

Myasthenia Gravis Association of Queensland Inc.

*Messages*

**JUNE**  
**MYASTHENIA GRAVIS**  
**AWARENESS MONTH**

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 2022

June is Myasthenia Awareness Month and what a big month it is proving to be. We all know that everyone with MG displays different symptoms and has a variety of treatments to ensure the best quality of life available. Because we are a minority group, it is important that we continue to advocate and June is the month when we should really make an extra effort in this area. Remind your family, tell your friends, hand out information – it all helps spread the word.

A significant project for June 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 May newsletter or on the web and take the time to visit and take photos of any in your area. 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. Our stance has become serious in relation to getting new members involved in the vitally important work we do. 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. Allow her to enjoy her contribution by helping out. She will be available to assist and will maintain her other roles. I also need to add that the workload and timelines can, at times, put stress and pressure onto ALL members of the management committee. Get involved and become a part of the strong team who make our work achievable.

Please 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.

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](mailto:treasurer@mgaq.org.au) to advise that you have paid directly into our bank account and the date of the transaction.

One of our members, Chloe Wigg, is asking people who take Mestinon to please keep their bottles (any size) and then hand them to their regional co-ordinator when you have a get-together. The reason is that she needs them for an art project that will help raise awareness about Myasthenia Gravis.

Remember that PATIENT VOICES MATTER so do not forget to complete the short survey on this link: <https://redcap.alfredhealth.org.au/redcap/surveys/?s=WXWKWDM4CMPAJH4N>

*Stay well and enjoy the cooler weather.*

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](mailto:info@mgaq.org.au)

Internet: [www.mgaq.org.au](http://www.mgaq.org.au)

#### COMMITTEE MEMBERS

**President** CAROL BUCHANAN

**Vice-President** SUSAN WHITE

**Secretary** YVONNE HORNBY-TURNER

E: [info@mgaq.org.au](mailto:info@mgaq.org.au)

**Treasurer** DENISE HANNAY

E: [treasurer@mgaq.org.au](mailto:treasurer@mgaq.org.au)

Anita Jackson, Donna Formosa, Rosalyn Holland,  
Kirstine Shrubsole, Karen Downes, Craig Streatfeild

**Newsletter Editor:** GREG BREADEN

E: [MGAQ.editor@gmail.com](mailto:MGAQ.editor@gmail.com)

**PATRON:** DR CECILIE LANDER AM, Neurologist

Supported by



Queensland  
Government

Ausenco

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



# MYASTHENIA ALLIANCE AUSTRALIA

## NEWS UPDATE

### ***JUNE AWARENESS MONTH IS BEING EXTENDED!***

How exciting that there is a huge push across the nation for greater Awareness of Myasthenia Gravis. It is happening in June with wonderful Light Ups across Queensland and in other cities throughout Australia. This is definitely a growing campaign. Well done to the MGAQ for adding new sites again this year and for having signage prominently displayed on the Story Bridge in Brisbane and on the Bruce Highway at Glenorchy (South of Maryborough). The MAA are very proud to continue this good work and delight in announcing the launch of an **Australia-wide "Art with Heart Auction"** in support of our condition. This Art Auction will run through until October and will have a focus on Art Therapy with the lead item for the Auction being a painting by our very own Lyn Church. Lyn is an award winning Artist from the Gold Coast and she also suffers with Myasthenia Gravis. News from Lyn will follow over the coming months.

The first step in this Awareness endeavour requires us, our strong and committed Myasthenia community, to reach out to our families, friends, neighbours, workmates, health professionals, government representatives at all levels and **everybody** to ask for contributions to the auction. By doing this we are creating conversation! Conversation is information! Information is awareness! Contributions of all types (large, small, service based or tangible object) will be greatly welcomed. Please see the flyer on page 4 of this newsletter for more information. Please call to discuss if you are uncertain Freecall 1800 802 568. And, please do get behind this MAA campaign. Together we chip away for a better life for all.

### ***SO HOW ARE WE PROGRESSING IN THE FIELD OF RESEARCH?***

The latest project **"Covid Impact on Myasthenia"** is off to a fantastic start with 90 completed surveys. Feedback resoundingly agrees that this survey is quick and easy to complete and very relevant for everyone with Myasthenia. It is definitely not just for those who have experienced Covid. These numbers mean that we are half way to the targeted 200 responses. The survey will close off in mid-July so be sure to participate and maintain our strong reputation of interest in fostering best care outcomes for people with our condition. Help the Doctors help us!

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

### ***AND NOW FOR SOME MORE GOOD NEWS ...***

The Victorian community is invited to a discussion about being Associated and having a meaningful Government voice and a co-ordinated support system. Sue Floyed is offering the framework to make this happen. Please see the poster on page 6 for more details.

I look forward to hearing about the many Awareness activities happening across Australia this month. Best wishes to all.

**Susan White- MAA Chairperson**

If you are not already registered with the Alliance please go to [www.myastheniaalliance.org.au](http://www.myastheniaalliance.org.au)



**SA Coffee & Chat - Adelaide**

**Saturday 2 July - 10.30am to 12 noon**

**Hope Inn (Apple Room)**

**348 Port Road, Hindmarsh**

RSVP to [mgsouthaustralia@gmail.com](mailto:mgsouthaustralia@gmail.com)



## 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](mailto: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](mailto:p.siriratnam@alfred.org.au)

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

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





# ART WITH HEART AUCTION



## Calling all warriors and supporters of the Myasthenia Community

To join in the fun and help raise vital funds for **Myasthenia Alliance Australia**, you don't need to be a professional artist. You can simply create something or gift an item that makes you smile.

**Let's see how much we can raise together!**

## DONATIONS

Send a high quality image of your donation to [treasurer@mgaq.org.au](mailto:treasurer@mgaq.org.au) or via message on [facebook.com/mgqld](https://www.facebook.com/mgqld)

## SUBMISSIONS

Submissions cut-off: 07/09/2022

## AUCTION

From 11/09/2022 to 08/10/2022

The hero piece for the **Art with Heart Auction** is the artwork donated by **Lyn Church**, a long term Myasthenia Gravis Warrior and a valued member of the **Myasthenia Gravis Association of Queensland Inc.**

Lyn is a modern impressionist artist who paints mainly in oils and on location. This becomes challenging as she needs to paint quickly before the natural scenery changes too much. It's pretty tricky when your vision is doubled, your arms are weak and you are wobbly when standing.

In her words:

***"Never give up! Even though we suffer from this rare condition, we are strong, and we can achieve!"***



**Myasthenia  
Alliance Australia**  
[myastheniaalliance.org.au](http://myastheniaalliance.org.au)



**Myasthenia Gravis Association  
of Queensland Inc.**  
PO BOX 16, Mt. Gravatt, QLD, 4122  
FREECALL 1800 802 568  
[mgaq.org.au](http://mgaq.org.au) • [info@mgaq.org.au](mailto:info@mgaq.org.au)







# QUEENSLAND LIGHTS UP

June is International Myasthenia Gravis Awareness Month.

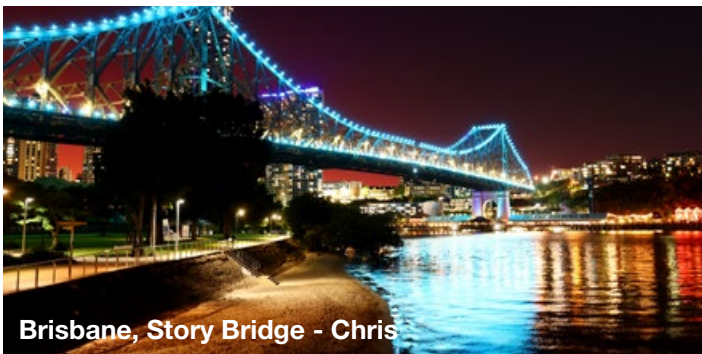
Townsville Sign - Carol



Jacaranda Tower, Underwood - Anita



Brisbane, Story Bridge - Chris



Cairns



The Court House Gallery - Mark McCormack

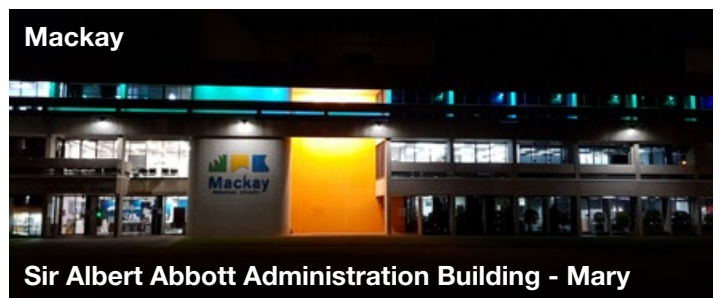
Telfer St Tower, Shailer Park, Anita



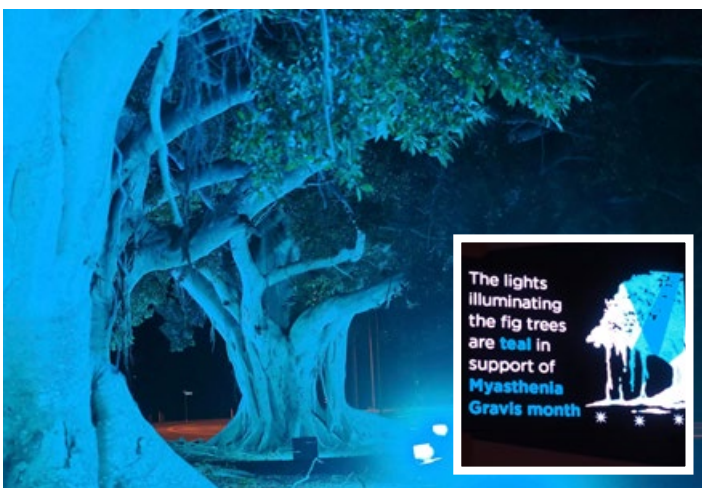
Wineglass, Hillcrest - Lisa



Mackay



Sir Albert Abbott Administration Building - Mary



Bundaberg Fig Trees - Denise



**LISTEN** to audio Newsletter via **MEMBER ACCESS**



## MYASTHENIA GRAVIS INC., VICTORIA HAS ARRIVED!



# MyastheniaGravis

Awareness and Research

WEBSITE: [www.myastheniagravis.org.au](http://www.myastheniagravis.org.au)

EMAIL: [info@mygravis.org.au](mailto:info@mygravis.org.au)

PHONE: 0408 944 183

**Myasthenia Gravis Inc (Vic) has arrived!** Joining other states throughout Australia, Victoria is now up and running.

As a Not For Profit and an advocacy voice for Myasthenia Gravis sufferers, the aim of the group is to raise awareness and assist those with MG where it can. Working alongside other established groups and committees that have been running for some time we will all come together to form a great knowledge group.

MG VIC will require a committee to assist with the running of the Not For Profit. If you would like to learn more or be involved, please contact me - let me know how you can help, what your strengths are.

*Looking forward to this exciting venture.*

Sue Floyed



Melbourne Town Hall - Joel



Kingston City  
Council Clock  
Tower - Joel

Thank you to Melbourne City Council for Lighting Up Melbourne Town Hall and to Kingston City Council for Lighting Up the clock tower for Myasthenia Gravis Awareness month.

Special thanks to Joel with support from Rare Voices Australia (RVA) for organising the Victorian Light Ups.

## JUNE AWARENESS CELEBRATION

# Myasthenia Gravis Friends Western Australia

## Coffee & Chat - Sunday, 19 June

Venue: Austria Club, 46 Staniland Street, Orange Grove

Date: Sunday, 19 June at 2.30pm

For more information, please contact Annette on 0413855077.

**PATIENT** Voices Matter





# Puzzlers

Puzzles by  
[www.thinkablepuzzles.com](http://www.thinkablepuzzles.com)  
[www.theteacherscorner.net](http://www.theteacherscorner.net)

## Sudoku

8			5					2
3	2					5	9	
6			3	2	7		4	
	8		9			1		5
	9		4		5			
1	6		7			9	3	
5				3	4	6	1	
	1	6	8				2	3
9				7				

## Math Challenge - 21

	+		-		-		7
X		+		-		-	
	X		-		+		105
/		/		+		X	
	-		-		+		-12
-		-		-		+	
	X		-		-		-15
95		3		7		-36	

## Bamboozable

intelligent smart wise	Dressed Dressed Dressed placeSTOP placeWAIT 60	WEIGH WHY
chair		WAKE suzie
	TIRE	

## Answers

95	3	7	-36
1	X	9	-15
-	-	-	+
2	-	3	-12
/	/	+	X
16	X	6	105
X	+	-	-
12	+	10	7

9	3	2	1	7	6	4	5	8
4	1	6	8	5	9	7	2	3
5	7	8	2	3	4	6	1	9
1	6	5	7	8	2	9	3	4
7	9	3	4	1	5	2	8	6
2	8	4	9	6	3	1	7	5
6	5	9	3	2	7	8	4	1
3	2	1	6	4	8	5	9	7
8	4	7	5	9	1	3	6	2

bamboozable 19 Answers: 1. Words of wisdom; 2. All dressed up and no place to go; 3. Split two ways; 4. High chair; 5. Flat tire; 6. Wake up, little Suzie



## NEWS FROM AROUND QUEENSLAND

### News from Cairns

Please join us on **Saturday, 20 August** in the **Boardroom** at **Cairns RSL Club, Esplanade** at **11am - 12.30pm**. If you are visiting 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](mailto:donnaformosa64@gmail.com)

### News from Townsville

For more information, please contact **Daphne** on **0400 778 637** or email [daphclay@gmail.com](mailto:daphclay@gmail.com)

### News from Mackay

For more information, please contact **Mary** on **4959 5251**

### News from Bundaberg

We would love to see you on **Saturday, 30 July** at **10.30am** at **The Spotted Dog, Railway Hotel**. The table is booked under MGAQ. Look forward to seeing you there.

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

### News from the Sunshine Coast

The Sunshine Coast Coffee and chat group enjoyed a morning catch up at the Kawana Club on Monday, 13 June. It was well attended and we welcomed Michael into our group. We were too busy chatting to get a photo. OOPS!

The next coffee and chat has been organised for **Monday, 1 August** at **1030am** at the **Kawana Club, 476 Nicklin Way, Kawana**. All welcome to attend. Contact **Vicki** on **0411 146 898** or email [avlplummer@gmail.com](mailto:avlplummer@gmail.com)

### News from the Gold Coast

Your local contact for the Gold Coast group is Nader. Contact number is **0415 834 401**.



## COFFEE & CHATS

RSVP Anita on 0414 588 312

### MANGO HILL

**Thursday 30 June at 10.30am – Coffee Club, Mango Hill Market Place,  
Cnr Anzac Ave & Halpine Drive – All Welcome!**

### WELLINGTON POINT

**Thursday 21st July at 10.30am - Farmhouse Restaurant and Coffee Shop  
625 Main Road, Wellington Point – Hope to see you there!**

## WELCOME TO OUR NEW MEMBERS

Ian, The Vines WA

Christine, The Vines WA

Ashleigh, Kallangur QLD

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





# 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](mailto: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](http://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](mailto: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 \_\_\_\_\_



## ANNUAL GENERAL MEETING ELECTION OF OFFICE BEARERS SUNDAY, 11 SEPTEMBER, 2022

### CALL FOR NOMINATIONS FOR THE MANAGEMENT COMMITTEE 2022/2023

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 2021/2022.

Nominations **MUST** be received by the Secretary by the close of business on **Friday, 5 August 2022**.

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 2022**.

**Should there be no nomination for a particular position, nominations will be called at the AGM to be held on Sunday, 11 September 2022.**

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:.....