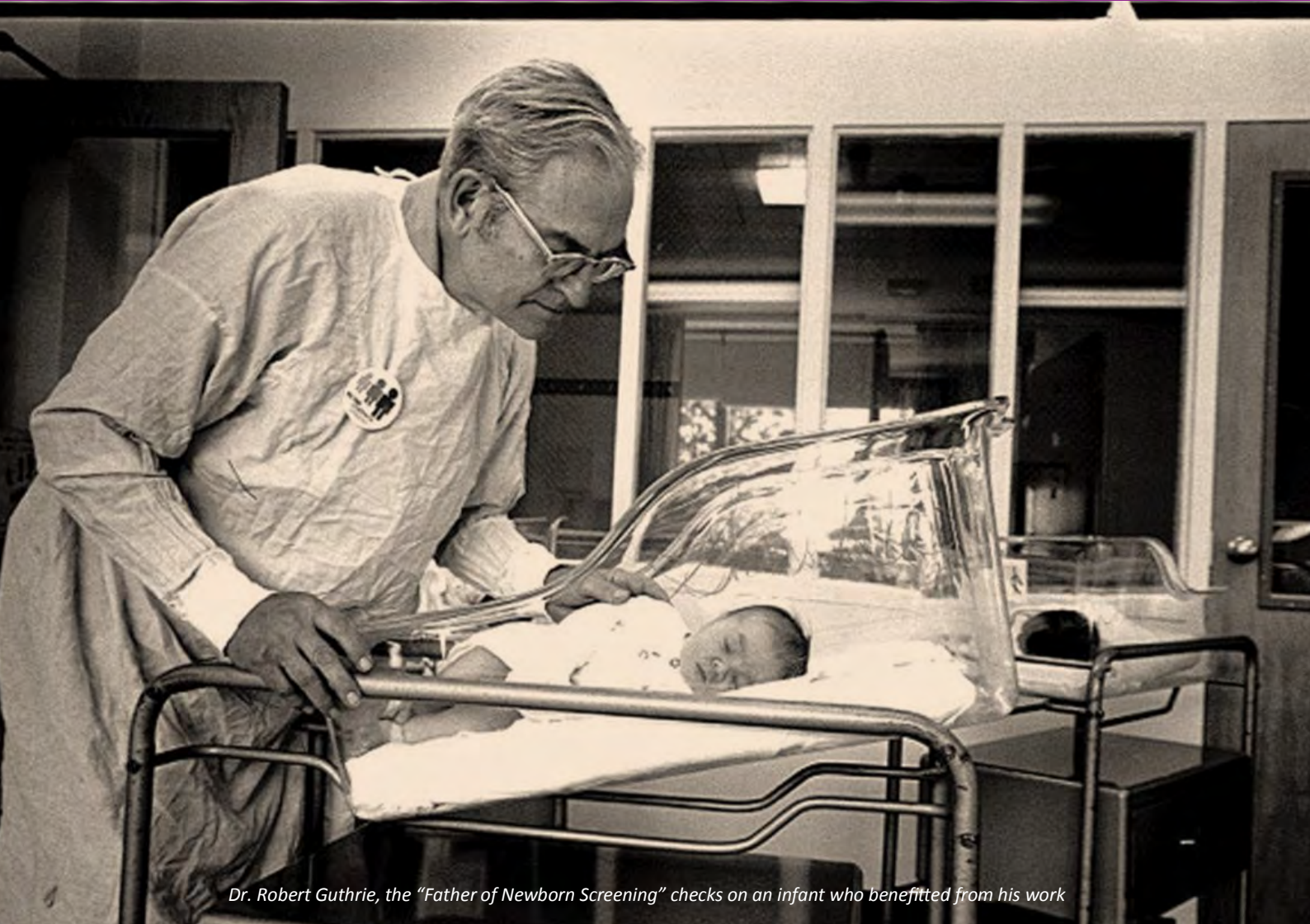


ANNUAL REPORT

2015 – 2016



Dr. Robert Guthrie, the "Father of Newborn Screening" checks on an infant who benefitted from his work

Celebrating 50 Years of Newborn Screening in Australia

METABOLIC DIETARY DISORDERS ASSOCIATION

www.mdda.org.au

President's Message

What a year for reflection and celebration!



With the announcement of the IEM Food Grant reinstatement on 30th July 2015, and after an incredible campaign, MDDA continued to shine. Capitalising on government liaison and media opportunities, MDDA furthered relations with key parliamentary/government officials and health sector influencers, reinforcing the need for ongoing commitment and support for the IEM community.

Success was also achieved with confirmation of extended clinical care provisions for the Western Australian adult clinic, ensuring sufficient ongoing resources for WA adults. In addition QLD announced their new Lifespan Clinical approach providing greater consistency of care from childhood through to adulthood. Complementing this, was the launch of the National PKU Guidelines by ASiEM, a great first step in striving towards a consistent and national framework for IEM management in Australia.

In September, we held our National Family Retreat and Teens camp in Alexandra Headland which was a great success. Shortly thereafter, MDDA received the news that Nitisinone for Tyrosinaemia Type 1 had been approved for the Life Saving Drugs Program, a great outcome for MDDA and many IEM families who played a pivotal role in the advisory process.

As our end of year Christmas celebrations were underway, MDDA received the welcome news securing our national secretariat grant for an extended three year period. Ensuring our work in achieving positive health outcomes for all Australians with an IEM could be continued and grown. This news was welcomed with open arms by a very tired and somewhat burnt out executive team.

Reducing Executive volunteer hours on administration and secretariat duties has meant the MDDA has been able to progress a number of member programs and initiatives this year including; our Adult Wellbeing program pilot launch, our cook at home master class series, state based member social events and a number of fundraising campaigns.

Early 2016, clinical relationships flourished with MDDA participating in several 50 years of newborn screening celebrations across the country. A highlight was being invited to present to over 300 health professionals, researchers, government representatives and Victorian midwife coordinators at the VCGS 50 year celebration. This provided a unique opportunity to share with them the journey many IEM families take following a newborn diagnosis, highlighting the importance of the program, and most importantly expressing our gratitude for its existence and their role. With this, our 'Miracles of Newborn Screening' educational and awareness campaign was launched.

Rare Disease day was celebrated on February 29 across Australia and globally. Collaboration with other rare disease groups on the national rare disease framework, newborn screening policy, and national patient registry for IEMs and other rare diseases continued.

After another successful year, the MDDA is pleased to be in such a position of strength after what has been 20 years of dedication and commitment from so many people (past and present) who have been fundamental in building the foundation for who we are today.

As this milestone is celebrated, we also recognise the work of our allied partner PKUNSW and acknowledge the commitment for further work and collaboration towards creating a single unified organisation and voice for all IEMs in Australia.

Finally, and most appropriately to top off the end of an epic financial year, we had the privilege of acknowledging our much esteemed Medical Pioneer Dr. Robert Guthrie whom would have celebrated his 100th birthday on 28th June 2016. The many families and individuals who make up the MDDA would not be here today if it was not for the great work and persistence of this most brilliant man – as it is for him that we will be forever grateful for giving so many people the chance at a normal life.

With so many incredible achievements, it is rewarding to reflect on what has been a monumental year for the MDDA, and I look forward to where the future is leading.

Monique Cooper, President MDDA

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1996 – 2016 – MDDA celebrates 20 years of representing and supporting the IEM community of Australia

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

*front cover picture from University Archives, State University of New York at Buffalo

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:	Melinda McGinley	PKU Parent VIC

General Committee

Peer Support Programs:	Susi Hendricks	PKU Parent VIC
Advocacy & Wellbeing:	Louise Healy	PKU Parent QLD
Adult Programs:	Katy Drewitt	PKU Adult VIC
IT Operations:	Richard Drewitt	PKU Spouse VIC
PKU Maternal:	Nicholla Kinscher	PKU Adult NSW



MDDA Committee

Special Interest Representatives:

State LINK Representatives

NSW	Andrew McDonald	PKU Parent
QLD	Zoe Mitter / Louise Healy	PKU Parent
VIC	Wendi Emmerson / Susi Hendricks	PKU Parent
SA	Cassie Graue	PKU Parent
WA	Maria Contera	PKU Parent

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

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.

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 within 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 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.

2015/2016 Key Achievements



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.



MDDA Vice President Louise Healy meeting with Stephen Spencer, Senior Advisor to Minister Ley



MDDA HTI Representative Shanna Driussi meeting with local member Kevin Hogan



MDDA President Monique Cooper with IEM Food Grant Program Administrators, Dept. of Health

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.



MDDA presenting at RCH Victoria 50 years of newborn screening celebration with 200+ health professionals and MDDA members



MDDA president and secretary speaking about 50 years of newborn screening on local Victorian radio



MDDA President Monique Cooper addressing Monash Medical Centre Midwives

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.

"MDDA opens the doors to new friendships and opportunities enabling us to learn more about our son's condition ... we have so much more confidence we are doing the right things now."

The year in review

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.

2015/2016 Key Outcomes



IEM Food Grant

July 30 2015 the government announced the reversal of the IEM Food Grant cessation. This was a ground breaking victory for MDDA and the entire IEM community. The previous 71 days saw the entire IEM community stand as one.

Parliamentary Visit

In November 2015, the MDDA met with key parliamentary and Department of Health officials involved in the IEM food grant reinstatement to express our gratitude and to share priorities and future plans for the MDDA. We met with the Department of Health and IEM Food Grant Program Directors and discussed matters concerning the ongoing provision and management of the food grant and the ongoing role of the MDDA.

State Clinic Resources

WA – July 2015, MDDA campaigned to WA health and worked closely with IEM adults and WA clinic to extend the existing funding model to enable greater service to be provided to patients, resulting in an extension of extended clinic hours and resources.

QLD - September 2015 QLD Minister for Health wrote to MDDA to advise a state wide Lifespan Metabolic Medicine service would be launched to provide multidisciplinary healthcare support to all people with IEM disorders.

National PKU Guidelines

Following MDDA's approach to ASIEM in 2014, by way of formal submission, for the implementation of consistent national guidelines for the management of IEMs, the protein counting guidelines were launched in August 2015. The finalisation of national PKU maternal guidelines are the first step towards progression of national PKU guidelines.

Food Labelling Policy

December 2015 FSANZ released the evaluation of 'Labelling Review Recommendation 17: Per serving declarations in the nutrition information panel'. 78 submissions were received, including 19 campaign submissions from those with (or caring for family members with) metabolic disorders such as phenylketonuria. FSANZ noted in particular, 'submitters emphasised the importance of per serving information in the management of lifelong diseases such as phenylketonuria...' If recommendation 17 be considered further, a number of standards in the Code would need to be assessed.

Adult Wellbeing Program

In June 2016, MDDA launched its pilot adult wellbeing program, focused on assisting PKU adults with total health and wellbeing strategies and an interactive peer support network.

Rare Disease Framework

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

Life Saving Drugs Program

30 September 2015, MDDA was advised that (Nitisinone) for Tyrosinaemia Type 1 was deemed suitable for the LSDP.

Unified Voice for IEMs

Signed an MOU with PKUNSW for intention to merge for one unified IEM voice.

Newborn Screening Celebration

50 years of newborn screening was celebrated in Victoria in 2016. MDDA president Monique Cooper presented to researchers, health professionals and families at the RCH focusing on the positiveness and gratefulness felt by those whose lives without NBS and diagnosis would have very different outcomes.

Newborn Screening Education

MDDA presented an educational in-service over 2 days to midwives at the Monash Medical Centre. MDDA presented on community radio to educate the wider community on the success of NBS.

2015/2016 Member Highlights

July

Ministers office contact MDDA to advise of the reinstatement of the IEM Food Grant.

PKUNSW members granted reciprocal (limited) membership rights.

August

Queensland Retreat and Youth Camp – Alexandra Headland Sunshine coast.

Release of National protein counting guidelines for PKU in Australia.

WA Adult Clinic Hours and resources extended.

September

SA Color Run fundraiser.

October

Educational member videos posted to MDDA YouTube channel.

November

MDDA President and Vice President meet with key parliamentary officials to express gratitude for the IEM Grant reinstatements as well as share plans for 2016 and beyond.

Met with Department of Health and IEM food grant Program Directors to discuss the ongoing provision and management of the grant.

MDDA AGM and End of year Vic family Fun night.

MDDA & PKUNSW end of year picnic.

QLD Clinic and MDDA Christmas party.

Low protein master classes held at member homes state wide.

December

Other state end of year gatherings.

February



MDDA members and committee attended 50 Year Anniversary of Newborn screening at the Royal Children's Hospital Victoria.

WA Members picnic.

Rare Disease Day Celebrations.

March

MDDA President and Vice President presented to ASIEM Dietitians at national conference.

MDDA President and Secretary took our message to the airwaves on 94.1 FM community radio.

April

Newborn Screening Education by MDDA president to Monash Medical centre midwives.

May

PKU Awareness Day, SA, QLD & NSW

Far North Queensland Clinic

Appointed MDDA Media Advocate Justin Smith

June

Major fundraising activity – RIDE WITH THE ACTON'S was launched.

Celebrations of Dr Robert Guthrie's 100th Birthday – Father of Newborn Screening.

International PKU Day – June 28.

Thank you

To the following member driven fundraising initiatives...

- Sarah and Philip Acton
Ride with the Acton's - QLD
- St Marks Anglican
Community School – WA
- Scott Greer and BNI Riverside
Business Group – WA
- Tracey Scott
Entertainment Books – VIC
- Katie and Cass Graue
Color Run - SA



Metabolic
Dietary
Disorders
Association

Looking for resources, information,
connection and support from other
families who are managing an IEM?

MDDA are here to help
you and your family



Member Services

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.

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.

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.

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 planning 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.

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.

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.

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.

News & Forums

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.



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.

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.



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.



Financial

The financial year of 2015/2016 has been a progressive one for the MDDA. This time, a little over 18 months ago, we were unsure we would be able to operate in the capacity we have done in the past and still do today, due to the expiry of our government funding. This funding pays for 100% of our administration and National Office costs. This enables us to ensure our **members hard efforts in fundraising** (and the donations we receive) can go into important member programs and subsidies.

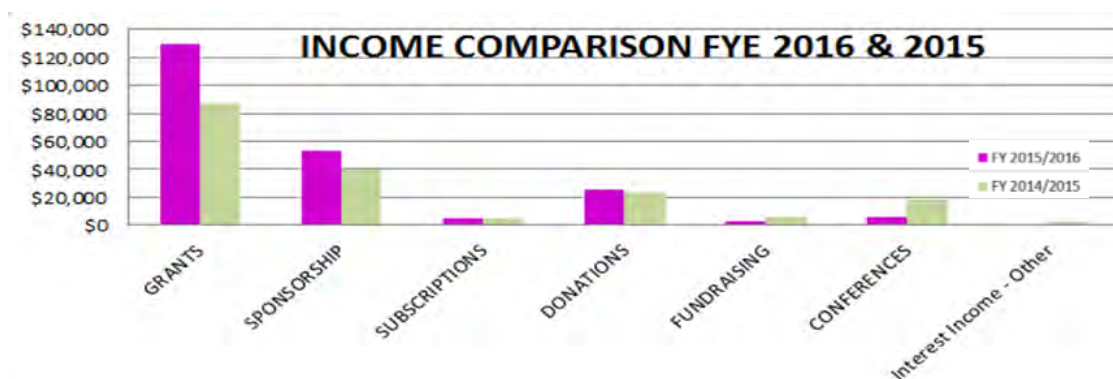
In December 2015, our previous funding arrangements expired and the continuation of such funding was uncertain, specifically due to changes in government and restructuring of their grants program. With these changes, the MDDA had to provide a new application for funding to cover the national secretariat and administrative services of the organisation. This process provided the opportunity to review our **organisational objectives** and national office requirements and provide a more thorough and accurate assessment on the resourcing needs of our national office.

It was a welcomed outcome to hear our submission was accepted, and as a result the MDDA has been able to extend national office resources to provide a more effective and far reaching support offered to our IEM community.

The cancellation of the IEM Food grant in May of 2015 highlighted the **importance of organisations like the MDDA** supporting individuals who may not have a voice if they stand solo. It shows when you come together, there is strength in numbers. Not only did this end up with a positive outcome of having the food grant re-instated, it also engaged more members to be involved and connect, and also turned the heads of other stakeholders. This included our sponsors, such as Vitaflo, Nutricia, Cortex Health & Menarini. They have continued to support the MDDA and have been key contributors supporting our retreats, cooking demonstrations and other programs.

INCOME

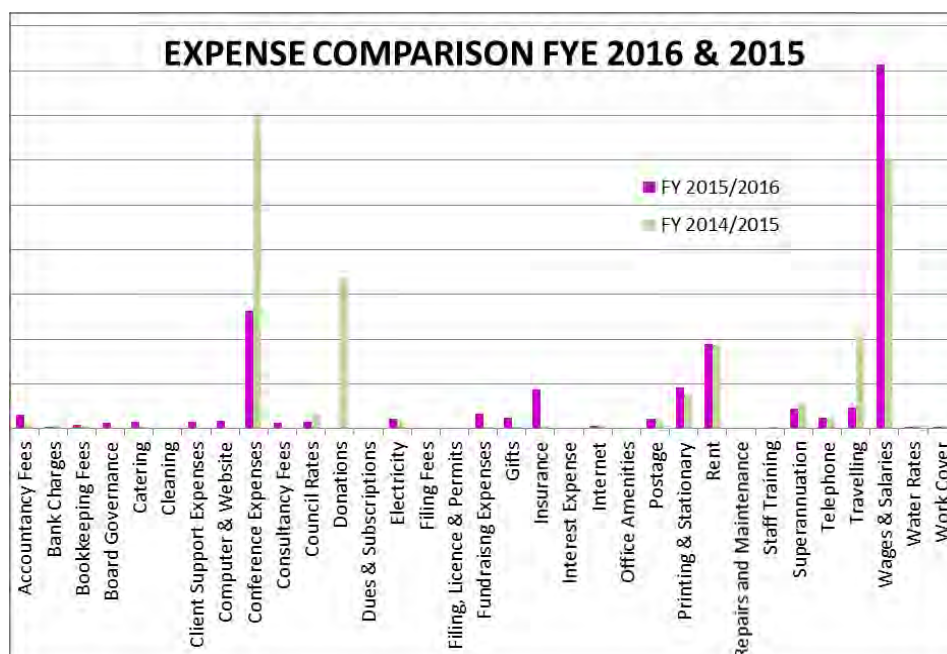
- Income accounts** have **increased** in relation to FY2015/2016. Grants (government), Sponsorship (suppliers), Donations have increased significantly.



- Conference income has decreased.** This is money paid to the MDDA by members to attend events, such as the retreats. (MDDA is able to subsidise the cost of these retreats due to sponsorship, donations and fundraising activities).
- Fundraising** was down. In actual fact, this is not a true reflection. The Acton's adventure happened on the cusp of the financial year and the fundraising was received in early 2017 FY.

EXPENDITURE

- Large donations expenditure** - as noted in last years financial report, this relates to the Children's Westmead Donation from the financial year 2014/2015.
- Wages & Salaries** - MDDA received new funding to allow for additional office support, with extra staffing resources. Part of this funding has also been allocated to updating our technology and systems, including the upgrade of our website. We have also been able to increase our client support services.
- Insurance expense**- our previous years insurance was paid in the financial year of 2015/2016.
- Conference Expenses** - last year included two retreats versus this year one.



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



Become a Team MDDA supporter

Become a Team MDDA 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.

Join MDDA and/or donate your time

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.

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.



www.givenow.com.au/mddapkuawareness



Our Supporters



MDDA is supported by funding from the Australian Government under the Health Peak and Advisory Bodies Program.

Contact Us

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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