



Myasthenia Gravis Association of Queensland Inc.

MessaGes

MAY 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 MAY 2022

Two years ago when I wrote my report for the newsletter I spoke about the trying circumstances under which we were all living. While the situation has improved we are now having to go through what is expected to be a difficult 'flu season. I am sure that all members are being vigilant in relation to having the required vaccinations.

June is a special month in the Myasthenia Gravis 'world' and it continues to be especially significant for Queensland. The MGAQ theme of **"Queensland Lights Up for Myasthenia"** is gaining momentum. Please take the time to see the wonderful teal-coloured page in this newsletter for the various towns and the buildings and landmarks that will be lit up on various dates. If you can manage it I am sure a drive and look at these in your local area will prove well worthwhile. If you are able to take a photograph of these structures the committee would appreciate an emailed copy of same. Remember to try to wear a teal coloured ribbon next month when you go out so that someone can ask you the meaning behind it.

If you live close enough to Brisbane I urge you to attend the get-together on **Sunday 12 June**. Full details are included in this newsletter. Our guest speaker is Louise Healy from Rare Voices Australia and her topic is *"Taking Action Together: Collaborating to Implement the National Strategic Action Plan for Rare Diseases"*. This topic is one that is vital to the MGAQ and MAA and should lead to better medical intervention for people living with rare diseases. We hope to see as many people as possible there.

One thing that is becoming more and more important in our work and that of the Myasthenia Alliance Australia is the need for research data to reinforce our stance in forums and our work with other groups in relation to improving the reality of living with Myasthenia. If you see, in any of our newsletters, a plea to be involved with research please consider it very carefully as, with a small population base, we need to get as many numbers as we can. Please be assured that the information collected remains confidential but is used in many ways to support our arguments with a variety of bodies, both political and social. Remember- **PATIENT VOICES MATTER**.

Please stay safe and enjoy the cooler weather that is on the way. .

Warm regards, Carol

Myasthenia Gravis Association of Queensland Inc

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



MYASTHENIA ALLIANCE AUSTRALIA

NEWS UPDATE

Where to begin! The agenda for the recent MAA Board meeting included **29 items of general business!** We are certainly spread across many areas of Research, Advocacy and Awareness. It was an exciting meeting as the Board realised the momentum that is now behind our work.

To show how traction has been gained, we have two new research opportunities. The Australian Myasthenia Community showed that it can provide credible and indicative data. In providing 280 accepted responses for the Patient Reported Outcomes Survey, our community demonstrated that we are indeed very interested in research, we do want to support researchers and we are keen to enhance our care. The first of these applications is progressing through a Government funding application process. With constraints occurring due to election mode, news on this project is still to come. The second is now ready for launch! It is the 'Covid Impact on Myasthenia' Project.

The **'Covid Impact on Myasthenia' Project** is an important undertaking. The past two years have seen a variety of approaches taken in regard to management of immune-suppression treatments, vaccination and Covid for people with Myasthenia. Whilst there is certainly no single correct answer due to individual needs, this project by Dr. Katherine Buzzard and Dr. Pakeeran Siriratnam (supported by A/Prof Steven Reddel and others) will capture consensus of care, look at general patient impact and seek out areas requiring greater attention. We are grateful to the Doctors for taking this interest as it is an area of on-going concern for many. Of note is the addition of a questionnaire for the 'Treating Physicians'. Please see page 3 of this newsletter for more details including how to participate. This survey will only be available for a two month period closing mid-July so please don't miss out. It is quite short to complete and as our community are now familiar with the Redcap programmes it won't be a big challenge at all! The MAA will advertise this opportunity in all the usual ways.

The **'Patient Reported Outcomes Study' Project** continues in the review and analysis phase. Work far beyond the initial brief has been completed and a draft report has been tabled. This report has led to further questions and more in-depth analysis has been requested. There have been some very significant findings highlighted. These need to be thoroughly understood. The MAA do look forward to bringing you information when the work is ready and thank the Project Partners for their high level commitment to the research.

MGBase! Check it out! Please visit the website at mgbase.org (formerly the eNID project). We think you will be impressed. Patient data is growing and successful entry is occurring at Monash Hospital Melbourne, Alfred Hospital Melbourne and Sydney Neurology (Brain and Mind) with Concord Hospital Sydney and Princess Alexandra Hospital Brisbane waiting for technical and ethical issues to be finalised. Additional technical experts have joined the Board and International interest is growing. **Please note that this is a 'Clinician only access site' and therefore view only for patients.**

In February, a letter was sent to Minister Hunt expressing the MAA's concerns about **access to Therapeutic Plasma Exchange for patients with Myasthenia Gravis**. This letter was supported by several key Specialists including Dr Reddel. A prompt reply was gratefully received. This matter is a complex issue and the reply covered a range of suggestions. Some action, as recommended in the reply, has commenced. Conversations will be on-going. We took the opportunity to offer good wishes to Minister Hunt in his retirement and to thank him for his support of Rare Diseases via the Action Plan.

The MAA are closely following the progress of both **Rituximab and Ruzurgi** through the PBAC process. A personal update on progress is next expected in June. We are assured that progress is within a usual time-frame and that we should remain confident.

Thankfully, it is not my plan to go through all 29 agenda items. However, the MAA team sure could use some extra support. The MAA needs to grow it's operational structure so perhaps you can offer some prudent Secretarial skills or have experience in Government processes. No harm in having a chat with the MGAQ or MGNSW Committee members to find out what may be involved.

Warmest regards, Susan White, MAA Chairperson.

Follow the work of the Alliance by registering at the website www.myastheniaalliance.org.au

DO YOU HAVE A MYASTHENIC SYNDROME?

(Myasthenia Gravis, Lambert Eaton Syndrome or Congenital Myasthenic Syndrome)?



theAlfred

THE IMPACT OF THE CORONAVIRUS DISEASE (COVID-19) PANDEMIC ON MYASTHENIA GRAVIS PATIENTS IN AN AUSTRALIAN POPULATION: A NATION-WIDE OBSERVATIONAL STUDY



Myasthenia
Alliance Australia

Your experience of the pandemic is critical to help your doctors and the public understand the impact of the pandemic on your wellbeing.

To complete a short survey (takes under 15 minutes) begin here:

<https://redcap.alfredhealth.org.au/redcap/surveys/?s=WXWKWDM4CMPAJH4N>

Your participation is voluntary, and all information will be de-identified. This is an opportunity to give us your voice, and we sincerely appreciate your valuable contribution towards representing your experiences.

Clinicians treating patients with myasthenia are also kindly invited to participate through the same link.

Principal investigators: Dr. Katherine Buzzard & Dr. Pakeeran Siriratnam

Any questions? Please email: p.siriratnam@alfred.org.au

Participant information statement

The aim of this project is to explore the various impacts of the COVID-19 pandemic on Australian patients with Myasthenia Gravis, with a focus on myasthenia management (timing and choice of immunosuppression, timing of vaccinations and access to care), quality of life and mental health. We hypothesise that the Covid-19 pandemic has had a negative impact on myasthenia management and quality of life of our patients. The survey is exclusively available through Myasthenia Alliance Australia (MAA) and invites all patients with myasthenia gravis in Australia to participate. The survey should take **no more than 15 minutes** of your valuable time. The survey is anonymous. The information will be collected via REDCap and stored in a password-protected Excel document.

The results of this survey will provide clinicians and the public with an increased understanding of how the covid-19 pandemic has impacted patients with myasthenia gravis. The findings are not only important as we continue to live with the pandemic in its various stages but may also provide useful information for planning and managing future pandemics. Please only complete the survey once.

THERE IS ALSO A SURVEY FOR CLINICIANS. ASK YOUR CLINICIAN TO PARTICIPATE

FOR CLINICIANS The clinician's survey should take under 10 minutes. Your unique position as treating clinicians of MG patients during the pandemic will provide great insights into the challenges both you and your patients have faced. The focus is on the impact of your management of myasthenia (timing and choice of immunosuppression, timing of vaccinations and access to care), and the mental health impact on your patients. You will only be asked to do the survey once.

If there are any questions, please address to Dr. Pakeeran Siriratnam via email p.siriratnam@alfred.org.au

Contact details for complaints: Complaints Officer, Office of Ethics & Research Governance, Alfred Health, email research@alfred.org.au, phone 03 90763619

QUEENSLAND LIGHTS UP

June is International Myasthenia Gravis Awareness Month.



June Awareness month for Myasthenia Gravis is worldwide and MGAQ has organised through local Councils and private organisations to “Light Up” landmarks in recognition of Myasthenia. Please go and view these landmarks. Take a moment to reflect on your MG journey.

Capture the image and share so Myasthenia can gain more awareness in the community.

This will help with research. This will help you with your MG journey.



ADOPT A
LIGHT-UP
FOR MYASTHENIA

BRISBANE - Thurs 9 and Sat 11 June

- Story Bridge
- Victoria Bridge
- Reddacliff Place Sculptures Donna Marcus: Steam 2006
- Tropical Dome
- Wickham Terrace Car Park Architectural wall
- Breakfast Creek Bridge at Newstead

BUNDABERG - 7 June

- Fig Trees

CAIRNS - 8 to 30 June

- The Court House Gallery

GOLD COAST - 3 and 4 June

- SkyPoint Observation Deck

LOGAN - 4 June

- Jacaranda Tower, Underwood
- Telfer Street Water Tower, Shailer Park
- Wineglass Water Tower, Hillcrest

LONGREACH - 10 to 20 June

- Longreach Water Tower

MACKAY - 6 to 12 June

- Sir Albert Abbott Administration Building

TOOWOOMBA - 8 to 13 June

- Victoria Street Bridge

TOWNSVILLE - 7 to 13 June

- Townsville Sign
- Victoria Bridge
- Wharton Reef Lighthouse
- George Roberts Bridge
- Old Magistrates Court House
- Central Park Boardwalk
- Little Fletcher Bridge

TOWNSVILLE - 12 June

- Queensland Country Bank Stadium

Please note that the venues reserve the right to change the advertised dates.

*Myasthenia Gravis Awareness also supported by Western Downs Regional Council;
Central Highlands Regional Council; Ipswich City Council*

LISTEN to audio Newsletter via **MEMBER ACCESS**

IF YOU CAN'T ATTEND THE MEETING - JOIN VIA ZOOM



Myasthenia Gravis Association of Queensland Inc.

JUNE FUNCTION

June 12, 2022 10am for 10.30am start

The Myasthenia Gravis Association of Queensland Inc. and Synergy Video

are inviting you to a scheduled Zoom meeting - June 12 2022 @ 10.30am AEST

To join the event please click the link below:

ZOOMING MEETING LINK TO GO HERE: <https://us06web.zoom.us/j/88547655039?pwd=czkxSDdjZHIPQ3JqRlIiZRIxYjRGQT09>

Meeting ID: 885 4765 5039 Passcode 383994

It is recommended that you use the zoom desktop client Version 5.3 or later for the best viewing experience, however this is not essential.

TO JOIN THE MEETING

Simply click on the link supplied above. This will connect you into the meeting and from there you can participate in the event.

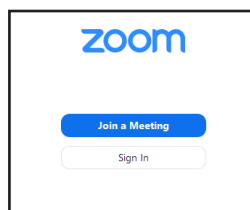
Alternatively:

1. Open the Zoom desktop client.
2. Join a meeting using one of these methods:
 - Click 'Join a Meeting' if you want to join without signing in.

OR

Sign in to Zoom then click Join.

3. Enter the meeting ID number **885 4765 5039** and your display name.
4. Select if you would like to connect audio and/or video and click Join.



Join a Meeting

Meeting ID or Personal Link Name

Grant MacLaren

☐ Do not connect to audio

☐ Turn off my video

Join Cancel

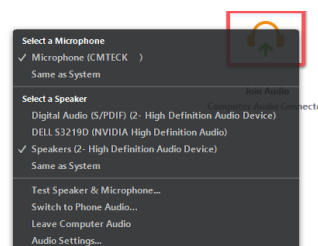
MICROPHONE AND VIDEO

If you are a participant / not presenting, please ensure Audio (and video if you wish) remain muted unless requested otherwise.



SOUND

If you are not hearing the presenters talk please check that you have your speakers or headphone volume turned up and have selected the right output device on zoom: (click the arrow next to the mic and select the right speaker in select a speak option).



TO ASK A QUESTION

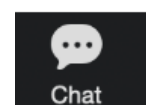
Should you wish to ask a question at anytime please click on the chat box and type your question in.

We may not get to everyone's questions but will endeavour to get to as many as possible in the time available.

The presenters will also allow time for discussion and Q&A throughout the meeting, and will request you to unmute yourself then. You can ask questions at this time or participate in the discussions.

SUPPORT

For all support requests please email support@synergyvideo.com.au or use the Chat function on Zoom and send a direct message to Tech Support



If members cannot participate on the day, the event will be recorded and made available to members via the MGAQ website, emailed link or in the usual format of a DVD if requested.

For more information about the June Meeting, please contact Susan, Freecall 1800 802 568 or email: info@mgaq.org.au

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.

Editing

Sitting down and writing regularly is a discipline that I am still getting used to. Like any new skill we learn, it takes time. Getting used to the new regime of medication when I was first diagnosed with Myasthenia Gravis (MG) took a while; ok, a long while! It took practice. I made some mistakes. I learnt, adjusted and improved with time. The changes I made eventually became part of my new stride.

Well, that makes it sound easy; but my journey with MG hasn't been. It took four years before a confirmed diagnosis. Gradually I found the confidence with MG to accept where I was at each day. As with any new skill, practice makes all the difference. It may sound that I have it all worked out and the MG doesn't bother me - 10 years after diagnosis – well no... I work with it and around it, but never through it! Each day is a new day.

One thing that helped me in the last few years - inspired by Covid19 lockdown and being at home - was the purging of extraneous things. I liken it to editing in writing. There is something freeing about having less clutter around. This purging ended up being both physical and emotional 'stuff' and I am feeling all the better for it.

I began by clearing out my wardrobe. Clothes that I had not worn at all in the past two years were given away. I then went from room to room deciphering what was important and what wasn't. I have found that I never did use those multiple baking tins, nor the numerous candles, nor the serving dishes and bowls that I had accumulated. Unnecessary things, be they physical or emotional, had become a weight that I didn't know I had been carrying. Thanks to this editing I not only have room in my cupboards, but more importantly I have more room in my life for the joy of each day.

Learning the art of editing in writing takes time and it has helped me in all areas of my life. I edit my garden when I weed it, I really consider thoughtfully when I go shopping; do I really need this? I consider carefully the emotions that come up, now that is much harder work; do I really want to hold on to that? Purging is freeing. I have found that editing leaves the best, and gives what remains the chance to shine.

Helen T

About the Author: I was diagnosed with Myasthenia Gravis in 2012. I live on the Far South Coast of NSW with my Husband and our big black Labrador. I enjoy creative endeavours like painting, crochet and knitting, reading and watching old movies, and writing.

WELCOME TO OUR NEW MEMBERS

John, Cornubia Qld

Lauren, Redlynch Qld

Margaret, Capel Sound Vic

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

NEWS FROM AROUND QUEENSLAND

News from Cairns

Please join us on **Saturday, 28 May** in the Boardroom at Cairns RSL Club, Esplanade at 11.00am-12.30pm. If you are visiting the Cairns region at this time, you are most welcome to come along. For more information, please contact **Donna** on 0414397462 or email donnaformosa64@gmail.com

News from Townsville

Dear Members, we are Celebrating **"International Myasthenia Gravis Awareness Month"** on **Sunday, 12th June at Grill'd Townsville, 3 Palmer Street at 6pm**. Please join us for dinner and to view the teal lights after dinner. Family members are very welcome to attend. **Please note change of Venue**. To RSVP or for more information, please contact **Daphne** on 0400 778 637 or email daphclay@gmail.com Looking forward to your company! Thanks for attending our April lunch.

News from Mackay

Come along to our next lunch on **Sunday, 5 June at 11.30am, Boomerang Hotel, 307 Nebo Road Mackay**. All are welcome. For more information, please contact **Mary** on 4959 5251

News from Bundaberg

For more information, please contact Denise on 0431 571 399

News from Hervey Bay – Wide Bay Burnett Region

For more information, please contact Jan on 0429 622 438 or janpowell3@bigpond.com

News from the Sunshine Coast

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

News from the Gold Coast

Our next meeting will be at **10am on Saturday, 18 June at Kurrawa Surf Club in Broadbeach**. Your local contact for the Gold Coast group is Nader. His contact number is 0415 834 401.



COFFEE & CHATS

RSVP Anita on 0414 588 312

ASPLEY

– Stellarossa Café, Robinson Road Marketplace, 605 Robinson Rd W
Thursday, 26 May at 10.30am

JUNE AWARENESS FUNCTION

SUNDAY 12TH JUNE – 10.30AM START

At Sunnybank Community & Sports Club, 470 McCullough St, Sunnybank

Guest Speaker: Louise Healy from Rare Voices

Topic: "Taking Action Together: collaborating to implement the National Strategic Action Plan for Rare Diseases"

Come along – Meet in Person

(Available via Zoom too – see Page 5 for details)

RSVP IS ESSENTIAL AND OPEN UNTIL SATURDAY 11TH JUNE

Email info@mgaq.org.au or phone Susan 1800 802 568 to attend or ask question

MEMBERSHIP SUBSCRIPTION RENEWAL

It's that time of the year again, when Membership Subscriptions for the financial year 2022/2023 are due.

The envelope in which your newsletter is enclosed will advise you when your membership expires. If you look along the top line you should see "YOUR NAME" followed by some figures in smaller print than your address.

If you receive the newsletter by email and are unsure whether or not you are currently financial, **please phone our 1800 802 568 freecall number or email treasurer@mgaq.org.au to enquire.**

The majority of members will have 6/22 which tells you (and us) that you are financial to 30 June 2022. Others may show 6/23 or even 6/24 to indicate they have saved time and postage by paying in advance.

If you are unfinancial, **please take a minute to phone on the FREE call number, 1800 802 568 and advise whether or not you wish to retain your membership and receive all resources.**

We are also giving you the option of paying your subscription directly into our bank account.

New payment option for members of "Perpetual membership"

Cat A (Myasthenia Member) & Cat E (Associate Member) \$250 and Cat D (Carer Member) \$125.

This one-off payment would mean that you never have to worry about renewing your membership again. Please note that a Cat D membership must be attached to a Cat A Myasthenia Membership, it is not a stand-alone membership.

MEMBERS CAN NOW ALSO PAY THEIR ANNUAL FEES VIA THE MGAQ WEBSITE

www.mgaq.org.au/membership-application-form and select **Membership Renewal**

Our bank details are:

BANK: Bank of Queensland BSB: 124 032 ACCOUNT NUMBER: 10263772

ACCOUNT NAME: Myasthenia Gravis Association of Qld Inc.

REFERENCE: Your Name and Initials

If you use the direct deposit method, it would help if you could email us at treasurer@mgaq.org.au to advise that you have paid directly into our bank account and the date of the transaction. This will assist the Treasurer in reconciling with the Bank Statement.

Your receipt will be emailed or forwarded to you by mail.



If you wish to pay by Cheque or Money Order, please use the following form and forward to:

The Myasthenia Gravis Association of Queensland Inc.

PO Box 16 MT GRAVATT Qld 4122

Herewith please find my cheque / money order / cash for the sum of \$_____ being annual subscription \$_____ and/or Donation \$_____.

NAME _____ **Category A Myasthenia \$20**
(or) Category E – Supporter \$20 Perpetual Membership Category A or E \$250

ADDRESS _____

And for _____ **Category D – Carer \$10**
Perpetual membership \$125 (Cat D Carer membership must be attached to a Cat A Membership.)

ADDRESS _____

Mobile _____ Email _____