



Myasthenia Gravis Association of Queensland Inc.

Messages

SEPTEMBER
2022

Myasthenia Gravis Association of Qld Inc **IN NO WAY** endorses any products, medical procedures or medical practitioners mentioned. Articles are provided as a guide, and/or for information purposes only.

We take this opportunity to thank Queensland Health, who by the provision of a grant, make the work of the Association and the publication of this Newsletter possible, and to those who take the effort to contribute to its success.

PRESIDENT'S REPORT SEPTEMBER 2022

Many thanks to those people who made the effort to either attend the 31st Annual General Meeting or join via Zoom. The main reason that we made Zoom available was so that all members from near and far could be involved in this very important meeting and then listen to our guest speakers.

The attendance level at both the AGM and the June meeting have reduced dramatically and it is disconcerting to have a guest speaker, who gives up their time on a weekend, to be speaking to such a small number of people. We must have a quorum for the AGM and even this is becoming a big issue with fewer and fewer attendees.

The committee works very hard to find the most appropriate guest speakers for both June and September and then we are feeling very let down by the very limited number of people who are prepared to come in person or join via zoom. In fact, the management committee is thinking of not having a guest speaker and thus not being so embarrassed when people do not turn up to listen to very intelligent and informative speakers. Also the videoing and production on the website, is another time-consuming activity for a committee member and, if they are useful, that is great but it is rare to receive feedback via technology or the 1800 number in terms of if they are being viewed and/or have been informative.

On behalf of the MGAQ Management Committee, I wish to sincerely thank Karen Downes for her tireless work and commitment to the association. Karen has been instrumental in the production of the podcasts as well as making contact with students studying in various sectors of the medical profession.

Welcome to our new committee member, Catherine

Bergin. It is always very beneficial to have a new member on the committee with fresh ideas and a commitment to making life easier for people with myasthenia. I also want to pass on my personal thanks to the committee members who continue to remain on the committee and work so hard for our members. As we have one less committee member we welcome people to come to our meetings, see the types of activities in which we are involved and decide if you feel that becoming a member of this dynamic, hard-working group is something which might interest you. Everyone has particular strengths and interests and we endeavour to link people to what they feel is important or of interest to them. Everyone can contribute in some way to enable us to offer the very best for our members.

As well as the election of office bearers for 2022-23 other business included acceptance of the Annual Operational Plan and the decision to keep the membership fees the same.

Many thanks to our guest speaker, Dr Geraldine Moses, for presenting a most informative and interesting information about people knowing and understanding the what's and why's related to their medication.

There has been a great response to the inclusion of Rituximab on the PBS. We know that many people with Myasthenia will benefit from this decision and the long and time-consuming process has paid dividends. Data from surveys completed by members can add great impetus to submissions to governments etc.

Remember to support the "Art with Heart" project and many thanks to those who have contributed articles for auction.

Thanks, Carol

Myasthenia Gravis Association of Queensland Inc

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Your Association is your **VOICE** with Government.



MYASTHENIA ALLIANCE AUSTRALIA

NEWS UPDATE

Job Done!! Rituximab available to all!

It is with great pride that the MAA can confirm the following news:- From 1 September 2022, Rituximab is now an unrestricted listing on both the S100 Highly Specialised Drugs Program and the S100 Efficient Funding of Chemotherapy Program. This means that the cost of this medication for

people with Myasthenia Gravis will be covered via the PBS and that there is equitable access to this medication for the Australian Myasthenia community. Thank you to everyone who contributed to bringing this about.

“Art With Heart” - BIDDING BEGINS!!

How exciting to see all the fantastic contributions that have come from our small community to ensure an engaging first “Art Auction Awareness” campaign. Who would have guessed that we have such talent amongst us. It is heartwarming to experience this support.

Thank you MG community. Of course the work of having a conversation is not done - with the bid-

ding open we now need to attract the buyers. I am very confident that this inaugural year will be hugely successful and thank each of you for getting behind this event. If you need flyers to share or additional support please call 1800 802 568 and you will be assisted. To start bidding <http://www.airauctioneer.com/art-with-heart-auction-myasthenia-gravis>

Patient Reported Outcomes Survey Project

A brief update on progress. An 80 page document has been produced which collates and cross references the data.

The Project team are currently in discussions with a view to deciding on the best opportunities for presenting this information.

Join the team!

It is amazing to reflect back to early 2014 when it was suggested that a National group should be formed. I was involved with these initial conversations and have been privileged to be the Chairperson overseeing the development and progression of the MAA during the subsequent years. The MAA Board remain focused and willing, with their knowledge growing constantly. The Specialist Doctors have muted the idea of another conference - maybe in spring 2023. Currently the MAA Board do not have sufficient manpower for such an undertaking and to outsource the work would see the costs potentially escalate six-fold making it unachievable for the majority.

This is just one of many great opportunities that are being discussed for 2023.

If you or a family member live in NSW or Queensland and can consider becoming involved to make a real difference to yourself or your loved one, please contact your State Association and learn more.

In considering this opportunity, it is estimated that 6-8 hours of time per month would need to be allocated (January is excluded). This time would involve meeting every 4-6 weeks via Zoom, following the email trails, seeking support in order to learn more about the work and becoming involved with small projects. Your careful reflection on this request will be appreciated.

Susan White- MAA Chairperson

If you are not already registered with the Alliance please go to www.myastheniaalliance.org.au

ART WITH HEART AUCTION

AUCTION NOW LIVE!

A lot of talented artists have joined Lyn Church to help raise vital funds for **Myasthenia Alliance Australia** and the donations are in!

Join the auction to start bidding – The highest bidder takes home the treasure!

Let's see how much we can raise together!

AUCTION

The auction is live between the
11/09/2022 to 08/10/2022

BIDDING

See items and links to bid on **www.airauctioneer.com/art-with-heart-auction-myasthenia-gravis**



SHIPPING

All items will be shipped to their new owners by the 31st of October 2022.



Myasthenia
Alliance Australia
myastheniaalliance.org.au



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of Queensland Inc.**
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The Australian Myasthenic Association in NSW Inc
www.myasthenia.org.au

MGAQ Inc. AGM - September 11, 2022

Anne writes...

Thank you all for an amazing meeting yesterday and for your dedication and commitment to spreading the word about MG in so many ways throughout the year.

Thank you for the amazing guest speaker. She was a breath of fresh air in our continued search for knowledge and understanding of MG.

With much love and appreciation to each of you.



Guest Speaker, Dr Geraldine Moses AM
with Susan White



HEALTHED PODCAST INTERVIEW WITH DR FIONA CHAN

While we are gaining momentum with awareness campaigns during MG Awareness Month in June and the current Art with Heart auction, we also endeavour to raise awareness among the medical community, particularly health professionals who don't know much about myasthenia.

Earlier this year MGNSW worked with medical education provider **Healthed** to produce a **podcast interview with one of their Neurologists** specialising in neuroimmunology including Myasthenia Gravis. This podcast helps to **educate healthcare professionals about our rare disease and to create conversation. Conversation is information, and information is awareness!**

The 45-minute interview with **Neurologist Dr Fiona Chan and Dr David Lim**, GP and Medical Educator, covers issues such as the increasing diagnoses of myasthenia symptoms, how to test for myasthenia, and referral and treatment goals. It was shared with Healthed's network of health professionals in Australia.

Thank you again to Dr Fiona Chan for her time and for sharing her valuable knowledge, and to the team at Healthed for making this podcast happen.

The information is available here:

<https://omny.fm/shows/healthed-australia/myasthenia-gravis/embed>

and will soon be available on the MGAQ website.

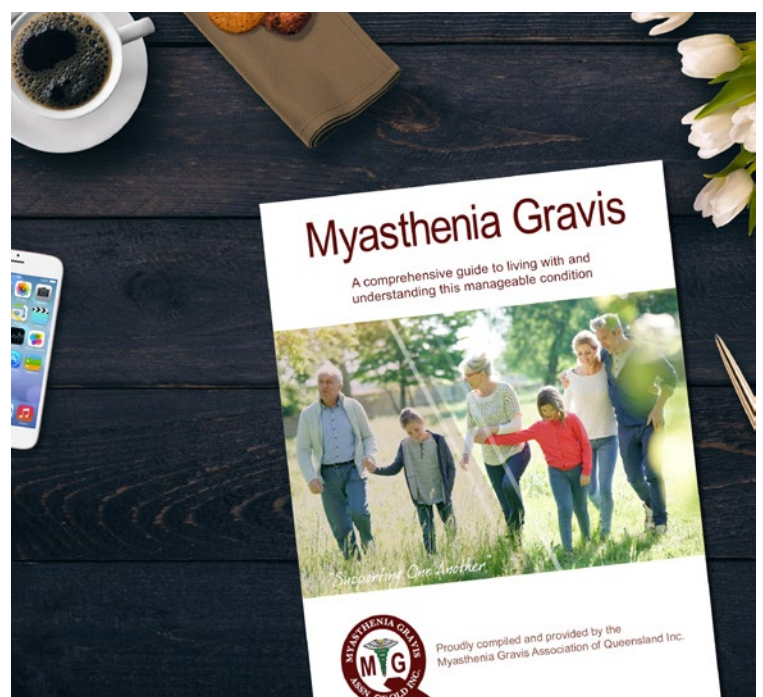


Healthed discusses,
"The Central Role of GPs
in Myasthenia Gravis"
with Dr Fiona Chan.



A WONDERFUL RESOURCE FROM THE MGAQ. INC.

The MGAQ Management Committee has now completed a revised version of the Information Booklet. We were very pleased to send all financial members a complimentary copy. Delightfully, it is being very well received. This booklet deals in detail with Myasthenia Gravis and mentions Ocular Myasthenia, Lambert Eaton Myasthenic Syndrome and Congenital Myasthenia.



Best **CARE** for all Australians is our **GOAL!**



- **Left-Right:** Robert Dadge (former Committee and current member), Dr Mike Freeland MP, Natalie Windle (President), Glenda Bidner (Vice-President), and Max Connelly (Secretary).

MGNSW held a celebration for their 40th anniversary in line with international Myasthenia Gravis Awareness month in June.

Both long-time and new members gathered together to share stories and more recent experiences of MG. Their special guest Dr Mike Freeland MP spoke about the importance of the patient voice and discussed advances for treatment of rare diseases but also acknowledged the ongoing issues such as access to treatment. The day was supported with messages from Dr Stephen Reddell and Dr Fiona Chan.

Natalie Windle, President MGNSW, thanked all past and present committees and members for their support of this association for forty fantastic years.

Myasthenia Gravis Association of Qld Inc. congratulates MGNSW on celebrating 40 years.

MEMBERSHIP RENEWAL

Would Paul Millar and Margaret Wood please contact the treasurer on 0431 571 399 or treasurer@mgaq.org.au regarding their membership. Thank You. Denise

MEMBERS' FORUM

Please send in contributions to the Members' Forum – it provides an ideal opportunity for members to share their experiences or questions. It is YOUR Forum and shared experiences with fellow MG sufferers makes understanding the condition just that little bit easier. If you have a response or an issue to raise, please forward it via mail to

PO Box 16 MT GRAVATT 4122 or via email to info@mgaq.org.au

Issues and Responses are published in the Members' Forum as-is without any recommendation as to their suitability or accuracy. The opinions expressed are entirely those of the contributor. Care should be taken if following advice or suggestions presented and it is strongly recommended that the advice of your GP or Specialist is taken in all cases.

Remember, we cannot offer medical advice – this can only be offered by a registered Medical Practitioner.

“Seeing Things Differently”

My name is Melissa Giles and I'm a member of MGAQ. You won't have met me at any MGAQ events because it's hard for me to hold my body (especially my head) upright for long. I must ration the use of my voice, hands, eyes, computer and phone, so it's difficult for me to connect with people. Sadly, this includes people going through similar experiences to me, who might be a valuable support. I've been trying to broaden my communication options by learning Auslan, but this isn't a perfect solution either. For me, the repeated upper body movements make signing unsuitable for conducting more than minimal conversations, and that's even if I can find people to talk to who also know Auslan.

My purpose in setting out this list of communication problems is not to dwell on my 'catalogue of misery', but to provide context for an alternative support network that I'm engaging with and wish to share with you. This virtual support network comprises published memoirs that I listen to, spoken by human voices or text-to-speech voices (although all of this listening gives me migraines, so add another entry to the catalogue!). I'm concerned with how I might adapt to changes to my eyes that affect my ability to read and write, and how I might keep working. So I've been seeking connections, through stories, with other writers, editors and journalists who've written about similar experiences. Through my research on this topic for a Doctor of Philosophy degree (a colossal undertaking given my physical difficulties!), I'm hoping to share knowledge about such virtual support networks with other people who are adapting to changes to their body.

One way that I'm trying to make sense of my experiences and connect with others is through my Seeing Things Differently blog. So far, four blog posts are online; the remaining six will start to appear over the coming months. My blog might interest you if you love reading memoirs. I've already included personal anecdotes from well-known authors who adapted to various kinds of vision changes, including Sue Townsend (1946–2014), who became famous in the 1980s for her humorous 'Adrian Mole' books. After developing diabetic retinopathy, Townsend had to find ways to keep writing – and deal with her reading addiction! My blog posts also include anecdotes from current writers who may be unfamiliar to you and details about a range of vision changes that you might not have heard of. In addition, the blog posts might be useful to you if, like me, you are experiencing vision changes (from MG or other causes) that affect your ability to read and write, and you would like to connect with others in a similar situation.

See the Seeing Things Differently blog: <https://story-telling.wixsite.com/seeing-things/blog>. The blog posts can be read using text-to-speech software and will also be produced as audio-recorded readings.

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NEWS FROM AROUND QUEENSLAND

News from Cairns

For more information, please contact Donna on 0414397462 or email donnaformosa64@gmail.com

News from Townsville

Our next Lunch is on **Saturday, 29 October 2022**, at Kirwan Sports Club, 159 Bamford Ln, Kirwan.
For more information, please contact Daphne on 0400 778 637 or email daphclay@gmail.com

News from Mackay

For more information, please contact Mary on 4959 5251

News from Bundaberg

For more information, please contact Denise on 0431 571 399.

News from the Sunshine Coast

The next **Coffee & Chat** will be on **Monday 3rd October 10.30am** at Kawana Club, 476 Nicklin Way Kawana. *The colour theme is **ORANGE** for this meet up.*

For more information, please contact Vicki on 0411 146 898 or email avlplummer@gmail.com

News from the Gold Coast

Hi Everyone. MG Gold Coast group had their get-together, sharing experiences with other members on Saturday, 14 August at Southport Sharks Club. Our next meeting will be at **10am on Saturday, 8 October, at Broadbeach Kurrawa Surf Club**. I hope to see all there. Kind regards Nader Amiri, Gold Coast Coordinator 0415 834 401.



COFFEE & CHATS

RSVP Anita on 0414 588 312

TOOWOOMBA

Saturday 24th September at 10.30am
Picnic Point Cafe, 164 Tourist Road, Toowoomba

MANGO HILL

Thursday 6th October at 10.30am
Coffee Club, Cnr Anzac Ave & Halpine Ave (Mango Hill Marketplace)

WELCOME TO OUR NEW MEMBERS

Jo-Ann H, Salisbury East SA

Ron E, Maddingley VIC

Become **INVOLVED** - make a **DIFFERENCE** to yourself and others.