



## Myasthenia Gravis Association of Queensland Inc

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### COMMITTEE MEMBERS

#### President

CAROL BUCHANAN

#### Vice-President

SUSAN WHITE

#### Secretary

RON STEPHEN

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#### Treasurer

DENISE HANNAY

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#### Committee

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DONNA FORMOSA

ROSALYN HOLLAND

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KIRSTINE SHRUBSOLE

KAREN DOWNES

#### Newsletter Editor

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#### PATRON

DR CECILIE LANDER

Neurologist

Founder Member, of Brisbane

# Messages



MYASTHENIA GRAVIS  
AWARENESS MONTH

Myasthenia Gravis Association Of Queensland Inc.

## JUNE 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

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 in terms of our condition, 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.

The management committee had a face-to-face meeting on Saturday, the day before the Brisbane get-together on Sunday, June 13. Our patron, Dr Cecilie Lander, spoke on the topic "Finding our way in the Myasthenia Community and the Journey of Life" and what a wonderful presentation it was. We are very grateful that Cecilie has been our patron since 1995 and is always interested in what the association is doing.

Tory Gill, the daughter of Jeff Gill who was a well-known rugby league player in Brisbane and Toowoomba, produced a video with the help of Steve Hadden and Anthony O'Brien. Jeff developed Myasthenia Gravis at the age of 42 but Tory feels he had the condition for quite a while before being diagnosed (sound familiar?). The video was very interesting and the sto-



ries Tory told focused on topics to which we can all relate. One of our committee, Susan White, also featured. This story will be shared with members.

Our Light Up campaign has grown significantly this year with events in Brisbane, Ipswich, Toowoomba, Townsville, Cairns and Longreach. See how fabulous the photos in this newsletter look. Hopefully, it can be even bigger in 2022.

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.

The form, Nomination for Membership of the Management Committee, is also in this newsletter. Please give this nomination serious consideration because the projects in which the MGAQ is involved continues to grow and the same number of committee members struggle to balance everything.

Stay safe and well and let's keep Queensland COVID safe.

*Thanks, Carol*

Supported by



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## MYASTHENIA ALLIANCE AUSTRALIA NEWS



### WORK WITH A GREAT TEAM!

The work of the MAA is growing and expanding rapidly with Government and Industry seeking us out for community engagement feedback. Opportunities to develop services and research for the MG community are opening up. The MAA need manpower to take up everything that is offered. NSW now have 4 representatives on the Board but Queensland cannot match this and we need to step up.

If you have a passion to bring about change, if you have health or industry experience, this could be an exciting addition to your interests. It is not necessary for you to have Myasthenia.

**What is required?**

An interested person will need to become a member of the MGAQ Committee. This committee meets 9 times per year, via ZOOM, teleconference or in person. Travel costs are supported. The sub-committee role of MAA Board member is then taken. The MAA meets solely via ZOOM or teleconference and communicates very effectively via email. Meetings times are by mutual agreement and occur approximately each 6-8 weeks. The MGAQ are now preparing nominations for the 2021 AGM. Please do phone Susan on 1800 802 568 if you can help or would like further information. We can accommodate two new members so don't think someone else will volunteer - we need you.

**Susan White, Chairperson**

Follow the work of the Alliance by registering at the website [www.myastheniaalliance.org.au](http://www.myastheniaalliance.org.au)

## JUNE 7-10 Queensland Lights Up for Myasthenia Gravis Awareness Month

- TOWNSVILLE** - Townsville Sign, Victoria Bridge, Wharton Reef Lighthouse, George Roberts Bridge, Old Magistrates Court House, Little Fletcher Bridge
- BRISBANE** - Story Bridge and Victoria Bridge
- CAIRNS** - Munro Martin Parklands
- IPSWICH** - Ipswich Civic Centre
- LONGREACH** - Water Tower
- TOOWOOMBA** - Victoria Street Bridge



Munro Martin Parklands: Donna



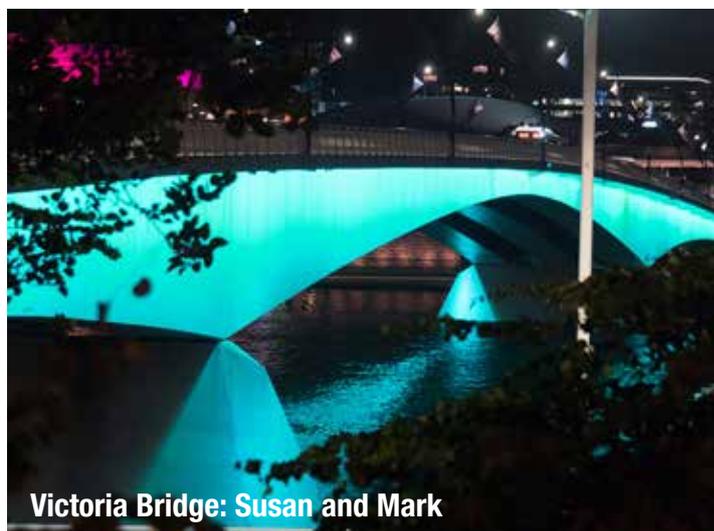
Longreach Water Tower

Queensland Lights Up for MG continues next page >

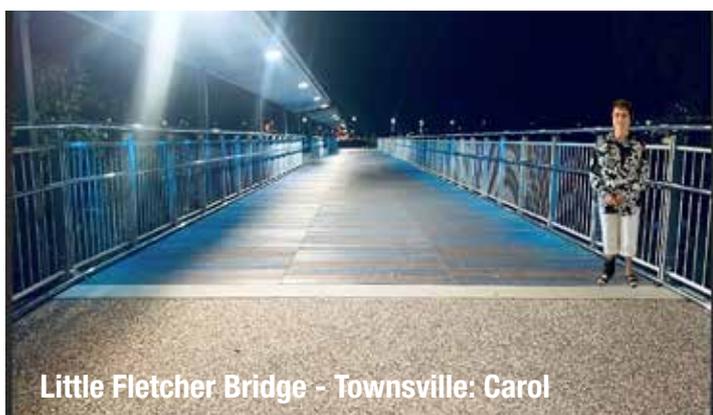
Brisbane, Story Bridge reflections: Hayley



Queen Street Mall: Susan and Mark



Victoria Bridge: Susan and Mark



Little Fletcher Bridge - Townsville: Carol



Townsville Sign



Wharton Reef Lighthouse - Townsville

# JUNE FUNCTION

Thanks to everyone who turned up today and those who watched on Zoom. It was a great presentation by Cecilie Lander our Patron with plenty of members meeting newly diagnosed members and plenty of laughs which the Association is renown for over the last 30 years. It is like a big family when we all come together and that has been impossible with Covid. It is gratifying for the Management Committee to know that members really appreciate what we do for the MG Community.



## MEMBER'S COMMENT

"I would like to thank everyone who made today's 30th Anniversary of MGAQ function possible. It was a very interesting and lovely presentation. Although I wasn't there physically, I watched and listened via zoom. Congratulations to one and all. Thank you to the volunteers who work tirelessly to make these events happen and give us ongoing support."

Vicki





# 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.



## **Myasthenia Gravis Friends WA** **Coffee & Chat - Sunday, 23 May**





## BOOK REVIEW

COPING WITH  
MYASTHENIA GRAVIS

MASTERING YOUR LIFE

AZIZ SHAIBANI, A. ZAHRA, H. AL SULTANI

**"NEW MEMBER  
LIBRARY RESOURCE"**

*This is a unique and innovative resource for patients who are trying to navigate the challenges of living with myasthenia gravis. It provides both patient insights and "pearls" as well as expert comment from an experienced clinician, Dr. Shaibani.*

Carlayne E. Jackson, MD, FAAN  
Professor of Neurology and Otolaryngology  
Chief, Neuromuscular section  
UT Health San Antonio  
President elect, American Academy of neurology

*In short, I strongly recommend this book. It belongs on the bookshelf of any patient dealing with myasthenia gravis.*

Anthony A. Amato, MD  
BWH Distinguished Chair in Neurology, Department of Neurology  
Chief, Neuromuscular Division  
Brigham and Women's Hospital  
Professor of Neurology, Harvard Medical School

*I believe Dr. Shaibani's latest book will be a valuable resource for patients with myasthenia gravis for years to come. It accomplishes on many levels what we try to do as neuromuscular docs for our patients - explain things so they can be understood and find ways to make their lives easier and more enjoyable.*

Gil I. Wolfe, MD  
Irvin and Rosemary Smith Professor and Chairman  
Dept. of Neurology, Jacobs School of Medicine and Biomedical Sciences  
Univ. at Buffalo/SUNY

The idea of the book was inspired by the need of the myasthenia gravis patients to learn from each other, strategies to cope of this disease and to concur difficulties associated with it and its treatment. Some coping mechanisms were discovered by patients after long suffering and therefore are precious. These information is not present in the medical textbooks and only patients can speak about their experiences.

AZIZ SHAIBANI is a an American board-certified neurologist and neuromuscular specialist who has been practicing in Houston for twenty-five years. He is the director of the nerve and muscle center of Texas which includes a large myasthenia gravis clinic. Shaibani is a clinical professor of medicine at Baylor college of Medicine and the author of the award-winning video "Atlas of Neuromuscular Diseases" published by the Oxford University Press.



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

## News from around Queensland

### News from Cairns

Please note in your diary our next get together is on **Saturday, 21 August at 11.00am at the Cairns RSL Club Boardroom, Esplanade**. If you are visiting Cairns at this time, you are most welcome to join us. For more information, please contact **Donna** on **0414 397 462** or [donnaformosa64@gmail.com](mailto: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. For more details contact **Daphne** on **0400 778 637** or [daphclay@gmail.com](mailto:daphclay@gmail.com)

### News from Mackay

For more information, please contact **FreeCall 1800 802 568**.

### 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](mailto: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

For more information, please call Vicki on **0411 146 898** or email [avplummer@gmail.com](mailto:avplummer@gmail.com)

### News from the Gold Coast

MG Gold Coast group had their get together sharing experiences with other members on Saturday, 29 May at Kurrawa Broadbeach Surf Club.

Our next meeting will be at **Saturday, 17 July, 10am on at Southport Sharks Club**.

I hope to see all there. For more information, contact Nader Amiri, Gold Coast Co-ordinator, **0415 834 401**.



**ANSWER NEXT EDITION**

**MAY: Mark C & David F**

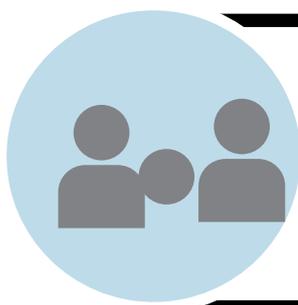


## Brisbane - Coffee & Chats

**Mango Hill - Coffee Club, Anzac Ave and Halpin Dr., Thursday, 8 July at 10.30am. Table booked in MGAQ.**

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

**SAVE THE DATE THURSDAY, 29 JULY 2021** at a coffee café around Toombul will advise in July Newsletter.



## Welcome to our new members

Graham B,  
Trinity Park Qld

Olwyn B,  
Wellington Point QLD

Grant K,  
East Toowoomba QLD

Craig C,  
Pimlico QLD

Roger S,  
Bundall, Qld

Melissa H,  
Rochedale QLD

Marshal K,  
Upper Mt Gravatt QLD



# ANNUAL GENERAL MEETING ELECTION OF OFFICE BEARERS SUNDAY, 13 SEPTEMBER, 2021

## CALL FOR NOMINATIONS FOR THE MANAGEMENT COMMITTEE 2021/2022

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, 8 AUGUST 2021**.

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, 6 September 2021**.

**Should there be no nomination for a particular position, nominations will be called at the AGM to be held on Sunday, 12 September 2021.**

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.**

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*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:.....



# ABOUT YOUR ASSOCIATION

- 1 Your Association is your **VOICE** with Government.
- 2 **SUPPORT** your Association by taking **MEMBERSHIP**.
- 3 The **STRENGTH** of your Association is determined by the work undertaken.
- 4 **SUPPORT** your Association by **VOLUNTEERING**.
- 5 With more people **VOLUNTEERING**, more **PROJECTS** can be undertaken.
- 6 **LEARNING** more about helping out is as easy as **PHONING 1800 802 568**.
- 7 Become **INVOLVED** - make a **DIFFERENCE** to yourself and others.
- 8 Best **CARE** for all Australians is our **GOAL!**