MYOSITIS ASSOCIATION – AUSTRALIA INC PRESIDENT'S REPORT 2023/24

Support for our Myositis members and Carers is always our focus, but once again we've extended our work to continue to strengthen relationships with other Myositis and rare disease groups, fund research and increase education.

Partnerships

On an international level, we have joined other patient advocacy organisations representing individuals living with Myositis globally. On the **21 Sep 2024 WORLD MYOSITIS DAY** was celebrated by us along with The Myositis Association (TMA USA), Myositis Canada, Cure IBM, Myositis UK, Myositis Support and Understanding (MSU), Cure JDM, Myositis Netherlands, Myositis Sweden, Myositis Cech Republic and Myositis India.

Our partnership with **Rare Voices Australia (RVA**), the peak body for rare diseases in this country continues to be important. Myositis is just one of more than 7000 rare diseases. By working closely with the implementation of the RVA Action Plan we endeavour to give Myositis a visible profile amongst the many rare diseases.

Since adoption of the RVA Action Plan, research grants specifically for Rare Diseases have been awarded including for an IBM drug trial (Sirolimus), research into reducing diagnostic delays for Myositis and very recently, funding to establish the new Canberra Clinical Phenomics Service to develop advanced diagnostic facilities.

Our very important informal partnership with the **Myositis Discovery Programme** led by **Professor Merrilee Needham i**n **WA has** continued and expanded. A key benefit for our members has been the opportunity to have input into research projects via the Consumer Research Panel and as participants in their research.

The objectives of our Myositis Association generally reflect the pillars and foundation principles of the RVA Action Plan.

Education & Awareness

- We've continued to provide education and build awareness for Myositis with our patients and their families through State and regional gatherings and online guest speakers. My sincere thanks to recently deceased New South Wales coordinator **Frances Colley** for organising and facilitating the National Zoom education sessions for our membership.
- World Rare Disease Day (Feb 28 each year), Myositis Awareness Month (May) and World Myositis Day (Sept 21 each year) were recognised with members being interviewed for TV, radio and print media articles, engaging in fundraising and gatherings where possible. Thanks to everyone involved in the awareness raising.
- Our website **www.myositis.org.au** including the online membership/renewal platform on the site was launched in May 2022. My sincere thanks to **Marc Bobolakis of Larkscapes** for our online membership and website construction and for maintenance of the site and membership/renewal aspects. The site is a great tool for providing education and awareness of Myositis.
- My special thanks to **Will Barger i**n his role as **temporary editor of the KEEPING IN TOUCH (KIT) newsletter which regularly contains educational material.**
- Instead of a National Myositis patient conference, online Zoom meetings were held with educational sessions being provided by various allied health practitioners. Most usefully these sessions were recorded and added to the website for all to access.

Care & Support

All our Committee members along with State and Area coordinators are involved in connecting and offering support to our 450 + members. Their assistance is invaluable.

Many hours are spent in listening and guiding members and their families through the bewildering diagnostic process and adapting to life with Myositis. The care and support by our leadership team reduces isolation, provides encouragement and reliable information.

Support group coffee mornings, lunches and meetings have taken place throughout the year when and where Covid allowed. My thanks to the Coordinators involved in organising these events.

Special thanks to **Kim Armstrong-Wood WA coordinator** for her initiative in collating and continuing to update the **Myositis Gadgets & Aids Catalogue**. A very helpful resource for members and carers and one which has now been shared internationally.

Research & Data

Fostering research is important to our Association and it's encouraging that our very passionate and dedicated doctors are committed to research.

Funding support is critical to continue the significant research being undertaken, and, as an Association, we need to prioritise fundraising.

The **Myositis Discovery Programme** established by the Perron Institute and led by **Professor Merrilee Needham** Neurologist in WA is funded by the **Marcia Sheath** bequest and other grants.

Importantly the world wide Sirolimus in IBM phase 3 drug trial is well underway across Australia and commencing overseas.

The Abcuro IBM phase 2/3 drug trial is fully subscribed with results expected by mid 2026. Both of these trials provide hope to IBMers.

The Myositis Discovery team is also involved in basic scientific research as well as allied health issues such as continence, exercise and assistive devices. This programme is of critical importance to our members and we can't thank Merrilee and her team enough for their passion and commitment to Myositis.

The Rouse research programme led by **Prof Stephen Reddel at the Brain and Mind Centre, Sydney is funded by a very generous donation from IBMer Richard Rouse.** The research involves a review of a large number of muscle biopsy tissue.

An Australian government grant is funding the College of Health and Medicine at ANU research looking at **diagnostic delays. A paper has been published together with a toolkit for GPs. A further paper has been accepted for publication.** The research is being overseen by **Prof Matt Cook Immunologist.**

Dr Jessica Day, Rheumatologist and Post Doctoral Fellow at the Walter & Eliza Hall Institute in Melbourne has established a Myositis Clinic at Royal Melbourne Hospital and is also undertaking a project to produce a mouse model for IBM. She's supervising a PhD student on this project who is being funded by MAA.

Dr Matthew Parker in Sydney is involved in establishing a patient registry and also muscle biopsy techniques.

Patient led research is a very exciting development. Members **Kevin Austin from NSW and Kerry McLaurin from WA** are embarking on research.

Kevin is involving IBM patients and Carers in a discovery process to identify and prioritise the issues of living with IBM. The outcome of this research will help guide the work of our Association to compliment the patient and carer priorities.

Kerry will be focussing her research on the impact of diet on Myositis.

Our Committee

Our Committee members, State and Area coordinators all have Myositis and all are volunteers.

We're very fortunate to be mentored and guided by our **Patron Prof Allan Sturgess** who has provided invaluable support to our Committee and members during the year.

- **Vice president, Will Barger** has assumed a busy role - not only as Vice President but also coordinating the Victorian group, editing the Newsletter and frequently being involved in numerous policy and decision-making matters which arise.

- **Secretary Anita Chalmers OAM** has scaled back her involvement ahead of retiring at the end of our 2023/24 year. She has been at the helm of the organisation for 20 years and undertaken the lion's share of the work for much of that time. Her contribution of ideas, responsiveness and networking has ensured that over the years we've been well positioned. More recently, Anita has been forging links in the local Shoalhaven region to improve disability service generally. Thank you also to Geoff for his ongoing support and especially in recent years as Anita's health has declined.
- **Treasurer, Richard Gysi** has also carried a very significant load in recent years year with the online membership/renewal system, new member numbers, record keeping and all things financial. It is so reassuring to have these matters well-managed but also increasingly difficult for Richard given his IBM.
- **Committee members Pam Taylor, Kate Christie and Peter Brown** have all made a significant contribution to the ongoing activity of the Association. Pam has been leading regular Zoom meetings for carers. Kate is assisting with supporting the Victorian members and Peter has bolstered the support in the SA group as well as getting involved in a recent meeting with Health Minster Mark Butler and World Myositis Day awareness building.

State and area coordinators contribute substantially to support our members through phone calls, emails, visits and meetings. This very personal effort is special and so valued.

I wish to especially acknowledge Trish Brown, John Armstrong, Sandra Chapman, Lyn Tunin, Kevin Austin who have all taken on roles over the course of the year to support people in NSW.

Kim Armstrong-Wood coordinator for WA has not only very successfully fostered a growing WA membership but also assisted with a fundraising, promotion of the MAA merchandise and education for Community leaders.

Thanks to Elizabeth Carter for connecting the South Australian group along with Tracy Abramovic and Peter Brown.

The Queensland group has been coordinated by Gordon & Robyn Burnett who have decided to retire from the role to spend more time travelling. Many thanks for years of effort to bring the group together and also be involved in student run projects to assist our Association. Thanks to Scott Griffiths who has agreed to take on the role as coordinator for Qld members.

Sadly, numerous members have passed away this year and we hold them and their families in our thoughts. We are very thankful for the donations received from family and friends in their memory. All donations received are directed to research or to improving the lives of those living with Myositis.

My thanks to everyone who has contributed to our success, growth and activities during the year. The support I receive from my husband Mark, as a sounding board for all manner of issues, along with the support from the committee, coordinators and wider membership makes each day in the role as President satisfying.

Christine Lowe
President
October 2024