

Introduction

The poster entitled Myositis Association Australia (MAA) presents an established patient organisation formed in 2003, with 420+ members across the country.

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Patient Group General Aims

- Providing a network of support for people with IIM (idiopathic inflammatory myopathies)
- Raising awareness of IIM among the public, patients, family / friends, carers, and health professionals, including general practitioners, rheumatologists, neurologists, and allied health.



About

MAA is a patient group run by volunteers who have Myositis. Our primary goal is to help more people with Myositis connect, share their experiences and learn practical ways to manage their condition. We also work to raise awareness of Myositis and support relevant research.

Short-term Goals

- Organising member events including regular support group meetups and triennial conferences
- Providing a patient newsletter with research updates, general news, members' stories, disability aid recommendations
- Myositis awareness month activities (see below)
- Fundraising for relevant medical research
- Maintaining our website with disease information, patient stories, health tips, event details, research updates and support contact details.



We cooperate with Rare Voices Australia (national peak body for Australians living with a rare disease), local hospitals, other patient organisations, health care professionals and pharmaceutical companies.

Cooperation with Local Organisations

Consumer Panel: 18 members volunteered to serve on a consumer panel established as a joint venture with the Myositis Discovery Programme, led by Prof Merrilee Needham (Perth, WA), Consumer and Community Involvement Program and our Association. The relationship between researchers and the consumer panel is very positive and productive. All patients actively engaged on the panel find the experience inspiring, respectful and encouraging. The panel has:

- Given feedback on content and timing of research communications
- Reviewed and provided input to grant proposals
- Reviewed documents for Sirolimus/Rapamycin drug trial
- Participated in an assistive technology survey
- Undertaken patient-driven studies of daily patient & carer priorities plus a diet-related study
- Advocated to the Health Minister to support trial funding

MUSCLE WEAKNESS?

It could be Myositis

May is Myositis Awareness Month

Planning for 2022 events is underway to include:

- Patient group gatherings (in-person & online) with presentations by health experts
- Publicity campaign (TV, radio and print media) to raise awareness
- Dissemination of patient information brochures to neurologists and rheumatologists
- Allocating funds to support appropriate research.



International Cooperation

Our Association is actively engaged in the World Myositis Coalition (which represents the support groups of TMA, Myositis Canada, Cure IBM, CURE JDM, Myositis Australia). We also have links with GCOM, iMyos, and IMACS.

We keep our members informed on Myositis research updates and communicate when studies with local trial sites recruit participants. Recent international projects our members have participated in:

- Phase 1 clinical trial by the Perron Institute in Western Australia, as part of a global study testing a new IBM treatment drug, ABC008
- Phase 2 clinical trial and an extension study sponsored by Novartis on drug BYM338 (bimagrumab) for IBM
- **Sirolimus for IBM clinical trial:** A global research team led by The University of Notre Dame Australia School of Medicine's Prof Merrilee Needham, in collaboration with Perron Institute, Fiona Stanley Hospital and Murdoch University.

Conclusion

The current average time to diagnosis is 5 years. Health professionals play a critical role in diagnosing this rare and progressive muscle disease. The earlier a patient is diagnosed, the better their potential health outcomes. It's why we did a recent publicity campaign targeting health professionals. It reached approx. 100,000 people with 5 detailed articles published in the magazines of various health professional associations.

Campaign tagline: Muscle weakness? It could be Myositis

