

FOR IMMEDIATE RELEASE

17 February 2025

Moderna Abandons Australian Rare Disease Community by Withdrawing from Clinical Trial

Melbourne, Australia – 17 February 2025 – The Metabolic Dietary Disorders Association (MDDA), along with patients and clinicians, are profoundly disappointed by Moderna’s sudden decision to withdraw the Australian clinical trial for Methylmalonic Acidemia (MMA) and are calling for Moderna to urgently reinstate the trial.

Moderna’s establishment of trial sites in Melbourne and Sydney in 2024 was positive news for clinicians as well as patients and families living with MMA, a rare disease, who currently have no treatments and face kidney and liver transplants as well as neurological impairment. The community have been anxiously preparing for the trial to start, with one family moving interstate to participate. This mRNA therapy trial offered hope to families who previously had no treatment options.

While the trial will continue in six other countries, it will not proceed in Australia and South Korea. Moderna’s reasoning for abandoning Australia in favour of six other countries is unclear, with the community being informed that “tough decisions needed to be made.”

"We are extremely disappointed that Moderna appears to be prioritising larger opportunities and money over the needs of the rare disease community here in Australia," said Monique Cooper, MDDA President.

"The initial Australian clinical trial announcement raised the hopes and expectations of this vulnerable rare disease community; it is not ok for Moderna to withdraw the trial in Australia at the very last minute without meaningful explanation.

“For individuals with rare diseases such as MMA, clinical trials are often the only way to access potential treatments due to the lengthy development, approval, and reimbursement processes. The withdrawal of this trial is devastating for families who are witnessing their loved one’s condition progress and who do not have time to wait until a treatment is approved,” Ms. Cooper added.

“I am devastated by this decision. It is impossible to describe what is it like to watch your child’s body be ravaged by this horrible progressive disease over years and to finally think there is a treatment that might work [about to be] trialled in Australia, only to have the possibility ripped away,” said Daphne Doukas, an MMA parent based in Melbourne.

Moderna’s decision is unacceptable to the MDDA community, particularly given the recent Australian Government investment Moderna received to support mRNA manufacturing in Australia. This investment underscores Australia's commitment to advancing medical research and supporting clinical trials, making the decision to exclude Australia from the MMA trial even more disappointing. Australians should be rightly outraged that a company in receipt of significant public funds would raise the hopes of such a vulnerable group of families and then abruptly withdraw the trial from Australia at the same time they are expanding their Australian operations.

The MDDA, clinicians, and patients urge Moderna to reconsider their decision and prioritise the needs of the rare disease community and patients in Australia. The impact of this trial could be life-changing for people living with MMA and their families.

---ENDS---