



Myasthenia Gravis Association of Queensland Inc.

MessaGes

JUNE
2023



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 JUNE 2023

This month is International Myasthenia Gravis Awareness Month. As part of the activities planned a significant project by the MGAQ is the **"Queensland Lights Up for Myasthenia"** project. It is amazing the number of buildings etc that will be lit up in teal/blue across many towns and cities in the state. Please have a look in the newsletter or on the web and take the time to visit and take photos of any in your area. You can also submit any great photos to Donna via info@mgaq.org.au. What a good conversation starter to have with friends and family.

You will see in this newsletter the call for nominations for the management committee. I can advise that Susan White will not be nominating for the position of Vice President. Her workload is significant and her health situation is changing. Please think about getting involved and becoming a part of the strong team who make our work achievable. Please also be aware that relatives of members can also nominate for the management committee and what they learn from that experience will be invaluable in supporting their family member and the association.

Fees for all types of membership remain the same

this year and the membership renewal was in last month's as well as this month's newsletter. You can also renew via the website. Just a reminder that, if you do pay by direct deposit, please remember to send an email to treasurer@mgaq.org.au to advise that you have paid directly into our bank account and the date of the transaction.

Information about registration for the MAA National Conference to be held in Sydney on 21 October will soon be available to all.

Once again, we will have very knowledgeable and well-respected neurologists plus some talented guest speakers all providing the most up-to-date information on living with MG, research and medical updates. Remember that there is also an early bird registration at a reduced cost. Numbers are limited so make sure you keep an eye out for this information.

Myasthenia Gravis Awareness month is an important time in our calendar so please make sure you take the opportunity to spread the word about MG with family and friends as well as with your medical team.

Thanks, Carol



Myasthenia Gravis Association of Queensland Inc

P.O. Box 16 MT. GRAVATT QLD 4122

NATIONAL FREECALL: 1800 802 568

ABN 92 055 613 137

Email: info@mgaq.org.au

Internet: www.mgaq.org.au

COMMITTEE MEMBERS

President: CAROL BUCHANAN

Vice-President: SUSAN WHITE

Secretary: YVONNE HORNBY-TURNER

E: info@mgaq.org.au

Treasurer: DENISE HANNAY

E: treasurer@mgaq.org.au

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ANITA JACKSON

DONNA FORMOSA

ROSALYN HOLLAND

KIRSTINE SHRUBSOLE

CRAIG STREATFEILD

Newsletter Editor: GREG BREADEN

E: MGAQ.editor@gmail.com

PATRON: DR CECILIE LANDER AM Neurologist

Supported by



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



MYASTHENIA ALLIANCE AUSTRALIA

NEWS UPDATE

CONFERENCE REGISTRATION AVAILABLE IN JUNE!!

**It is with great pleasure that the MAA team
are ready to open registrations
for the October 21 Conference to be hosted in Sydney
at the Concord Hospital Education Centre.**

All Association members will receive, via post, an invitation to the conference inclusive of all the details provided. Registration will be available to the myasthenia community via a link on the MAA website www.myastheniaalliance.org.au and this will be shared via the Alliance news feed and then again via an MGAQ news alert as well.

Registration information will include the draft programme (see page 3 of this newsletter), an application form and payment options plus general information about the venue, the day, accommodation deals that have been secured for you should this be helpful and the offer to gather together with the organising Committee members for an informal chatty dinner on the Friday evening. Exclusive use of a restaurant near the suggested accommodation has been arranged and people are welcome to bring along their supporters irrespective of attendance at the conference the next day. Both the dinner and the conference have restricted numbers so it is important that people lock it their interest as early as possible.

As an additional reward for your patience, an early bird discount will be available for the first two weeks after the launch. The closing dates listed will be adhered to.

The MAA team is small and participants cooperation in ensuring that our preparations run as smoothly as possible is essential. The Doctors are offering us wonderful support and time in bringing this event to you and our appreciation cannot be too strongly expressed. The programme offers such a variety of topics and the day has been prepared with careful consideration for the needs of people with Myasthenia Gravis.

See you in Sydney!!!

Best regards

Susan White - MAA Chairperson

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



Myasthenia
Alliance Australia

MYASTHENIA GRAVIS 2023 NATIONAL CONFERENCE

CONFERENCE PROGRAMME

21 OCTOBER 2023 | 9 AM - 4:30 PM
CONCORD MEDICAL EDUCATION CENTRE
1H HOSPITAL RD, CONCORD WEST, 2138

TIME	PRESENTER	TOPIC
9.00am	Carol Buchanan	Welcome
9.10am	Susan White (MAA)	MAA Update
9.30am	A/Prof. Stefan Blum	Overview of Myasthenia Gravis
10.10am	Dr. Katherine Buzzard	Thymectomy
10.30am	MORNING TEA	
11.10am	A/Prof. Stephen Reddel	New and Emerging Treatments for Myasthenia Gravis
11.40am	Dr. Katherine Buzzard OR Dr. Stefan Blum	Cognitive Issues in Myasthenia OR Treatment Concerns in Myasthenia
12.10pm	Prof. Steve Vucic	Patient Reported Outcomes Project Findings
12.50pm	Louise Healy (RVA)	The Importance of Both Self and Patient Group Advocacy
1.20pm	LUNCH	
2.10pm	Dr. William Phillips	Disease Mechanisms of Myasthenia Gravis
2.50pm	Dr. Katherine Buzzard	MGBase Update
3.20pm	Dr. Kirstine Shrubsole	The Development and Evaluation of a Patient-led Symptom Tracker to Improve Referral Pathways in Myasthenia Gravis
3.40pm	Anna Peuwirth	The Myasthenia Gravis Tracking and Referral Tool – (MG SyTReT)
3.50pm	Interactive Presentation	Q&A panel (Questions to be received in writing)
4.20pm	A/Prof. Stephen Reddel	Closing Address

PROUDLY SUPPORTED BY





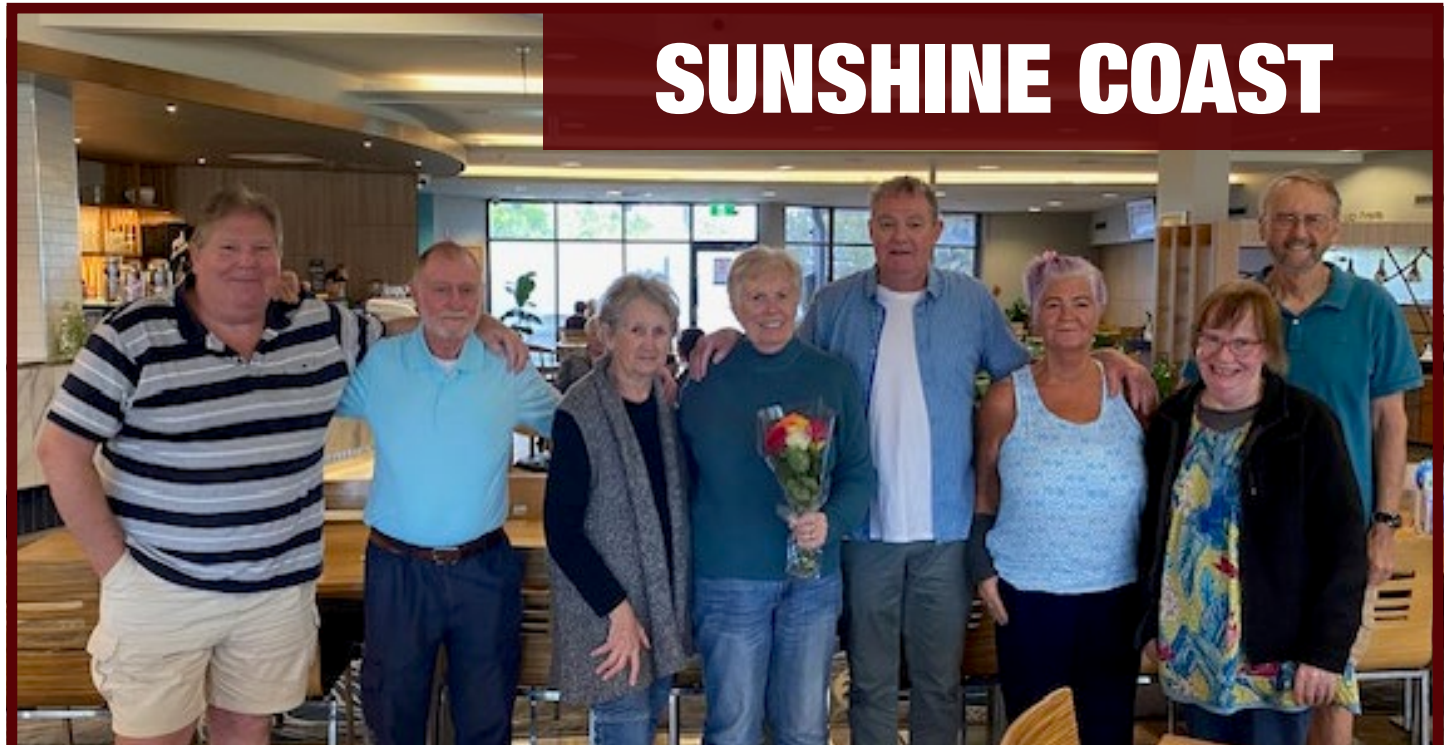
NEW MEMBERS

Christina, Beaumaris VIC

Antony, Birtinya QLD



TOWNSVILLE



SUNSHINE COAST

- The MGAQ thanks Vicki for her valuable contribution to the Association, particularly as Sunshine Coast Coordinator. We also welcome Michael who has kindly offered to take on the role of Regional Coordinator for Sunshine Coast.

SUPPORT your Association by **VOLUNTEERING.**



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.



Beck's Facebook Frame

With 1 June marking the start of Myasthenia Gravis Awareness Month, I decided to create a frame for my Facebook profile as I noticed there wasn't one within the Facebook frames. I am happy to share it with anyone who wants to use it".

Beck is a member of MGAQ and is the creator of this Facebook Profile Frame. If you are interested in having this frame on your profile picture, please email info@mgaq.org.au and we will pass it on.

Beck



VICTORIAN REGIONAL MG LUNCHEON

to be held on

Sunday, 25th June at 12 noon

Shepparton RSL Club, 88 Wyndham Street Shepparton

RSVP by Friday 23rd June.

For all bookings please call/text Pauline on 0419 332 260



Join us for lunch on

Sunday, 18 June - 11.30am/12 noon

**at Matthew Flinders Hotel,
667 Warrigal Road, Chadstone.**

Please RSVP to Catherine 0418 563 557 (text or ring)

RSVP: Greg Bowman 0407 371 877 or enquiries Catherine Bergin 0418 563 557

SUPPORT your Association by **VOLUNTEERING.**

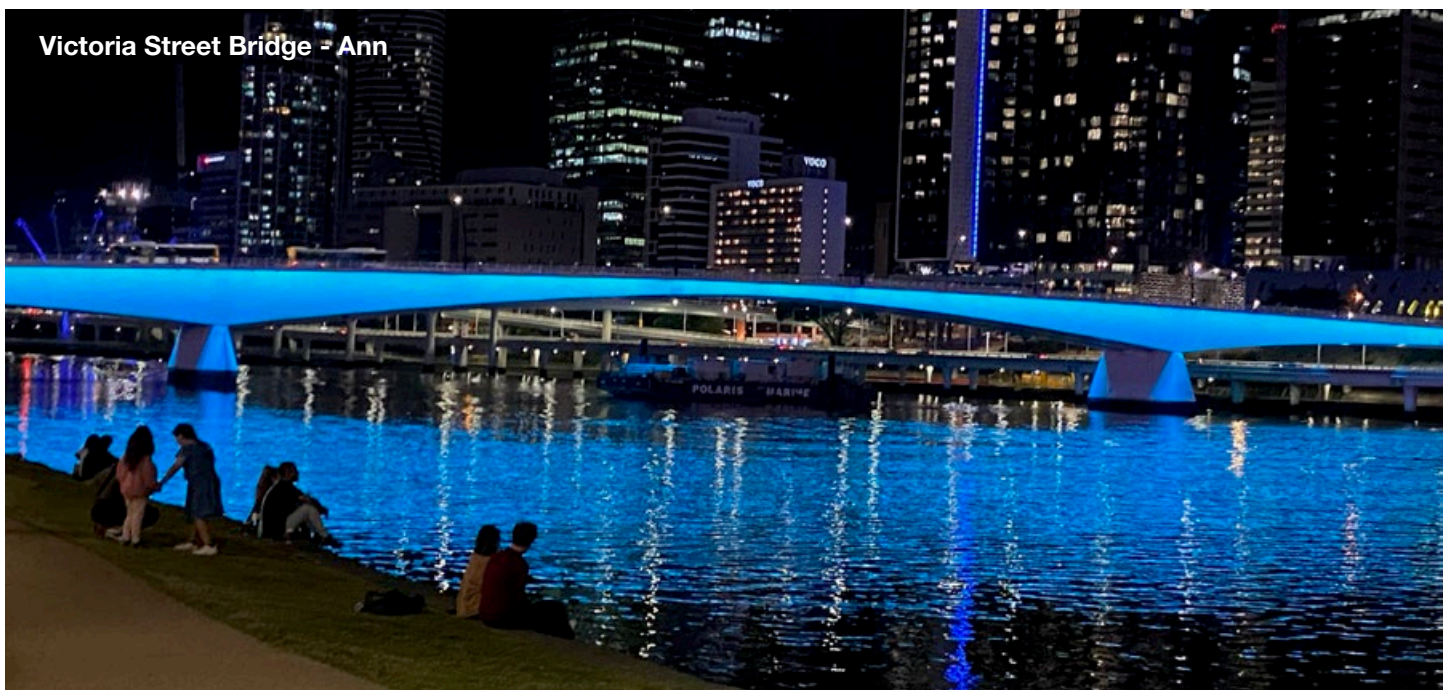


MYASTHENIA AWARENESS



QUEENSLAND LIGHTS UP

June is International Myasthenia Gravis Awareness Month.



Victoria Street Bridge - Ann

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



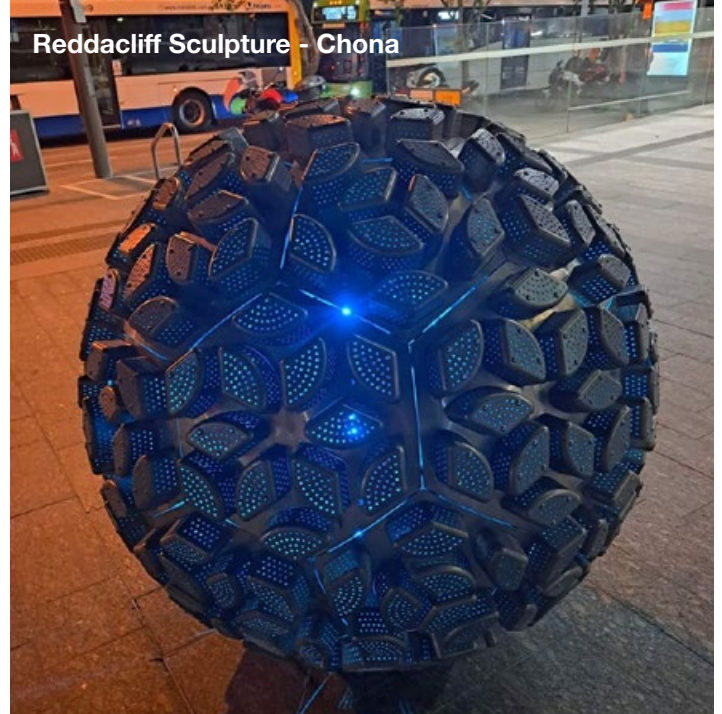
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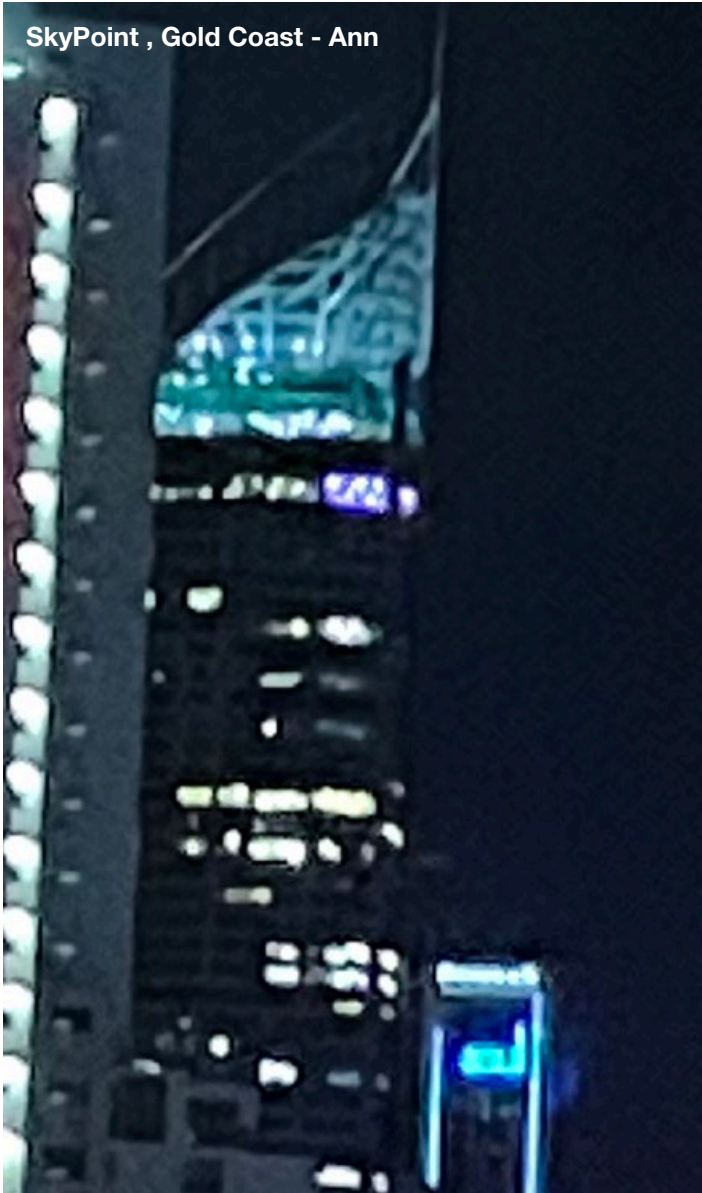
Story Bridge - Chona



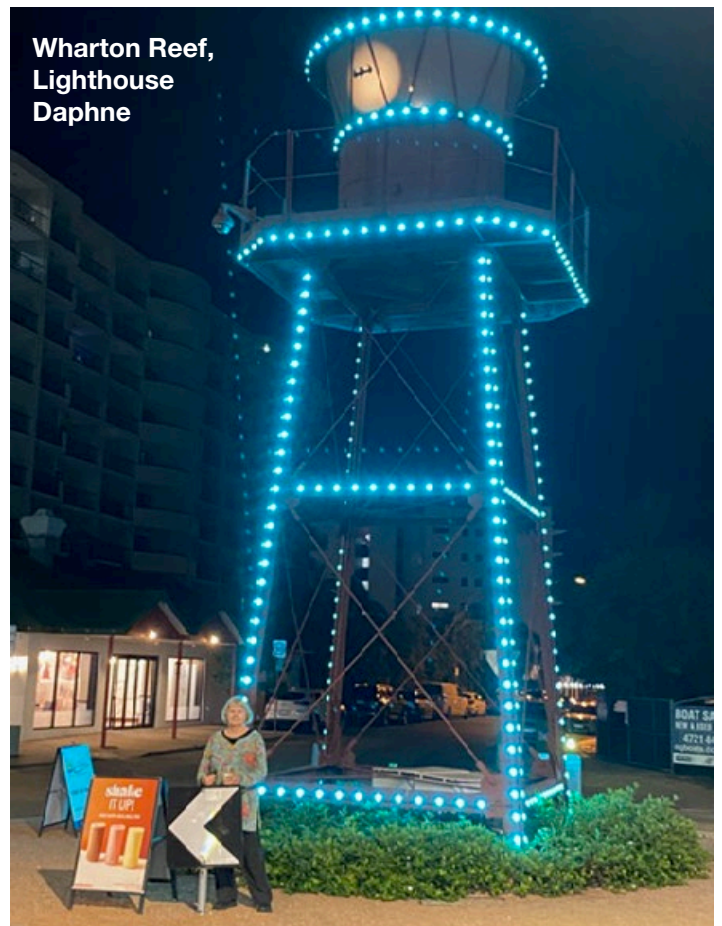
Reddacliff Sculpture - Chona



SkyPoint , Gold Coast - Ann



Wharton Reef,
Lighthouse
Daphne





NEWS FROM AROUND QUEENSLAND

News from Cairns

For more information, please contact **Donna** on 0414 397 462.

News from Townsville

Townsville MG lunch **Saturday, 22 July 2023, 12noon** at Sports Club, 159 Bamford Lane. Kirwan. If you can come, please RSVP Daphne on 0400 778 637 or email daphclay@gmail.com

News from Mackay

For local support, please contact **Mary** on 07 4959 5251

News from Bundaberg

We would love to see you at an informal Coffee & Chat on **Saturday, 1 July at 10am, The Spotted Dog, Railway Hotel North Bundaberg**. Susan who is the MAA Chair, MGAQ Communication Officer and also the voice behind the MGAQ freecall 1800 number will be in attendance. This will be a great opportunity to have general questions answered. For more information, please contact **Denise** on 0431 571 399.

News from Hervey Bay

For local support, please contact **Jan** on 0429 622 438.

News from the Sunshine Coast

For more information please contact **Michael Maggs**.

News from the Gold Coast

Hi Everyone! MG Gold Coast group had their get-together sharing experiences with other members on Saturday, 27 May at Southport Sharks Club. Our next meeting will be at **10am on Saturday, 29 July at Broadbeach Kurrawa Surf Club**.

I hope to see all there. For more information, please contact **Nader** on 0415 834 401.



COFFEE & CHATS

RSVP Anita on 0414 588 312

Mango Hill – Thursday 29th June @ 10.30am

The Coffee Club, Mango Hill Market Place,

Cnr Anzac Ave & Halpine Dr, Mango Hill, – All Welcome!

WHAT'S COMING UP

What's On?	When Is It?	Where Is It?
Meet & Greet MGAQ AGM	10.00am Sunday 10 September	Hornet's Football Club, Graham Road Carseldine
MAA Conference	Saturday 21 October 9am-4.30pm	Concord Hospital – Education Centre, Sydney

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



MEMBERSHIP SUBSCRIPTION RENEWAL

It's that time of the year again, when Membership Subscriptions for the financial year 2023/2024 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 7/23 which tells you (and us) that you are financial to 30 June 2023. Others may show 6/24 or even 6/25 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 or email treasurer@mgaq.org.au

Herewith please find my cheque / money order / cash for the sum of \$_____ being annual subscription \$_____ and/or Donation \$_____ MGAQ/MAA (Please circle)

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 _____



ANNUAL GENERAL MEETING ELECTION OF OFFICE BEARERS SUNDAY, 11 SEPTEMBER, 2023

CALL FOR NOMINATIONS FOR THE MANAGEMENT COMMITTEE 2023/2024

Eleven places are available for Committee nomination due to the MGAQ having an increasing range of projects in this new and exciting era of the Association. We always welcome anyone who wishes to nominate.

People can nominate themselves or anyone else they feel would be a suitable member of this very progressive and dynamic Committee.

Interested people need to be comfortable with using a range of technology and will need to maintain regular communication in order to stay abreast of issues throughout each month. Meetings are a full day held each second Saturday of the month excluding January and attendance via Zoom or in person is required for a majority of meetings.

To gain more information, discuss these roles and commitments you can phone **Freecall 1800 802 568**. Members with Myasthenia and those with an interest in Myasthenia are welcome to apply. Carers and supporters also very welcome to nominate. To nominate, you must be a financial member 2022/2023. Nominations **MUST** be received by the Secretary by the close of business on **Friday, 5 August 2023**.

If more than one nomination is received for the same position, a ballot to all financial members will be conducted with the votes to be returned by **Friday, 5 August 2023**.

Should there be no nomination for a particular position, nominations will be called at the AGM to be held on Sunday, 11 September 2023.

Nominee (*Print name*):..... Ph:.....

Nomination Accepted (*Signature*):

(*Circle position of interest*) **President Vice-President Secretary Treasurer Committee Member**

Nominee (*Print name*):..... Ph:.....

Nomination Accepted (*Signature*):

(*Circle position of interest*) **President Vice-President Secretary Treasurer Committee Member**

Nominee (*Print name*):..... Ph:.....

Nomination Accepted (*Signature*):

(*Circle position of interest*) **President Vice-President Secretary Treasurer Committee Member**

Nomination(s) (above) Seconded by (*Optional*)

Additional Nomination Forms available on request.

Members may be interested in offering support, but would prefer to nominate themselves for special project work rather than taking a Committee position. If this is preferred, provide your name, best contact details, and a little about the skills you can offer to the Association.

Name:.....Skills Offered:

.....Best Contact:.....