



Myasthenia Gravis Association of Queensland Inc

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Neurologist

Founder Member, of Brisbane

Messages

Myasthenia Gravis Association Of Queensland Inc.

MAY NEWSLETTER

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

One year 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 all still living with that COVID cloud hanging over our heads.

I hope that all financial members received the very informative position paper "COVID-19 vaccination discussion – immune mediated neuromuscular diseases" which had a great deal of input from Dr Stephen Reddel. Those people who were unsure about having the vaccination should have been reassured by what the first section outlined in relation to information for people with Myasthenia. It is sad that the only way we will beat this virus is by taking note of what is being recommended by top medical professionals. While our lives change daily, I think that Australia is the envy of most other countries.

June is a special month in the *Myasthenia Gravis 'world'* and it is especially significant for Queensland this year. As well as being **International Myasthenia Gravis Month**, it is also a celebration of thirty years of operation of your association. I am sure you have read with interest the information that has been in each newsletter this year and some of you would probably recognize either yourself or others in the photographs. If you live close enough to Brisbane I urge

you to attend the get-together on **Sunday 13 June**. Remember to try to wear a teal coloured ribbon next month when you go out so that someone will ask you the significance of it. Further details are contained in this newsletter.

The MGAQ theme of **"Light Up Queensland"** for June is gaining momentum. We are hoping that members will come out and look at the displays. (Dates and places found on page 3) Please do take a photo, maybe write a comment, and send it into info@mgaq.org.au so that it can be included in the June 13 celebrations.

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.

Please stay safe and well as we hopefully move closer to a better quality of life.

Thanks, Carol

Supported by



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Government

Ausenco

MYASTHENIA ALLIANCE AUSTRALIA NEWS



MAA UPDATE

For 15 months now, the MAA has been fostering conversation with regard to establishing a research project. This project is designed to develop a unique patient-reported survey. The information to be collected will be invaluable in assisting with forward planning for health departments and for providing evidence based conversation for Doctors and Patients when making informed treatment choices. Today's preliminary conversation via this Update is aimed at engaging with our community about an opportunity that we hope will come to fruition in the latter part of this year.

The survey will be lengthy. Careful consideration of answers will be important. Hopefully by adding extra data collection features, it will be achievable for as many sufferers as possible.

The figure of achieving '1000 Australian participants' has been tossed around! Wow! With this in mind, it is important that our MG Community rally to the challenge by taking the time to complete the survey, by discussing it with others and by helping to facilitate it for all. This will be a community endeavour.

Unfortunately, further details are not yet available but be assured that the MAA are working hard to bring about this Australian research opportunity.

Readers may recall that the MAA made a Submission in August 2020 to the Parliamentary Inquiry into the Approval Processes for New Drugs and Novel Medical Technologies. With 188 responses returned to the Federal Government, the MAA did not expect to be called to the witness stand. However, five patient organisations have been selected for the Brisbane sessions and the MAA has been chosen. People with Myasthenia Gravis will be represented at these hearings and the case for better access to treatments will be put forward.

Please do visit the MAA website regularly. Some improvements have been made which we hope will make it easier to explore. www.myastheniaalliance.org.au

UPDATE TO DISCUSSION PAPER

Dr Stephen Reddel has shared an updated version of the COVID Vaccine Discussion Paper to reflect the issues raised about blood clots. Please note the advice for Myasthenia Gravis patients largely remains the same.

Susan White, Chairperson

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

Sunshine Coast News

Our last coffee and chat catch-up was very enjoyable. Covid didn't stop these 7 maskateers 😊😊.

L-R: Colleen, Les, Alan, Donna, Sonia, Vicki & Michelle.

Thank you Sonia for the Mothers' Day gifts.

Our next coffee and chat morning will be on **Monday, 7 June at 10.30am at the Kawana Bowls Club, 476 Nicklin Way Kawana**. Hope to see everyone there.

Phone Vicki on 0411 146 898 for any queries.

Table booked under MGAQ Vicki.



JUNE IS MYASTHENIA GRAVIS AWARENESS MONTH

QUEENSLAND *Lights up*

LIGHT UP VENUES

TOWNSVILLE	7-9 JUNE	Townsville sign Victoria Bridge Wharton Reef Lighthouse George Roberts Bridge Old Magistrates Court House Little Fletcher Bridge
BRISBANE	7-13 JUNE	Story Bridge Victoria Bridge
CAIRNS	8-9 JUNE	Performing Arts Centre Munro Martin Parkland
IPSWICH	8-9 JUNE	Ipswich Civic Centre
LONGREACH	8-10 JUNE	Water Tower
TOOWOOMBA	8-10 JUNE	Victoria Bridge

Lighting up is being organised by MGAQ Inc.

"Can you help?" We need people to visit the venues and send the photos to ***info@mgaq.org.au*** before ***June 12*** to assist with the ***30 Year Celebrations!***

More History of the MGAQ

Some committee members have been rewarded for their commitment and dedication to the Association with a Life Membership. These include Kath Ross, Shirley Johnston, Cecilie Lander, Graeme Peters and Anita Jackson. The receiving of a Life Membership of any association is something of which to be very proud and we, as an Association, appreciate the many years of service and support given by the Life Members of the MGAQ.

Cecilie Lander became our patron in 1995 and has always been a valuable, supportive member of our Association. While Cecilie is not directly involved with the management committee she is always there to give her opinion, advice and commitment.

Technology has changed a lot since the early years of the Association. When the committee first introduced a newsletter it used to be produced on a typewriter, copied and then posted to all members. There were always articles of interest and information that members appreciated. Shirley Johnston's recipes were always a favourite and many of those recipes are still being made in kitchens across the state today. It was quite an effort for the committee to do the newsletter from start to finish with much copying, folding and gluing to be done. Today the newsletter is emailed and posted to those who do not have access to a computer. It is also posted on the MGAQ website. The association has just introduced a Podcast where the newsletter is read so people who have vision problems can listen to all the information contained in each newsletter.

As the use of technology has grown the Association has used it to allow members better access to services as well as using it to distribute useful information. The introduction of podcasts for financial members has been a big innovation. The number of podcasts containing a wide range of topics continues to grow. They are very valuable for anyone who has just been newly diagnosed or for people who are interested to keep up to date with the latest information and other people's journeys with Myasthenia.

Another significant step in the development of the Association occurred when a collaborative agreement with other Australian State Associations was drafted to form an Alliance. This occurred in 2014 and facilitated the representation of the MGAQ to include Federal issues, researchers and contacts.

After a tentative start, this Alliance Committee have sought out representation with Federal Government Departments, Industry Partners and with Researchers. Australia wide Conferences were organised in 2015, 2017 and 2019. Each time, numbers grew by 50%.

The Alliance and the MGAQ partner with not-for-profit group Rare Voices Australia to bring about best possible outcomes for people with Myasthenia Gravis.



• Shirley Langshaw, Marlyn and John Chester and Robyn Smeaton



• Barbara and Kris Klitgaard, Frank Ross, Gordon Jiear and Anita Jackson

JUNE FUNCTION

30 years anniversary
1991~2021

Celebration

Sunday, 13th June 2021 - 10am

at Hornets Football Club, Graham Road, Carseldine

COME ALONG - MEET IN PERSON

JOIN THE FESTIVITIES - EVERYONE WELCOME

(Available via ZOOM too - see Page 6 for details)

GUEST SPEAKER - DR CECILIE LANDERS

TOPIC "Finding our Way: Myasthenia, Community and the Journey of Life"

Commemoration gifts included and many celebrations.

Please stay on and join the Committee for lunch.

There is a good selection of food available from the venue.

RSVP is essential and open until Saturday, 12 June.

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



Myasthenia Gravis Friends *Western Australia*

Coffee & Chat - Sunday, 23 May

Venue: Byford District Country Club, 88 Linton Street North, Byford

Date: Sunday 23rd May 2021, at 11am for coffee/chat - Lunch to follow for those who want to stay on.

Contact for RSVP (we have to book) **Yvonne 0431 324 885 or Annette 0413 855 077** this is all pending no further snap lockdowns here in Perth



LUNCHEON

**Shepparton RSL Club,
88 Wyndham Street, Shepparton,
Sunday, June 27, 12 noon**

RSVP necessary for Reservations by June 25.

For further information, please call Pauline 0419 332 260.



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



Myasthenia Gravis Association of Queensland Inc.

JUNE MEETING

June 13, 2021 10.00am AEST

The Myasthenia Gravis Association of Queensland Inc. and Synergy Video
are inviting you to a scheduled Zoom meeting - June 13 2021 @ 10am AEST

To join the event please click the link below:

<https://us02web.zoom.us/j/86343555920?pwd=bUVSMWtQTVR0M0k2NEdUQWZrZ1RyZz09>

Meeting ID: **863 4355 5920** Passcode **504657**

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.

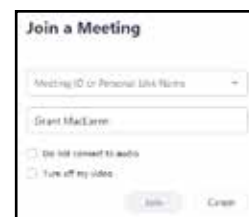
Alternatively:

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 **63 4355 5920** and your display name.
4. Select if you would like to connect audio and/or video and click Join.



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 speaker option).

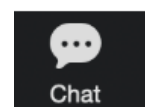


TO ASK A QUESTION

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

MEMBERSHIP SUBSCRIPTION RENEWAL

It's that time of the year again, when Membership Subscriptions for the financial year 2021/2022 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 6/21 which tells you (and us) that you are financial to 30 June 2021. Others may show 6/22 or even 6/23 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 _____

RSVP ARE NOW REQUIRED FOR ALL FUNCTIONS DUE TO COVID-19 RESTRICTIONS

News from around Queensland

News from Cairns

Our next function will be at the **Cairns RSL Club, Esplanade on Saturday, 22 May, 11am**. For more information or to RSVP please contact **Donna** on 0414 397 462 or donnaformosa64@gmail.com

News from Townsville

Next lunch **Saturday 19 June, 12 noon** at The Avenues Hotel (07 4723 8000), 70 Kern Brothers Drive, Kirwan Townsville. If you can come please RSVP Daphne.

Details for the month of June 2021- Try to go and see the lit-up buildings and take some photos please. For more details contact **Daphne** on 0400 778 637 or daphclay@gmail.com

News from Mackay

For more information, please contact **Muriel** on (07) 4954 1221.

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 Gladstone – Wide Bay Region

For local support in the Gladstone – Wide Bay region, call **Garth** on 0408 155 954.

News from the Sunshine Coast

The next Sunshine Coast coffee and chat will be held on **Monday, 7 June at 10.30am, Kawana Club, 476 Nicklin Way**. For more information, please call **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 27 March at Southport Sharks Club. Our next meeting will be at **10am on Saturday, 29 May at Kurrawa Broadbeach Surf Club**. I hope to see all there. Kind regards **Nader Amiri**, Gold Coast Co-ordinator, 0415 834 401.



ANSWER NEXT EDITION

April: Yvonne



Brisbane - Coffee & Chats

**- Crusoe Cafe, 12/152 Shore Street West, Cleveland
Saturday, 26 June 2021 at 10.30**

Please contact **Anita** on 0414 588 312.



Welcome to our new members

Leone H
North Bondi
NSW

Gayle McA
Emerald,
Qld

Daniel S,
South Brisbane,
QLD

Ravindra U,
Townsville,
Qld