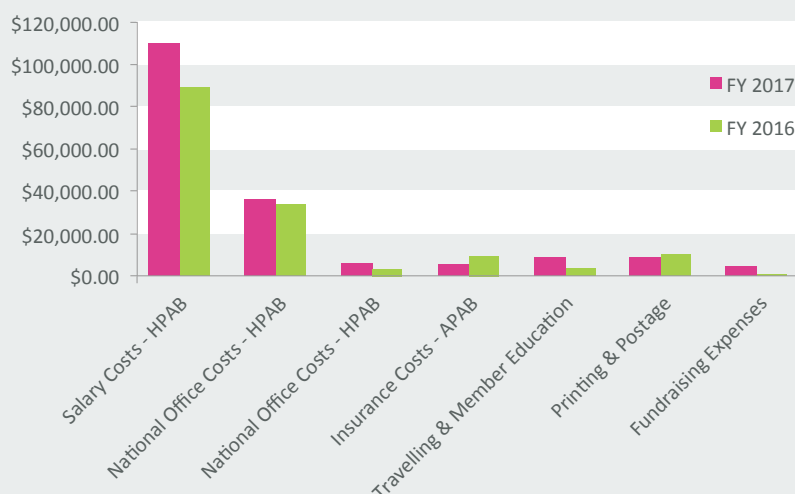
#### Income Comparison FY16 & FY17



#### Comparison financial highlights:

- Our Grant funding has increased with the continued support from the government.
- Our Sponsorship funding has remained steady.
- Subscriptions have remained steady however new members get the first years membership fee for free. We have seen over a 10% increase in our membership.

#### Expense Comparison FY16 & FY17



#### Comparison financial highlights:

- Salary & Wages costs are for the MDDA National office permanent & casual staff and contractors. This is funded by the HPAB government grant. These costs have increased with the demand increasing with the different projects and initiatives the MDDA is involved with and focused on delivering.
- National Office Costs –Rent, outgoings, utilities, maintenance. These costs have remained steady.
- Client support costs, fundraising and member education have all increased. This indicates we are focusing more on giving back to our members in the new support/ wellness programs and activities and events that are either running or in the pipeline.

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

## OUR SPONSORS



**MENARINI**



## OUR SUPPORTERS



## 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.



Metabolic  
Dietary  
Disorders  
Association



CONNECTING | EMPOWERING | ENABLING  
ALL IEM AUSTRALIANS

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