



ANNUAL REPORT

*Achieving positive health outcomes for
individuals living with inborn errors of
metabolism*

METABOLIC DIETARY DISORDERS ASSOCIATION
www.mdda.org.au

Message from the President

Reflecting upon the last financial period, there is a great deal of pride in the outcomes and accomplishments achieved. A year of hard work and dedication by our executive office, committee of management and volunteer network has resulted in a year of many positives returns.

MDDA's policy work in the field of IEM's has seen us grow relationships extensively with key organisations and metabolic professionals driving the health agenda of our country and ensuring IEMs are not left behind.

Advances in metabolic clinical care with the forming of the new "Full life" metabolic clinic in Queensland, along with the appeal for additional resources in Perth have been much welcomed developments. So too has the acceptance by ASIEM on the need for a national PKU care plan and protein counting chart which developments are soon to be launched.

The importance of Newborn screening is an area of continual focus for MDDA, contributing to the RACP national positioning statement and participating in the Australian Governments Newborn Screening working party. With 2016 representing 50 years of newborn screening in Australia, and PKU being the first condition to be screened. MDDA advocates for consistent and broader newborn screening opportunities for all rare diseases as well celebrating the opportunities it has brought to our IEM community currently today.

Working with other rare disease groups (through Rare Voices Australia) and contributing to and endorsing the national rare disease framework ensures IEM's gain their share of much needed attention with the national health agenda. Advocating for life saving and life changing medications to be available and included on PSBA (such as Nitisinone's recent recommendation for the Life Saving Drugs program) continues to sure all patients have access to necessary medicines to ensure effective treatment. Our work will continue in the space with the goal to see other newer medications and trials become available for IEM patients in the future.

Throughout the year, MDDA has facilitated several submissions to FHANZ in relation to the proposed changes to the 'per serve" food labelling information panels and their importance in managing an IEM low protein diet. We are yet to hear the outcome of these submissions but will continue to represent the needs of IEMS in this area.

The year has seen a heightened presence and influence of MDDA on matters of Government Policy in particular with the recent IEM Food Grant program cessation. MDDA advocated very strongly direct to all areas of Government in the importance of the grant y. Working closely with other IEM groups such as HCU Network and PKU NSW has provided a unified voice for IEMs in Australia.

In October 2014, MDDA and PKU NSW signed a memorandum of Understanding for the intention to consider a merger and have plans to progress this in the coming financial year with close consultation of our

members and concerned stakeholders. This unity will ensure one single voice for all PKU Australians whilst still respecting and preserving the strengths and foundations of both organisations.

The year was an active one for members with several member social gatherings, awareness and fundraising activities taking place. Almost \$15,000 from member fundraising activities and donations was received, and member renewals were strong. Considerable growth in member engagement was seen with record participation at events and in online forums, and we had a significant 37 new members sign up for the year. Our success with our "IEM Faces" social media campaign saw our public reach exceed all expectations and soar with new followers and supporters, and IEMs became "talked about" in the news, on the streets and in parliament with the IEM Food Grant cessation dispute.

Amongst all of this, MDDA ran two family retreats and youth camps in Sydney and Perth, each receiving record attendees and excellent feedback. The Sydney retreat brought International guest and PKU Advocate Kevin Alexander and his wife Mara to Sydney (with thanks to Nutricia) to share his global perspectives on PKU and also put his film making skills to great work in capturing many of our local stories on film. This event also saw the establishment of our Tyrosinaemia support group (with thanks to Menarini) with eight families meeting for the first time to provide each other with much valued support.

MDDA members Kylie and Lachlan Doonican also had the opportunity to participate in the NSPKU conference (with thanks to Vitaflo) bringing home some excellent stories and information to share with the wider PKU community.

Ours appreciation is extended to all MDDA supporters (both organisations and individuals volunteers), and MDDA would not exist and be able to contribute in such a way without them.

The year has been grand and future is bright for continuing to ensure positive health outcomes for all IEM Australians.,

Monique Cooper
President

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 or resource.

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 diseases 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 it is 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 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.

Who we are

Executive Committee

President	Monique Cooper	PKU Parent VIC
Vice-President:	Richard Drewitt	PKU Spouse VIC
Treasurer:	Paige Moore	PKU Parent VIC
Secretary:	Tiffany Dean	PKU Parent VIC

General Committee

Peer Support Programs:	Susi Hendricks	PKU Parent VIC	(VIC LINK)
Advocacy & Wellbeing:	Louise Healy	PKU Parent QLD	(QLD LINK)
Adult Programs:	Katy Drewitt	PKU Adult VIC	

Special Interest Representatives:

State Representatives

NSW	Andrew McDonald	PKU Parent	
QLD	Zoe Mitter	PKU Parent	
VIC	Wendi Emmerson	PKU Parent	
SA	Cassie Graue	PKU Parent	(SA LINK)
WA	Maria Contera	PKU Parent	(WA LINK)

IEM Representatives

MSUD	Faith Cochrane	MSUD Parent	(MSUD LINK)
HT1	Shanna Driussi	HT1 Parent	(HT1 LINK)
HCU	Tara Bowman	HCU Parent	(HCU LINK)
UCD	Beth Engwirda	UCD Parent	(UCD LINK)
GA1	Janine Hafey	GA1 Parent	(GA1 LINK)



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.

“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

Over the past twelve months the MDDA has co-ordinated over **6,000+ volunteer hours** from its dedicated executive committee members alone - covering activities from newly diagnosed support, development of patient support resources and programmes, to participation in advisory bodies on medications and newborn screening and preparing submissions for government on the impact of government policy decisions on people with IEMs.

2014/2015 Key Outcomes

IEM Food Grant

Coordinated the national submission to government educating them on specialised dietary management requirements to justify the continuation of the Australian Government funded IEM Food grant.

PKU Counting System

Facilitated the publication of a standardised PKU counting system by ASIEM - providing consistent and clear advice on counting protein in non-medical foods for the purpose of more accurately and effectively managing protein intake in the IEM diet.

Food Labelling Policy

Coordinated over 20 individual submissions and provided on organisational submission to the Food Standards Australia and New Zealand review of food labelling guidelines. Accurate food labelling is an integral part of effectively managing the IEM diet.

Newborn Screening Policy

Participated in the development of the Royal Australian College of Physicians (RACP) position statement on newborn screening in Australia.

Represented IEMs on the Australian Government's national Newborn Screening Working party.

PBAC Submissions

Co-ordinated member submissions to PBAC on medications relevant to management of IEMs, as well as preparing our own national submission and representing Hereditary Tyrosinaemia Type 1 (HT1) members at the Pharmaceutical Benefits Advisory Committee meeting regarding the listing of Nitisinone on the PBS.

Life Saving Drugs Program

Briefed our members on the Life Saving Drugs program review to give members the opportunity to provide feedback via the public consultation survey.

National PKU Guidelines

Made a formal submission to ASIEM for the implementation of consistent national guidelines for the management of IEMs. ASIEM to first sign off guidelines for maternal women. This innovation represents best practices being adopted in Europe and North America.

Rare Disease Framework

Attended the Rare Voices Australia Rare Disease Summit and contributed to the Rare Voices communiqué regarding rare disease framework in Australia.

Unified Voice for IEMs

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

Newborn Screening Policy

Provided information and advice to members regarding the Australian Government's "primary care of people with chronic and complex conditions" public consultation process.



2014/2015 Member Highlights

July

RCH Newborn screening Lab visit and educational tour.

October

International Advocate Kevin Alexander arrives in Sydney

November

MDDA visits WA metabolic clinics.

QLD end of year gathering

0-5's kids playdate.

MDDA NSW Family retreat and PKU NSW Teens camp takes place.

December

MDDA visits SA, VIC & NSW metabolic clinics

Other state end of year gatherings.

August

Misleading Media article sparks new clinic response mechanism for members.

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

January

MDDA attended Newborn screening working party

PKU NSW veteran Jill Colyer awarded OAM.

WA Trivia fundraiser night

September

Walk for Ava member fundraiser.

February

MDDA visits QLD metabolic clinic.

March

MDDA representatives attend NSPKU international conference.

PKU adults night in, QLD

MDDA attends Rare disease summit

April

MDDA WA family retreat and teens camp

May

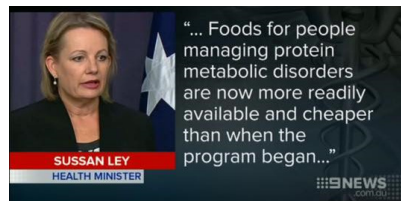
PKU Awareness Day, SA

PKU Awareness Day, QLD

PKU Awareness Day, NSW

MDDA attends Nitisinone PBAC meeting in Canberra

Cessation of IEM Food Grant announced.



MDDA meets key Government representatives in Canberra.

Reinstatement campaign commences

June

RUN Deano Run



MDDA Member survey

IEM awareness and campaign kicks in – Government reconsiders

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:

- 390 IEM individuals (or their carers)
- 94 health professionals, IEM clinicians, product providers and representatives from allied support groups

Financial members include 124 pre-existing members + 37 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 supporters

Organisations and Professionals

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



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.

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.

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.

Dietary Resources

Dietary management resources include:

- Online recipe catalogue
- Online product catalogue
- Printed Recipe book (& inserts)

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

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.

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 with a person to call on (or be called upon) to obtain one on one support, information and advice. This is particularly important during early diagnosis when often parents experience feelings of uncertainty and being overwhelmed with information and emotion

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.

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.

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.

Social Functions / 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.



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 consequences 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.

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

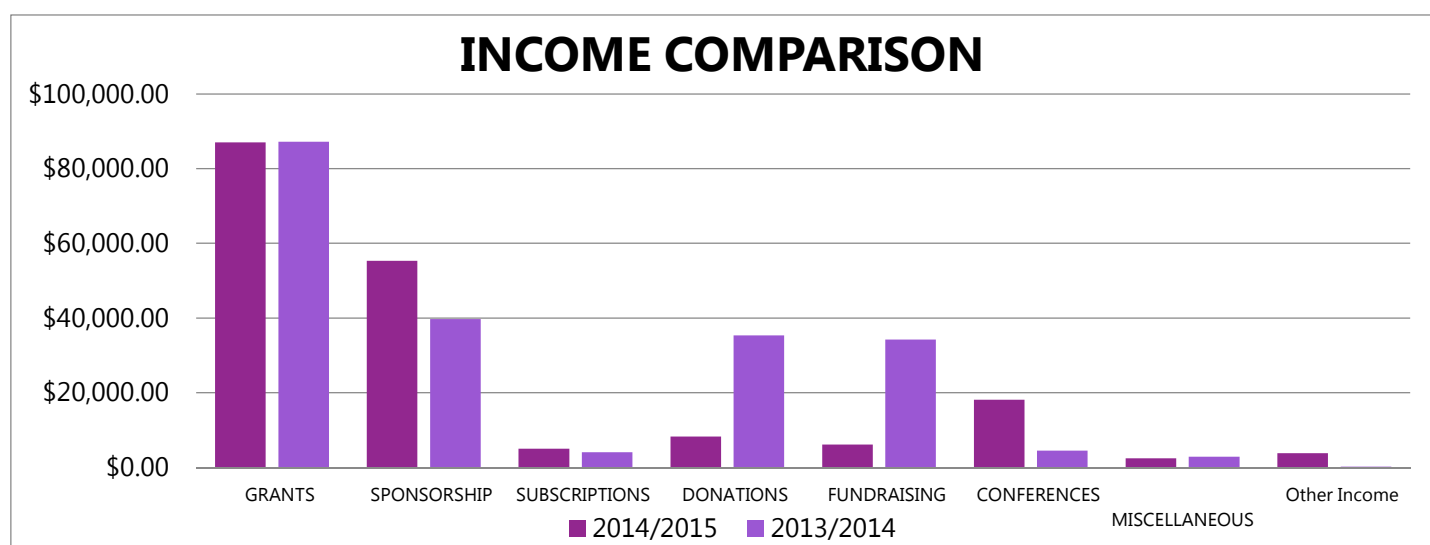
The financial information provided sets out to demonstrate the direction the MDDA will take in supporting its members and to promote awareness of the incidence of Inborn Errors of Metabolism in the Australian community.

The Association will continue to be reliant on a mix of community based funding, government support, and private enterprise sponsorship.

This statement outlines our income and expenses over the period from July 1 2014 to June 30 2015 and it also shows the figures from the previous financial year. Given MDDA uses the Cash basis accounting method some income and expenses are relevant to the 2013/2014 financial year or the 2015/2016 financial year. These are outlined below.

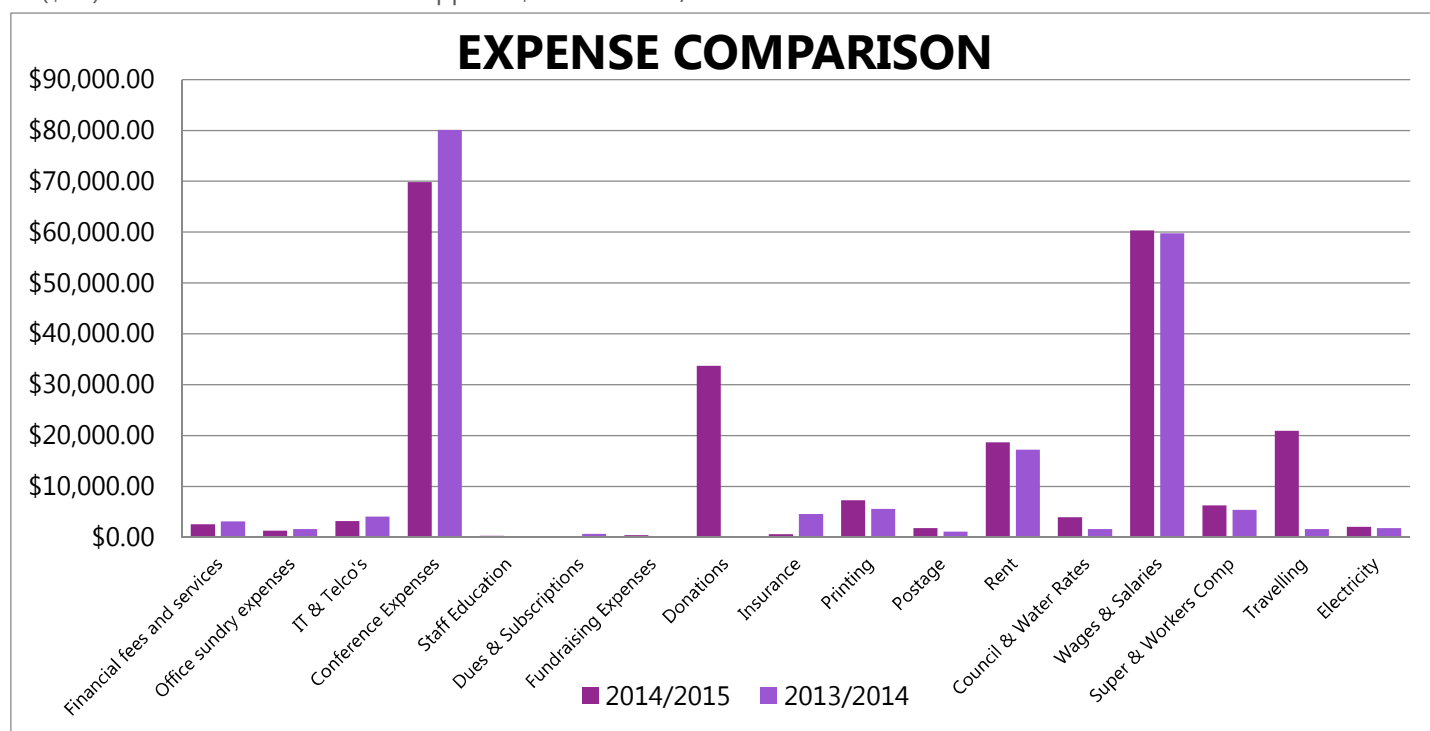
Income

In comparing 2014/2015 to 2013 you can see that our overall income has decreased from \$208K to \$186K. It must be noted that there was a \$33K donation to Westmead that was included as part of the 2013/2014 income. Donations & Fundraising Income was then forwarded onto the Westmead Hospital for PKU Research in July of 2014. There was also a further \$9K of sponsorship funding that was recorded in the FYE 2014 figures that relates to FYE 2015.



Expenses

With regards to the expenses, the conference expenses are made up of NSW Retreat, WA retreat and QLD retreat costs. The Qld Retreat Costs also relate to the 2015 -2016 FY. Our insurance expenses have also fallen into 2015-2016 FY (\$4K). This leaves a Net Loss of approx. \$206 for 2014/2015.



Highlights

Key areas to highlight within this statement include:

- **Bookkeeping** – we no longer employ external bookkeepers but manage internally with a small software fee.
- **Printing**- These costs have increased slightly with the production of 3 newsletters
- **Wages and Salaries**- We employ one Executive Officer and a part-time administrative assistant.
- **Rent & Electricity**- Our rent and electricity expense actually decreased as we received a temporary reimbursement for rent for six months. Also, council and water rates are in separate categories for this year.

FY 2014 / 2015 Profit & Loss

Income	2014/2015	2013/2014		
GRANTS	\$87,013.00	\$87,233.00	(\$220.00)	-0.25%
SPONSORSHIP	\$55,363.63	\$39,764.25	\$15,599.38	39.23%
SUBSCRIPTIONS	\$4,994.14	\$4,047.75	\$946.39	23.38%
DONATIONS	\$8,243.68	\$35,329.40	(\$27,085.72)	-76.67%
FUNDRAISING	\$6,161.03	\$34,272.76	(\$28,111.73)	-82.02%
CONFERENCES	\$18,128.34	\$4,505.24	\$13,623.10	302.38%
MISCELLANEOUS	\$2,448.16	\$2,879.57	(\$431.41)	-14.98%
Other Income	\$3,840.00	\$261.41	\$3,578.59	1368.96%
Total Income	\$186,191.98	\$208,293.38	(\$22,101.40)	-10.61%

General & Admin Expenses	2014/2015	2013/2014		
Financial fees and services	\$2,524.83	\$3,114.08	(\$589.25)	-18.92%
Office sundry expenses	\$1,283.91	\$1,632.34	(\$348.43)	-21.35%
IT & Telco's	\$3,165.29	\$4,081.01	(\$915.72)	-22.44%
Conference Expenses	\$69,852.11	\$80,088.00	(\$10,235.89)	-12.78%
Staff Education	\$259.09	\$0.00	\$259.09	
Dues & Subscriptions	\$209.36	\$643.07	(\$433.71)	-67.44%
Fundraising Expenses	\$400.09	\$0.00	\$400.09	
Donations	\$33,692.35	\$0.00	\$33,692.35	
Insurance	\$595.25	\$4,555.11	(\$3,959.86)	-86.93%
Printing	\$7,259.67	\$5,556.46	\$1,703.21	30.65%
Postage	\$1,777.18	\$1,104.39	\$672.79	60.92%
Rent	\$18,687.00	\$17,245.28	\$1,441.72	8.36%
Council & Water Rates	\$3,922.69	\$1,606.67	\$2,336.66	145.43%
Wages & Salaries	\$60,299.56	\$59,735.70	\$563.86	0.94%
Super & Workers Comp	\$6,237.75	\$5,354.68	\$629.26	11.75%
Travelling	\$20,942.46	\$1,587.43	\$19,355.03	1219.27%
Electricity	\$2,035.04	\$1,817.23	\$217.81	11.99%
Total General & Admin Expenses	\$233,168.63	\$108,026.99	\$55,239.53	51.13%
Net Profit/(Loss)*	(\$46,951.65)	\$20,331.04	(\$67,282.69)	-330.94%

Adjustments

*Income and expenditure cash/accrual adjustment breakdown to reflect actual financial year performance:

▪ 2014-2015 Net Profit /Loss	= -\$46,952 Loss
▪ Add sponsorship income recorded in 2013/2014	+9,091
▪ Add donation to Westmead made in July 2014	+\$33,692
▪ Add Qld 2015 Retreat Cost	+\$ 4,569
▪ Add sponsorship Income (not yet received)	+\$5,000
▪ Add sponsorship Income received in 2015/2016 FY	+\$7,500
▪ Deduct Aon Insurance for MDDA Annual Insurance	-\$4,049
▪ Deduct Conference Expenses NSW 2014 (recorded in 13/14)	- \$9,057
▪ Actual 2013-2014 Net Profit/Loss	= \$206.00 Loss (breakeven)

How you can help

There are many ways to support the MDDA and get involved.

Sponsor a program, initiative or event

MDDA has a number of programs and events looking for financial support

- 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

Donate your time

Join an MDDA 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 – you take your pick.

- MDDA is a regular support 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 new research initiatives in the area of progressing knowledge and potential new treatments and cures for PKU and other IEMs.

www.givenow.com.au/mddapkuawareness



Innovation in Nutrition



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The MDDA recognises its state based partner and strategic alliance PKU NSW, 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.



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