10 Years

A BRIEF HISTORY OF

Myasthenia Alliance Australia

THE MAA WAS FORMED TO UNITE THE MG PATIENT VOICE ON NATIONAL ISSUES IN AUSTRALIA. HERE'S A BRIEF HISTORY OF THE MAA AND KEY MILESTONES SO FAR.

2014
The Myasthenia Alliance Australia (MAA) was officially established

FROM 2014
The MAA partnered with Rare Voices Australia (RVA) and established a Medical Advisory Board

2015
The first national MG conference was held in Sydney

2017
The second national MG conference was held in Sydney

2017
The MG community commenced fundraising for the eNID/MGBase project, reaching a total of $130,000

2019
The third national MG conference was held in Brisbane including the launch of the new 'Drugs to be Used with Caution' booklet

2019
MAA support for Allied Health research with the University of Queensland

2020
MAA involvement in the government (MSAC) review of immunoglobulin use for MG

2020
MAA Chairperson (Susan) attended the Parliamentary event to launch the National Strategic Action Plan for Rare Diseases

2020-21
Submission and hearing for the Parliamentary Inquiry into new drugs and novel medical technologies

2021
National research survey: Patient reported outcomes on side effects of treatments, journal article published in 2023

2021
MGBase officially launched

2021
Collaboration with medical advisory board and clinicians for the COVID-19 vaccine discussion paper for MG patients

2021
MAA representatives attended the Health Technology Assessment (HTA) Consumer Symposium 'Making Connections'

2021-22
Submissions made to the National Medicines Policy (NMP) Review

10 Years

Myasthenia Alliance Australia

2022
MAA representative attended the Health Technology Assessment (HTA) Consumer Symposium and contributed to the 'Conversations for Change' consultation

2022
First 'Art with Heart' national awareness campaign

2022
MAA advocacy and communications regarding the Mestinon supply shortage

2022
Submission made to the Repurposing Medicines consultation

2022
MAA Chairperson (Susan) invited to present at the RVA Summit

2022
Research survey: Impact of the COVID-19 pandemic on MG patients in Australia

2022
Rituximab listed on the PBS for MG patients following ongoing advocacy by the MAA since 2018

2022+
Submission and ongoing advocacy concerning Therapeutic Plasma Exchange (TPE) access (work commenced in 2019)

2022+
Ongoing participation in RVA activities: RARE portal & RArEST

2023
Submission made to the Health Technology Assessment (HTA) Review and attendance at the HTAi annual global meeting in Adelaide

2023
The fourth national MG conference was held in Sydney

2023-24
MAA became a member of the Neurological Alliance Australia (NAA) and MAA representative attended NAA Summit

2024
Submissions to and engagement with the Pharmaceutical Benefits Advisory Committee (PBAC) for new treatments

2023-24
Partnering on the VALUE-Ig study and other patient lived experience research with academic and industry stakeholders

2024
Second 'Art with Heart' national awareness campaign

2024
MAA representatives attended the Rare Disease Day Parliament event in Canberra and a roundtable with the Health Minister in Sydney

2024
MAA representative appointed to National Immunoglobulin Governance Advisory Committee Board