

Dear SSIEM,

On behalf of the Metabolic Dietary Disorders Association (MDDA), I extend our heartfelt gratitude for your generous donation towards our recent patient event and conference, which aimed to benefit the Inborn Errors of Protein Metabolism (IEM) population of Australia. As the recognised National Peak Body representing the Australian IEM patient community and health sector, MDDA plays a vital role in providing information, support, education, and advocacy for individuals living with IEM conditions. With your support, our MDDA National Conference themed "Reaching Your Potential - Supporting, Connecting & Educating," held in Sanctuary Cove, Queensland from October 6th to 8th, 2023, exceeded all expectations.

The conference brought together over 130 attendees, including 40 individuals affected by IEM, offering a wealth of education, support, and networking opportunities. Our objective to assist IEM individuals and their carers in attaining the highest possible health and wellbeing outcome was met with resounding success. Through a diverse range of sessions, including educational presentations, workshops, and discussions, attendees gained insights into current metabolic treatments, clinical trials, and research advancements, while also receiving practical advice and strategies for managing IEM in daily life.

The SSIEM donation played a pivotal role in ensuring the success of the conference by directly supporting venue expenses. Furthermore, your generous contribution enabled us to innovate and adapt to the evolving landscape of events by implementing a hybrid conference model. Leveraging technology, segments of the conference were delivered virtually, fostering greater inclusion and participation among attendees. This innovative approach not only broadened access to valuable educational content but also reinforced our commitment to serving the diverse needs of the IEM community across Australia.

Specialist health professionals presented on education and advancement on current metabolic treatments, clinical trials, and research. Interactive workshops and educational sessions focused on promoting best health, skills to develop independence, mindfulness, resilience, connecting to the wider community to lead a valued life, promote participation and increase good health and wellbeing.

Conference Sessions included:

- *Research Updates from 2023 SSIEM Conference*
- *Combining stem cell and gene-editing therapies to treat liver-related IEMs - Dr Kiryu Yap*
- *Clinical Trial Considerations – What you need to know*
- *PTC 923 Trial Updates*
- *BH4 adult testing Q&A*
- *QoL review pre and post Kuvan*
- *IEM Lifestage Transitional Considerations*
- *IEM Tweens/Teens Workshops*
- *Bloodspot collection Q&A*
- *IEM Adult – Mental Health & Nutritional Considerations*
- *Round Table discussion groups from birth to adulthood*
- *Formula & Supplements nutritional considerations*

- *Low Protein Meal planning*
- *Kids Club*
- *Teens Club*
- *IEM Lifestage Panel Q&A*

*'My Jaws are stiff from smiling, my eyes are full of happy tears and my heart is full from an amazing weekend, Thank you MDDA for giving every attendee inspiration and a renewed sense of confidence to deal with an IEM in every aspect of our lives post retreat.'*

*'A fantastic weekend of information updates, clinical education sessions and social networking for the Australian IEM community. Thank you to the MDDA for hosting this event each year.'*

*'Thank you MDDA for all the great info and fun you bring to these events. But most of all bringing this community together where friendships and bonds can be made.'*

*'Every MDDA Retreat we attend adds value to our family. It has been amazing watching our daughter (Sophie, 4) to continue to make friends with IEMs especially PKU and knowing she is not alone. Sophie asks to return all year.'*



Once again, we extend our sincerest thanks to the SSIEM for your generosity and commitment to making a difference in the lives of those affected by IEM. Your support is invaluable as we continue our mission to support, connect, and educate the IEM community in Australia.

Warm regards,

Metabolic Dietary Disorders Association