

*Metabolic
Dietary
Disorders
Association*

Goal

To support and achieve **greater health outcomes** for individuals living with an Inborn Error of Metabolism.

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.

Last 2 years

Key Focus Areas

- Clinic relationships & referrals
- IEM Food Grant re-instatement
- IEM Awareness
- External Relations/Advocacy (Govt, pharma, affiliates)
- Community/Volunteer/Member engagement
- Organisation Structure
 1. Value prop & IEM representation (What & Who)
 2. Org structure, committee & resources (long term sustainability)
 3. Umbrella approach - PKUNSW & Other IEM groups

Status

- 600+ subscribers/members
- 418+ online forum members
- ~ 10% membership growth

Priorities

CONNECT:

- Member/Subscriber acquisition
- Early diagnosis – LINK Network
- Forums, member profiles, story telling
- Events (retreats, camps, cook days, social events)
- Membership Communications (stories, n'letters etc.)

Priorities

EDUCATE:

- Awareness Campaign
 - 2015 – IEM Grant reinstatement & baseline awareness
 - 2016 – Miracles of NBS celebration/gratitude campaign
 - 2017 – ... Progressing IEM wellbeing
- Online/Social Networking (Forums, profiles, virtual Roundtables)
- Events (retreats, camps, cook days, social events)
- Member communications (website, articles, n'letters)
- Dietary resources (recipes, products, menu planners)
- National Guidelines
- National advocacy (PBAC, FHANZ, IEM food grant, NBS)
- Travel Grants (international & local)

Priorities

ENABLE:

Programs cultivating healthy supportive relationships

- Adults - Wellness Program – skills development (returning, set in, maternal)
 - Holistic approach (balancing compliance issues with addressing...)
 - Physical – Healthy body
 - Psychological – Healthy mind
 - Social wellbeing – Healthy Relationships
 - Broadbase support: social emotional & physical structured, outcome driven program
- Adolescence - Compliance Program – peer mentoring
 - Less structured socially inclusive, non disorder focused approach
 - Focused on fun and socially tangible outcome driven

Supporting Research initiatives

- Establish Patient registry project

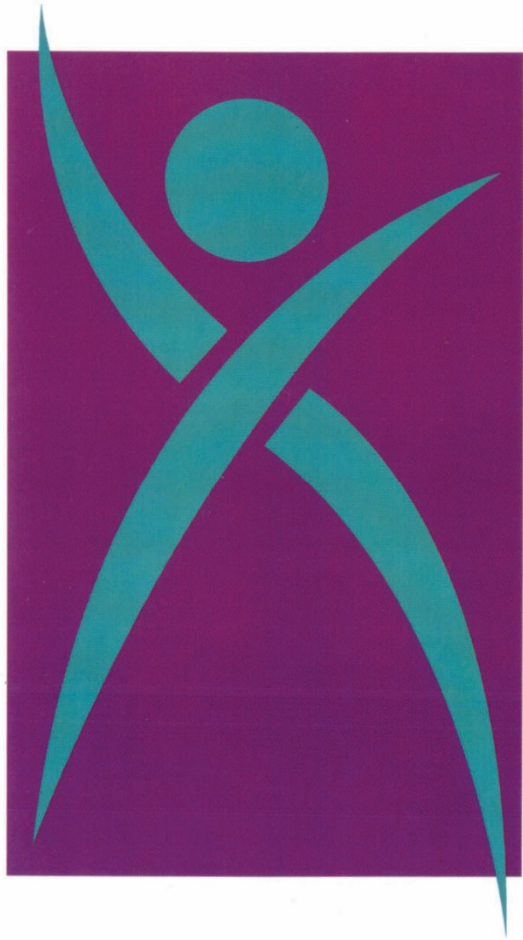
Member Engagement

- Volunteer/Member Contribution: Surveys, volunteer projects, in-kind resourcing etc.

Looking forward

Clinical based priorities

- National guidelines
- Clinical resource succession planning
- Rural/Remote clinical servicing
- Adolescent transitioning (full-life clinics)
- Facilitating research (national data registry)
- PBAC applications



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