Metabolic Dietary Disorders Association

# 2023 ANNUAL REPORT

*The Metabolic Dietary Disorders Association (MDDA) offers support services and resources to educate, connect and enable all families living with a protein IEM in Australia.*

# TABLE OF CONTENTS


01 Cover
02 Table of Contents
03 Message from our President
04 Our People
05 Key Highlights
06 Strategic Priorities
07 Achieving greater IEM Patient Health Outcomes
08 Informing government Health Policy
09 Government Grants/Research and Clinical Trials
10 Pathways Support
11 Power of Shared Experiences
12 Power of Shared Advocacy
13 Collaborations
14 Education & Awareness
15 Education & Awareness/My LowPro Pal App
16 Fundraising
17 National Family Conference
18 National Family Conference
19 Member Donations
20 PKUGlobe22/Social Media
21 Acknowledgements
22 Financials
23 Contact us

# MESSAGE FROM OUR PRESIDENT

Dear Members and Supporters,

As we take a moment to look back on the past year, my heart is genuinely full of gratitude for the incredible resilience and unity that define our extraordinary community. In the face of numerous challenges, our journey with the IEM community has been nothing short of remarkable, and I'm beyond delighted to be a part of it all.

This year brought one of our most significant achievements to date—an outcome of years of dedicated advocacy. The announcement of sapropterin becoming available on the PBS for all PKU individuals who respond to this medicine is truly the highlight of our year. Witnessing the entire IEM community coming together to fight for equitable treatment has been nothing short of inspiring. You can find more details on this exciting development inside the annual report.

Our commitment to education and awareness has remained steadfast. We've organized informative webinars featuring experts in various facets of living with an IEM. These sessions have provided valuable insights, updates on the latest research, new treatments, and government and IEM support. The knowledge shared has empowered our members, fostering a sense of empowerment and informed decision-making. In addition to our virtual efforts, we've joyously returned to in-person events. Our carefully planned gatherings allowed for genuine face-to-face connections, creating an irreplaceable sense of community. The joy and camaraderie experienced during these events stand as a testament to the strength of our bonds.

A heartfelt thanks goes out to the dedicated health professionals who generously shared their expertise and time with us. Their contributions, both online and in person, have enriched our events, providing a deeper understanding of the medical aspects of IEM and strengthening the bridge between the medical community and those directly affected.

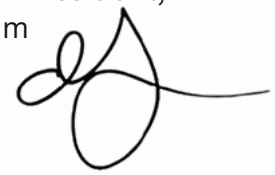
Our Committee of Management, a group of incredibly committed individuals, has worked tirelessly behind the scenes. Their dedication to steering our organization and advocating for resources and recognition for individuals with IEM has been instrumental in our progress.

I also want to express sincere gratitude to our sponsors—BioMarin, Menarini, Nutricia, Vitaflo, Cortex Health, and PTC Therapeutics—for their invaluable financial support. Their commitment allows us to continue offering essential services, support, and programs to the IEM community.

As we look ahead, our focus is on developing a strategic plan that addresses the evolving needs of our community. We aim to expand our support services, enhance our advocacy efforts, and further collaborate with medical professionals and researchers to advance the understanding and treatment of IEM.

I am profoundly proud of what we have achieved together this year. The resilience, compassion, and determination of our community continue to inspire me. As we embark on the journey ahead, let's carry this spirit forward, knowing that together, we can make a meaningful impact in the lives of those affected by IEM.

**Monique Cooper**
MDDA, President,
PKU Mum



# OUR PEOPLE

## MDDA EXECUTIVE COMMITTEE

These individuals serve as the backbone of MDDA, and their commitment as volunteers, dedicating their time and expertise, deserves special acknowledgment. Their unwavering dedication and enthusiasm significantly impact our organisation, and we recognise their exceptional skills and generous contributions to MDDA.

**Monique Cooper**
President, PKU Parent VIC

**Louise Healy**
Vice President, PKU Parent QLD

**Bianca Albanese**
Secretary, PKU Adult NSW

**Paige Moore**
Treasurer, PKU Parent FNQLD

## OFFICE TEAM

**Jenny Briant**
Executive Officer

**Joanne Campbell**
Patient Pathways Telehealth Nurse

**Isabella Hendricks**
Communications and Marketing

**Mel Briant**
Special Projects Manager

# KEY HIGHLIGHTS

## MEMBERS

**22**

New Members

**3350**

Voluntary Hours

## SUPPORT & EDUCATION

**1600**

Support Emails and Calls

**1**

National Family Conference

**23**

Compendiums distributed

**5**

Peekabu Bags Delivered

**3**

Online forums

**1**

Member survey

## FUNDRAISING & DONATIONS

**$94k**

Raised through The Great Protein Challenge, donations and **3** Member ran fundraising initiatives.

## HEALTH PROFESSIONALS

**40**

Medical practitioners attending MDDA education and training sessions

**5**

Group Meetings Attended

## SUBSCRIBERS

**75**

New Email Subscribers

**2.7k**

Facebook Likes

**547**

Instagram Followers

**8**

Active Facebook groups with **1200+** Members

**6**

New Youtube Subscribers and **1787 new views**

**15**

eNews

## GOVERNMENT

**40**

Resources & materials developed and distributed

**130**

Requests for information to the community on health policy matters

**1**

Reviews

**6**

Advisory Responses

# STRATEGIC PRIORITIES

**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 Inborn Error of protein Metabolism in Australia.**

## OUR VISION

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

## OUR 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.

## OUR GOAL

Achieving positive health outcomes for individuals living with IEMs, and requiring life-long metabolic dietary management skills, resources and support.

# ACHIEVING GREATER IEM PATIENT HEALTH OUTCOMES

**MDDA is persistent in advancing IEM Patient health outcomes. Our efforts focus on fostering awareness, advocating for accessible treatments, and driving initiatives to positively impact the lives of those with IEM. Through collaboration with stakeholders, research, and educational endeavours, MDDA aims to contribute to the overall well-being and improved health outcomes for all individuals affected by IEM.**

### Australasian Society for Inborn Errors of Metabolism (ASIEM)

MDDA maintains close communication with ASIEM to facilitate access and development of 'world-class' best practice management and care for treating IEMs. Regular communication with state-based metabolic clinics fosters discussions for improving metabolic healthcare services, evidence-based policy advice, program management, research, and regulation.

### Support for IEM Research and Clinical Trials

Further research is essential to ensure better health outcomes for those with IEM. MDDA supports and promotes research by:
-advocating for international clinical trials to establish sites in Australia
-liaison with ASIEM to ensure that clinical trials are patient centred and meet the high-quality requirements of trials conducted in Australia
-education and recruitment for research programs
-collaboration with Australian researchers to collect Australian based IEpM data
-fundraising for Australian research

### Updating Resources

Routine Website Updates: Regularly update resources on our website to empower patients through education and information provision for health services and the wider community.
Online Resource Creation: Develop new online resources, such as information on medications, artificial sweeteners, safe sweetener choices for IEM individuals, guidance on taking blood samples, and links to COVID-19 advice resources.

### Education for Health systems and professionals

As IEM is a rare condition, many non-metabolic specialist medical professionals know little about the conditions. MDDA provides resources, education, support and referral services to increase awareness and understanding of these conditions. Including providing education for midwives about newborn screening, liaising with public hospital and primary care providers to ensure care considers IEM, development of personalised care resources for those in residential care settings or those who receive home based disability or aged care support.

### Rare Disease Project ECHO®

MDDA actively participated in Project ECHO, providing health professionals with learning and expert support for high-quality care to patients with rare diseases. We presented at ECHO to promote Rare IEM chronic disease health management to general practitioners.

# INFORMING GOVERNMENT HEALTH POLICY

**MDDA plays a pivotal role in collaborating with the Australian Government to enhance and promote the health agenda. We build positive relationships with the government at all levels. Our focus is on strengthening connections, fostering networks, and facilitating cooperation among our members, the health sector, and the broader community. Through ongoing consultations with our members and individuals with lived experiences, we actively seek input to shape our policy initiatives and inform our responses to government reviews, strategies, and the evolving health agenda.**

### Newborn Bloodspot Screening program

Australia's newborn bloodspot screening remains a highly successful population health initiative, sparing our patient population from lifelong disability or death. Throughout the year, MDDA shared the opportunity to participate in the consultation of the program expansion and further actively promoted the Government's Newborn Bloodspot Screening Program.



### Inborn Errors of Metabolism Program

We collaborate closely with the government to ensure the ongoing support of the IEM Food Grant, actively keeping our members informed about guidelines, procedures, payment timelines, and renewal processes. In the current year, MDDA played a pivotal role in supporting the Department of Health and Aged Care's compliance efforts initiated in early 2023. We disseminated the Department's broadcasts and information regarding the monthly review of the IEM program and the annual reapplication process for clients. Additionally, in March we facilitated a webinar and live Q&A session with Director and Assistant Director of the Infrastructure Programs: and the IEM Program Officer and department staff.

### Department of Health

We actively contribute to government consultations, including the Pharmaceutical Benefits Advisory Committee, Life Savings Drug Program, and forums on chronic/rare diseases. Our role involves coordinating national responses to key discussion documents in IEM care. We provide expertise on special medical foods, submit responses to government consultations, and identify and advise on gaps in Department of Health policies and programs.

### Pharmaceutical Benefits Advisory Committee (PBAC)

In August, MDDA shared significant updates regarding the recommendation from the PBAC to include Kuvan (sapropterin hydrochloride) on the Pharmaceutical Benefits Scheme (PBS) for all Australians with phenylketonuria (PKU) responsive to this treatment. After many years of dedicated advocacy by MDDA, we were thrilled with this positive development. Palynziq was not accepted for listing on the PBS. MDDA remains steadfast in its commitment to advocating for access to all available treatments on behalf of all Australians with PKU and other IEM.

MDDA supplied information to the PBAC regarding PBS price reductions and the potential delisting of nutritional supplements vital for the health of individuals with IEM. This communication underscored the impact on IEM healthcare, emphasising the critical need for equitable access to essential medicines.

# GOVERNMENT GRANTS

As of June 2023, MDDA is no longer a recipient of government funding under the Health Peak and Advisory Bodies Program. Despite receiving government funding for the 2023 financial year, we now require sustained support from stakeholders to continue our crucial role in informing the Government's health agenda and improving health outcomes for Australians with inborn errors of metabolism. We are dependent on membership, fundraising, donations, and sponsorships to carry out our mission. Nevertheless, MDDA remains dedicated to consulting with members, the broader health sector, the community, and the government, providing sector knowledge and expertise, and delivering education to enhance the quality of health services for the IEM community.

**National Disability Conference Initiative (NDCI)**

In the 2023 financial year, MDDA secured funding from the Australian Government through the NDCI. This grant empowers MDDA to enhance the inclusion and participation of members and their carers in our nationally focused, disability related conference hosted in Queensland October 2022.

# BREAKING BARRIERS: RESEARCH AND CLINICAL TRIALS

In Australia, a wave of optimism is sweeping through our landscape, fuelled by the advancements and efforts in research and clinical trials for PKU and other rare inborn errors of metabolism.

First and foremost, clinical research allows scientists and clinicians to deepen their understanding of the underlying mechanisms of rare inborn errors of metabolism. This knowledge is crucial for developing targeted therapies that can alleviate symptoms and improve the quality of life for patients.

For those living with rare metabolic conditions, being part of these trials isn't just about treatment; it's about being part of something bigger. It's a chance to have a say in the future of healthcare and to help others facing similar journeys.

MDDA is committed to staying at the forefront of current research and trials. The annual national conference serves as a pivotal platform, not only showcasing these advancements but also fostering discussion and knowledge dissemination within the community. We maintain an online presence, regularly updating members via our e-newsletters and website to ensure everyone stays informed about the latest developments and breakthroughs. We actively forge new connections between researchers, healthcare professionals, and the IEM community.

As we travel these new pathways together, MDDA remains committed in its mission—building bridges, fostering understanding, and propelling us towards a future where those affected by these conditions can thrive and live a fulfilled life not limited by choice.

# PATHWAYS SUPPORT:

## Empowering Every Step of the Journey

**The MDDA Patient Pathways Program serves as a comprehensive outreach support system, offering mentoring, educational programs, and resources for individuals and families navigating life with an Inborn Error of Metabolism (IEM). Our initiatives span every life stage, from initial diagnosis to adulthood.**

### Pathways Coordinator: Bridging Gaps in Care

MDDA's Pathways Coordinator, a specialist telehealth nurse, provides members access to a coordinated case management service. This service crafts tailored care plans, offering practical and emotional support, education, and connections within existing services. Funded through donations, this crucial service is at risk without secured funding.

### Newborn Diagnosis Support: PeeKabU Patient Support Bags

In support of newly diagnosed families, eight "PeeKabU" patient support bags have been distributed this year. Acknowledging the emotional challenges of an IEM diagnosis, these bags include management tools, information, and insights from families who have navigated similar journeys.


### Zest Adult Wellbeing and Vitality Program: Transformative Health

This year we held two Zest programs in August and December. Our innovative health and wellbeing program has been designed to specifically focus on supporting adults with an IEM. This year we saw the need to include a specific session for parents of newly diagnosed infants. Addressing the challenges such as the complex dietary requirements, co-occurring conditions and the impact on a family of a rare disease diagnosis Zest helps to create life-altering changes, improving skills to cope with challenges, help staying motivated, talking openly and honestly to empower the IEM community to lead healthier, more fulfilling lives.

### Pathways Compendiums: Elevating Support

We proudly announce the completion of our third compendium in the series, including the newly added PKU Maternal Compendium, alongside the Return to Care and Carers Compendiums. With over 40 distributed this year, these compendiums exemplify our commitment to enhancing the quality of life for those affected by IEM, made possible through a rewarding collaboration with the Royal Melbourne Hospital.

### Online Resources: Empowering Through Education

Our website features updated resources for Care & Education, aiming to empower patients through education and information provision for health services and the broader community.

PKU PATHWAYS

Zest
ZONE • ENERGISE • SOAR • THRIVE

MEMBER CONNECT HUB
A welcome place for the IEM community to connect,share and learn

PeeKabU Kids

# POWER OF SHARED EXPERIENCES

**We take immense pride in our commitment to sharing member stories that showcase the resilience, hope, and determination of our IEM community.**

Another remarkable journey we were honoured to share is that of Anna, an adult member who embarked on her life-changing journey with sapropterin (Kuvan©). For Anna, the diagnosis of Phenylketonuria (PKU) had always been a challenge, limiting her dietary choices and affecting her overall well-being. However, Anna's story takes a turn for the better as she courageously embraced the opportunity to trial responsiveness for Kuvan, a potential game-changer in the management of PKU. Her determination and the innovative strides made in the field of rare disease treatment not only transformed her life but have given hope to countless others facing similar challenges. Anna's journey exemplifies the power of medical advancements, and her story resonates with our commitment to supporting research and breakthroughs that improve the lives of our members.

Anna

Ava

This year, we were privileged to introduce you to Ava. At 16 days old, Ava was diagnosed with Maple Syrup Urine Disease (MSUD) via the newborn screening heel prick test. MSUD is an inherited metabolic disorder that affects the breakdown of protein containing foods. High levels of leucine are toxic as it can enter the brain and damage it, left untreated, high leucine levels can be life threatening. Treatment for MSUD is a strict low protein diet for life, in addition to a protein-free supplement. Despite the challenges and daily obstacles Ava and her family face, their response is simple, “You just do it. It is what it is and it’s better than the consequences. Thankfully for us, we were able to connect with other families in Victoria who are on the same journey through the MDDA, and now we now catch up and support each other. She’s a very brave and tough individual and has not let MSUD get in the way of her living her best life.” Ava’s story serves as a testament to the strength that can be found in the face of adversity and reminds us of the profound impact our organisation can have on the lives of individuals and families like Ava’s.

# THE POWER OF ADVOCACY

## a win for equitable treatment for the PKU Community


3 April 2023

MDDA were absolutely delighted and overwhelmed with the long-awaited news that as of 1 April 2023, Kuvan (sapropterin dihydrochloride) will now be available on the Pharmaceutical Benefits Scheme (PBS) for the treatment of sapropterin-responsive adults living with phenylketonuria (PKU). This followed the positive recommendation from the Pharmaceutical Benefits Advisory Committee (PBAC) in July 2022, which found that "sapropterin provides, for some patients, a significant improvement in efficacy over a Phe-restricted diet alone" and acknowledging "there was a high clinical need in a small patient population."

As many of you know, Kuvan is an oral medicine that was the first prescription medicine to become available for the treatment of PKU. While it was registered for use in Australia by the Therapeutic Goods Administration (TGA) in October 2010 for the treatment of HPA in sapropterin-responsive adult and paediatric patients with PKU or tetrahydrobiopterin (BH4) deficiency, our community has had to wait for many long years to receive subsidised access to Kuvan through the PBS.

It wasn't until 1 May 2019 that Kuvan was first listed on the PBS for people with PKU aged under 18 years. This was followed by access for people with maternal PKU on 1 July 2021. As a result of the Australian Government's decision to expand the listing of Kuvan on the PBS, PKU people of any age who are sapropterin-responsive, may now be eligible to access this treatment.

Your voice matters – Thank you!
MDDA, with the support of our PKU/IEM community, have been actively campaigning for a number of years to secure access to this therapy for PKU people of all ages who are responsive to treatment. This outcome would not have been possible without the extensive and ongoing political, media and public advocacy by our PKU and broader metabolic dietary disorders communities.

Thank you to all of you who shared your stories and raised awareness of the challenges of living with PKU and the need for equitable access to all treatments that have been approved as safe and effective by the TGA. Your voice matters and has helped to achieve this important outcome.

Importantly, consumer comments and personal lived experience helped to build the PBAC's understanding of the impacts of living with PKU, including:

Difficulties maintaining low Phe levels with dietary management alone, particularly into adulthood.
The high levels of unmet medical need faced by adults with PKU, and the inequity in treatment access for this group.
The impact of low Phe levels on quality of life, cognitive function and psychosocial aspects.

Advocating for all Australians living with PKU
We were pleased to see the PBAC acknowledge the PKU patient and clinical community in providing "meaningful consumer support and engagement" through the consumer comments process last year, saying: "The PBAC considered that consumer input was valuable in decision-making in terms of establishing the clinical need for sapropterin by identifying and describing outcomes that were not well-captured in the clinical evidence."

This public acknowledgement by the PBAC demonstrates the true power of advocacy.

On behalf of all Australians living with PKU and other IEM, MDDA will continue to work hard to advocate for the need to ensure equitable access to the latest safe treatments as they become available.

Thank you for your support.

# FOSTERING PURPOSEFUL COLLABORATIONS

**MDDA maintains a strong partnership with Rare Voices Australia, a key stakeholder in implementing the National Strategic Action Plan for Rare Diseases. Our collaborative efforts involve ensuring equitable access to treatments, supporting clinical trials for rare conditions, contributing to a project focused on metabolic conditions within the rare disease workforce, and providing condition-specific input for the development of a multi-stakeholder digital rare disease portal funded by the Australian Government.**

As we embark on a new year, MDDA remains committed to fostering collaborative efforts that make a meaningful difference in the lives of those affected by inborn errors of metabolism and other rare diseases, working towards a future of enhanced knowledge, improved treatments, and continued support.

MDDA maintains a strong partnership with Rare Voices Australia, a key stakeholder in implementing the National Strategic Action Plan for Rare Diseases. Our collaborative efforts involve ensuring equitable access to treatments, supporting clinical trials for rare conditions, contributing to a project focused on metabolic conditions within the rare disease workforce, and providing condition-specific input for the development of a multi-stakeholder digital rare disease portal funded by the Australian Government.

rare voices AUSTRALIA

MDDA served as the host patient group and organiser for the Global Association of PKU (GAP) third Global PKU Patient Conference, held online in December 2023. This event brings together the global PKU patient community to celebrate achievements, share knowledge on new developments, and advance PKU as a global health priority. Participants from over 65 countries, actively engage in informative and inspiring presentations, showcasing scientific endeavours, research, studies, clinical trials, and best practices in PKU care on a global scale.

gap GLOBAL ASSOCIATION FOR PKU

*Bridging the gap for PKU worldwide*

Collaborating with the Royal Melbourne Hospital, MDDA launched the PKU Maternal Compendium addressing the crucial aspects of planning a pregnancy for women with PKU, ensuring optimal health outcomes for both mother and baby. This is the 3rd compendium in the series adding to the Return to Care and the Carers Compendiums.

The Royal Melbourne Hospital

# EDUCATION & AWARENESS

## Raising our Profile

### Rare Disease Day

Rare Disease Day is a globally coordinated movement on rare diseases, working towards equity in social opportunity, healthcare, and access to diagnosis and therapies for people living with a rare disease. Australia first participated in Rare Disease Day in 2009 and has since hosted many events all over the country to raise awareness among the public. This annual occasion serves as a reminder that over 2 million Australians bear the weight of a rare disease diagnosis. MDDA use the opportunity to shed light and educate people about those living with IEM.

### PKU Awareness Month-June

Phenylketonuria (PKU) Awareness Month is dedicated to raising awareness about phenylketonuria. Celebrated in different months throughout the world, we choose June to highlight PKU as this is the birthday month of PKU stalwarts, Robert Guthrie and Horst Bickel. PKU is an inherited metabolic disorder in which the body is unable to process an amino acid called phenylalanine properly. This leads to a buildup of phenylalanine in the blood, which can be toxic to the brain, causing intellectual disabilities and other serious health problems if not treated. The awareness month aims to educate the public about PKU, its symptoms, and the importance of early detection and treatment. It also seeks to support approximately the 1600 individuals and families in Australia affected by PKU and promote research efforts to find better treatments or a cure for the condition. Events throughout PKU Awareness Month include educational seminars, fundraising activities, social media campaigns, and community gatherings. The goal is to foster understanding, increased awareness for those living with PKU and to encourage support for research initiatives aimed at improving the quality of life for individuals with this rare disorder.

# EDUCATION & AWARENESS

## Raising our Profile

In a joint effort with Anne-Marie Desai, a metabolic dietitian at the Royal Melbourne Hospital, MDDA played a crucial role in developing a valuable guide specifically for pre-conceiving and expectant mothers with Phenylketonuria (PKU).

Every woman who has had a baby has a unique pregnancy story. For some pregnancy comes easily and for others it can have its ups and downs. The PKU Maternal Compendium, the first of its kind in Australia, is here to assist those considering starting a family. Developed collaboratively by the MDDA and the Royal Melbourne Hospital, this resource serves as part of the PKU Patient Pathways program.

Key features of the compendium include personalised details and contact information, an overview of Maternal PKU management, guidelines for a low-protein diet and protein substitutes, menu and snack ideas, as well as practical information on Guthrie Testing, IEM Food Grants, and a dedicated PKU resources page.

The guide will be distributed around Australia. Patients with the condition can pick up a copy from their treating hospital.


*"I have never met a more motivated patient than a pregnant woman with PKU – they are so determined to follow the advice to deliver a healthy baby,"*
*Anne-Marie*

# MY LOWPRO PAL

The MDDA have been busy working on the MyLow Pro Pal app this year and its finally on the verge of being released! We have had both members and medical practitioners test the app and the reviews have been absolutely incredible! We're almost there, just a few minor tweaks away from its big debut, expected at the end of this year.

We can hardly contain our excitement for this long-awaited resource, which we believe will make a significant impact on the lives of our members and families living with an IEM.

# FUNDRAISING

## Phenomenal Year for the Great Protein Challenge

Fundraising is the lifeblood of not-for-profit organisations, serving as a vital cornerstone that empowers them to fulfill their missions effectively. As MDDA reflect on the tremendous success of the Great Protein Challenge, it's essential to understand the profound significance of fundraising in the not-for-profit sector.

First and foremost, fundraising provides the financial resources necessary for MDDA to sustain and expand our programs and initiatives. Our programs, like support services for members, education, new innovative programs, advocacy campaigns, and awareness initiatives, rely on the generosity of supporters to thrive. The funds raised enable us to create better support programs for our members, offer resources that enhance our advocacy and awareness campaigns, and back critical research endeavours that hold the potential for groundbreaking discoveries.

In addition to the financial aspect, fundraising extends far beyond monetary contributions. It fosters a sense of community and collaboration among supporters, forging a shared commitment to our cause.

The collective effort in the Great Protein Challenge not only reached a fundraising goal of $33,000 but also elevated awareness about PKU/IEMs to new heights. This collective action showcases the power of unity and demonstrates that, together, we can make an enduring, positive impact.

We are profoundly grateful to each and every individual who contributed to this achievement, and we encourage everyone to continue spreading the word, raising awareness, and supporting each other, as your efforts truly drive positive change.

THE GREAT PROTEIN CHALLENGE AUSTRALIA

**30** Individual Players

**33k** Raised in donations

**10** Teams

## Member-driven fundraisers

Member-driven fundraisers hold a special significance for MDDA for several compelling reasons. These initiatives, led and supported by the very individuals the MDDA aims to serve, bring a unique and powerful dynamic to the MDDA fundraising landscape.

Members, often those personally impacted by MDDA's mission, are passionate advocates with a profound understanding of the cause. Their personal connection and firsthand experiences lend authenticity and credibility to the fundraising efforts, resonating strongly with potential donors. This personal connection humanizes the cause, making it relatable and compelling.

Additionally, member-driven fundraisers often tap into unique talents and networks that members bring to the table. These initiatives frequently involve innovative approaches, resulting in diverse and imaginative fundraising strategies.

Beyond the funds raised, these initiatives strengthen the sense of community, ownership, and shared purpose, making them an invaluable and impactful component of the fundraising landscape.

#team MDDA

# NATIONAL FAMILY CONFERENCE

MDDA's National Conference and Family Retreat is our hallmark event that occurs just once a year. This event attracts all types of family groups and members from the IEpM Australian community including; newly diagnosed infants, kids and teens through to well experienced adults, those returning to diet, supportive family members, spouses, parents, grandparents, siblings and carers representing all protein IEM. We also welcome special guests and speakers from Metabolic clinics, research and other health institutions from around the country.

The National Family Conference/Retreat is dedicated to providing IEM patients, their families, and caregivers with essential information about their condition, including the latest research, treatment options, and self-care strategies. Attendees enjoy detailed sessions that explain IEM advancements and Clinical Care practices.

The conference creates a supportive space where IEM patients connect and share their experiences, fostering a sense of community where they offer each other emotional support and practical advice. The conference provides insights, motivation, and tools to help manage IEM, encouraging treatment adherence.

Dealing with the emotional and psychological aspects of living with IEM is addressed at the conference by offering coping strategies and mental health support.

In addition to medical treatment and therapies, our conference plays a vital role in educating, empowering, and supporting individuals and families living with an IEM. They foster a sense of community, provided access to resources, while inspiring and motivating patients to manage their conditions more effectively, ultimately improving their quality of life.

**243**
Total Attendees

**60**
IEM Individual Attendance

**12**
Educational sessions & workshops

**#MANY**
Friendships and connections made

*The MDDA retreat is crucial to my child's emotional and physical wellbeing and also mine. The retreat normalises my child's condition and challenges. It reignites your drive to work towards treatment, cures and wellbeing. It's wonderful to "reset". We hope MDDA will be able to continue this wonderful event.*

# NATIONAL FAMILY CONFERENCE

*Sophie has been desperate to meet other children with PKU. Watching her develop friendships over the past 3 days has been amazing. We look forward to coming again next year.*

*These retreats mean everything to me as a parent of a child with PKU. Having the support network here with people who "just get it" is phenomenal. I feel like we are extended family. The chance for my child to meet friends with other children with an IEM is invaluable. These retreats are also a chance to remember why it's important to stay on diet and to learn about new future treatments. THANK YOU for organising an amazing retreat one again. Everyone was catered for in every way.*

*It was my first retreat. Oh my god it was the best to actually meet other PKU adults. Loved the sessions and learnt so much and cannot wait to implement them back at home. Cannot wait for next year.*

# MEMBER DONATIONS SPOTLIGHT

**Allow us to introduce two extraordinary members of our community whose unwavering commitment shines through their consistent monthly contributions.**

Meet Ryan, a compassionate advocate for our cause, who firmly believes in the collective power to drive change. His generous monthly donations not only exemplify his dedication to our mission but also provide a stable foundation for us to plan and execute long-term projects effectively. Ryan's strong commitment shows how much he believes in our mission, and his contributions significantly enhance the impact of our ability to create substantial change for the IEM community.

Similarly, Ingrid, another remarkable member, shares a passion for our cause and recognises the importance of ongoing support for sustaining our efforts and making a lasting impact. Ingrid's consistent monthly donations testify to her dedication and desire to see our initiatives thrive. Her generosity empowers us to pursue our mission with confidence, knowing we have steadfast supporters like her by our side. Together, Ryan and Ingrid demonstrate the incredible impact individual contributions can have when given with a spirit of commitment and compassion.

We extend our appreciation to every donor for their invaluable contributions to our cause. Their generosity forms the cornerstone of our mission, providing the resources and momentum needed to effect real change in the lives of those we are committed to helping. The support from our donors serves as a powerful reminder of the impact individuals can have when aligned with a shared purpose. Thank you all for being a vital part of MDDA's mission.

*"MDDA have been a great support to our family and in particular Samuel who is now 11 years old. Our monthly donations help the MDDA to support other families in their journey and make it not so hard when times get tough. We're fortunate to be in a position to be able to donate on a regular basis but any donation will assist with the important work that is carried out daily by the MDDA." Ryan.*

*"I would like to say that doing a "Gift Donation" through my pay each fortnight is easy to set up. You don't have to think about doing a donation manually as it goes out of your pay automatically. My employer does "Matching Gifts", so every dollar I put in, my employer matches that amount. If your employer does this, even better to get on board. MDDA is such a wonderful organisation and has done so much for our children and adults with IEM's. I can't thank them enough for all their hard work." Ingrid*

# PKU GLOBE 2022


## GLOBAL 2022 CONFERENCE

Pioneering Our PKU Future was the theme of PKUGLOBE22 that took place Thursday 8th to Wednesday 14th December. MDDA are proud to be GAP members and the host nation of the virtual event for the second year. It truly was a great experience that saw people from over 70+ countries come together to learn and engage.

The event featured live presentations, pre-recorded scientific presentations, documentaries, panel discussions and ways to connect with other PKU people from around the world.

Australia was well represented with presentations from Debbie Colyer OAM, Dr Bianca Albanese and Anne-Marie Desai Senior Dietitian from the RMH. Taking place virtually provides the opportunity for people across all continents to hear different presentations from experts in their fields.

# THE IMPACT OF SOCIAL MEDIA: CONNECTING, ADVOCATING, AND GROWING TOGETHER

**In today's digital age, social media has become an important tool for MDDA's connection and engagement.**

### Our Online Hangout Spot

Our private Facebook groups are our virtual hangout where we chat, share info, and build a community that's not limited by location and distance. It's the place where our members feel like they fit in, creating a place of togetherness and belonging.

Metabolic Dietary Disorders Association

@lowproinspo1314

@metabolicdietarydisordersa442

@mdda_australia

### A Megaphone for Advocacy

Beyond just chatting, social media is our go-to megaphone for spreading the word. Whether it's raising awareness, sharing real stories from our members, or championing our important causes. Real-time updates, event shout-outs, and quick info drops.

### Reaching Out and Teaming Up

Most importantly, social media helps us cast a wider net. We're finding new members, getting support from passionate advocates, and teaming up with others who share our goals. It's all about growing together and making an even bigger impact on the IEM community.

## SUBSCRIBERS

**8** Active Facebook groups with **1200+** Members

**2.7k** Facebook Likes

**6** New Youtube Subscribers and **1787 new views**

**547+** Instagram Followers

# ACKNOWLEDGMENTS

We want to express our appreciation to all our dedicated sponsors who embrace our vision of empowering individuals living with Inborn Errors of Metabolism (IEM) to lead a life at full potential, free from limitations of choice. Their unwavering support and generosity are the driving force behind the realisation of our mission, and we cannot thank them enough.

Our partners and sponsors are more than just financial supporters; It's their compassionate commitment and generosity that make our National Family Conference/Retreats and other essential projects a reality.

We genuinely value the collaborative spirit and dedication of our sponsors, who continue to stand by our side as we strive to make positive change in the lives of those affected by IEM. We are deeply grateful for their continued partnership.

## SPONSORS

Vitaflo
Enhancing Lives Together
A Nestlé Health Science Company

PTC THERAPEUTICS

MENARINI

NUTRICIA
LIFE-TRANSFORMING NUTRITION

BIOMARIN

cortexhealth
Find your balance

## SUPPORTERS

gener8 EVENTS

THE GRAND WARRANDYTE

# FINANCIAL RESULTS

## SUMMARY OF FINANCIAL RESULTS 30 JUNE 2023

### INCOME 2023

| | |
|---|---|
| Donations | $60,880 |
| Fundraising | $33,102 |
| Grants | $189,000 |
| Subscriptions | $7,422 |
| Sponsorship | $90,387 |
| Events | $68,488 |
| Other | $3,670 |
| Total Income | $452,947 |

### EXPENSES 2023

| | |
|---|---|
| Operating Costs | $89,979 |
| Secretariat Expenses | $137,925 |
| Member Support, Programs, Events | $241,960 |
| Total Expenses | $469,864 |

The financial statements of our organisation represent more than just numbers; they tell a compelling story of generosity, commitment, and the impact of our collective efforts. As we reflect upon our financial achievements, we extend our heartfelt gratitude to the individuals and entities that have made it all possible—our sponsors, donors, and dedicated members.

First and foremost, our sponsors have been instrumental in providing the financial support that sustains our mission. Their unwavering commitment to our cause has allowed us to expand our reach, improve our programs, and make a meaningful difference in the lives of those we serve. We are profoundly thankful for their generosity, as it enables us to continue our vital work.

Our donors, both large and small, have played a crucial role in our financial success. Their contributions have allowed us to initiate new projects, maintain existing ones, and respond swiftly to emerging needs within our community. Their belief in our mission and their willingness to invest in our cause is truly inspiring.

Our members, the backbone of our organisation, have consistently shown their support through their membership fees and active participation. Their dedication not only bolsters our financial stability but also fuels our sense of purpose and unity.

Our financial statements are a testament to the strength of our partnership with sponsors, the generosity of our donors, and the dedication of our members. It is with profound gratitude that we acknowledge the pivotal role each of you plays in our not-for-profit's success. Your support empowers us to continue making a positive impact on the IEM community we serve, and for that, we are truly thankful.

### MAKE A DONATION

Donations are crucial, empowering us to better serve and enhance the needs of the IEM community. Donations are directed to research initiatives, potential new treatments, new initiatives, programs and support.
Donations over $2 are fully tax deductible.

**Make a Donation here!**

### VOLUNTEER

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

### HOST A FUNDRAISING EVENT

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

**Find out more on how to volunteer and Fundraise here!**

Metabolic
Dietary
Disorders
Association

# Contact


**Metabolic Dietary Disorders Association Inc.**

Phone 03 9723 0600 Freecall | 1800 288 460 |

Website www.mdda.org.au

Email office@mdda.org.au

Address Suite 4, 6 Thomas Brew Lane
Croydon VIC 3136
PO Box 33 Montrose VIC 3765