



Myasthenia Gravis Association of Queensland Inc.

MessaGes

JULY
2024



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 JULY 2024

The end of the financial year is upon us and that means a wide range of very important activities and commitments need to be met. Reports to Queensland Health are needed so their generous funding is continued. All the reports and paperwork need to be done for the **Annual General Meeting** to be held on **Sunday, 15 September at Aspley Hornets Football Club, Carseldine**. We hope that as many members as possible attend this important meeting and take the opportunity to chat with others over lunch.

The management committee has noticed a decrease in the number of members renewing their membership each year. The category A membership is only \$20 and the Perpetual Membership which covers you permanently is \$250. This membership money covers the three Association insurances, printing and distributing newsletters, the 1800 number, information packs, stationery etc so that the committee can function each year. Information about how to pay is on **page 10** of this newsletter.

Our management committee is in need of a Secretary. According to our Rules, which are linked to the Office of Fair Trading in relation to being fulfilled, we **MUST** have a Secretary. Please consider nominating for this position knowing that a great deal of support will be provided by management committee members until you feel comfortable with the requirements of the position.

It is amazing how this association has grown over the past years in relation to the amount of work and projects in which we are involved. This level of support and advocacy for our members can only continue if we have the personnel on our management committee and/or others who put their hand up to help with the multitude of 'jobs' to be done. Some of these require a level of skill but many just require people who are prepared to contribute their time and take on particular projects which occur during the year. As well as the position of Secretary mentioned above, please consider nominating as a committee member of the management committee. The nomination form is on **page 9** of this newsletter. Nominations close on 02 August.

The Queensland Light Up Project for International Myasthenia Gravis Month in June was a great success. The photos in the June newsletter were certainly stunning. Many thanks to everyone who got behind this project, particularly Donna from our management committee who spent many hours organising this very successful activity. It was also pleasing to see that this idea has spread to some other states.

I trust that everyone will consider the information above and act accordingly.

Thanks, Carol

Myasthenia Gravis Association of Queensland Inc

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Internet: www.mgaq.org.au

COMMITTEE MEMBERS

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Secretary: YVONNE HORNBY-TURNER

E: info@mgaq.org.au

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PATRON: DR CECILIE LANDER AM Neurologist

Supported by



Queensland
Government



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



MYASTHENIA ALLIANCE AUSTRALIA

NEWS UPDATE

Thank you, thank you, thank you to our Myasthenia Community and to the family and friends who assisted with the Art With Heart project.

The second **Art With Heart Awareness Campaign** has now been completed and the MAA Board are delighted with the outcome. There was a lovely and varied range of items made available to bidders. Hermann Pekel and Chris Searle, two renowned Australian artists, were very generous in their support of this campaign and we thank them profusely. The total number of direct donations was extremely pleasing with the proceeds to indeed assist the awareness work. These generous donors came from a wide variety of sources. This reflects that greater community awareness did occur. The MAA was able to reach out more broadly in sharing news of this project, even achieving some radio time. A profit was returned, allowing the MAA to continue developing their advocacy work and ideas for a bigger campaign next time have flowed!

The more serious side of MAA work continues. Without the unwavering support from patients who repeatedly show a willingness to share their personal stories this could not be the success that it is. Please continue this support as the research opportunities come our way. Regrettably all seem to require a level of on-line engagement which does exclude some. The degree of technology required varies with each project so please do continue to consider each option. We expect to offer one new project each month for the remainder of the year.

At times people say that the work of the MAA goes over their heads. This is understandable as it has been a lot for the MAA team to grasp also and our skill levels need to step up regularly. It is exciting and challenging work and it is making a big difference to how life is managed with this condition. If anyone would like to understand more, has a simple question or wants to become involved I would be delighted to chat with you. Please call Susan on 1800 802 568.

Wishing everyone well over the coming month. Hoping you can find joy between the ups and downs of MG and the medical appointments.

Kind regards
Susan

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

HELP! HELP! HELP

The MGAQ management committee needs urgent help with some secretarial work. The work would not be onerous but would help some members of the committee manage their ever-increasing workload. The help would only be for the next two months as we hope to have a successful nomination for the position of Secretary at the AGM.

For more information please contact Susan on 1800 802 568

BECOME INVOLVED - MAKE A DIFFERENCE

For membership payments and donations, the MGAQ account details are:

BSB: 124032 A/C: 10263772

MGAQ.org.au Member Log-in

The MGAQ website has many additional features available only to financial members. These include videos of presentations from past speakers inclusive of leading specialists. All general meetings of the Association are recorded and posted.

In addition, the complete list of Podcast recordings are available too.

Don't forget you can find this on your PC and also your phone.

An access code with username and password is sent out to all current financial members via email.

Log on to: **www.mgaq.org.au**
Click on Log In
Enter username and password
Click on Member Only



Available Now

Associate Professor Jan Sansoni -

"Myasthenia Gravis Research: Capturing Health Outcomes and Patient Perspectives"

If you have problems signing in please contact 1800 802 568 or email info@mgaq.org.au



MGAQ Inc. PODCASTS

CAN YOU SEE YOURSELF CREATING PODCASTS?

The MGAQ owns a suite of podcast and vodcast equipment. It is currently stored at the house of one of our management committee members. However with the downsizing of their residence there is no longer the space to store this equipment. Do you live in Brisbane and environs? Do you think this volunteer activity could be a new interest for you or a family member? The role comes with all the equipment provided plus tuition from our current Dr Podcast. What you see in the photo is what you will receive. Interested?

Please contact Dr Podcast at podcast@mgaq.org.au



SUPPORT your Association by **VOLUNTEERING.**



QUEENSLAND LIGHTS-UP

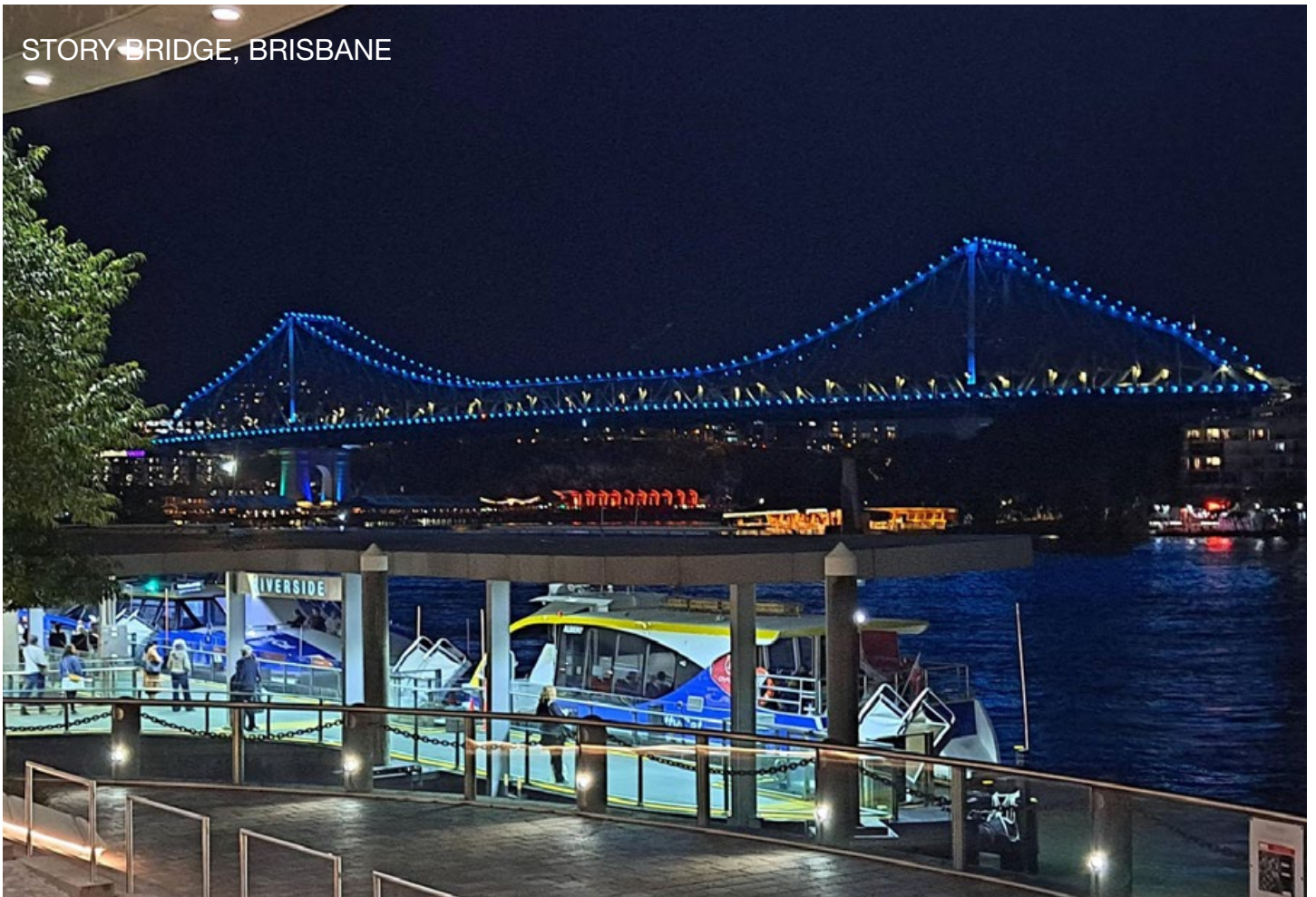
Thank you to the following providers for their support in promoting a conversation raising awareness in local communities during International Myasthenia Gravis Awareness Month.

- Brisbane City Council
- Bundaberg Regional Council
- Cairns Regional Council
- Central Highlands Regional Council
- City of Gold Coast
- Hinchinbrook Shire Council
- Ipswich City Council
- City of Logan
- Longreach Regional Council
- Mackay Regional Council
- Toowoomba Regional Council
- Townsville City Council
- Queensland Country Bank Stadium

MGAQ also acknowledges Rare Voices Australia for their support with the Light Up of Matagarup Bridge, Perth.

Also thanks to Grain Corp Newcastle for once again lighting up in teal for Myasthenia Gravis Awareness.

STORY BRIDGE, BRISBANE



CONVERSATION CONNECTION COMPANIONSHIP

WELLINGTON POINT - JULY



CARER GATEWAY IS A NATIONAL SUPPORT SERVICE FUNDED BY THE AUSTRALIAN GOVERNMENT.

If you are providing care for a loved one with disability, mental illness, a chronic medical condition or frailty due to age, then you are a carer, and this service is for you.

Wellways
Carer Gateway

**Free
support
for carers**

1800 422 737

 Carer Gateway
An Australian Government Initiative

 wellways

There are many ways you could be caring for a loved one...

A parent preparing meals and medication for a child living with a disability.

A friend cleaning and shopping for someone with a mental health condition.

A child providing emotional support to a family member.

A family member caring for an elderly parent with a chronic illness.

SUPPORT your Association by **VOLUNTEERING.**

The importance of collaboration



RAREST

Rare Disease Awareness,
Education, Support, and Training

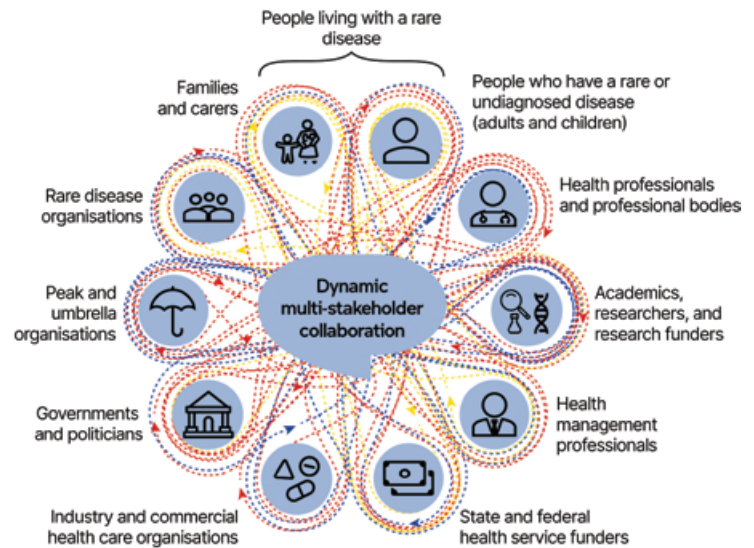
Championing change

Everyone involved in providing or receiving healthcare related to rare diseases is a stakeholder in the rare disease sector.

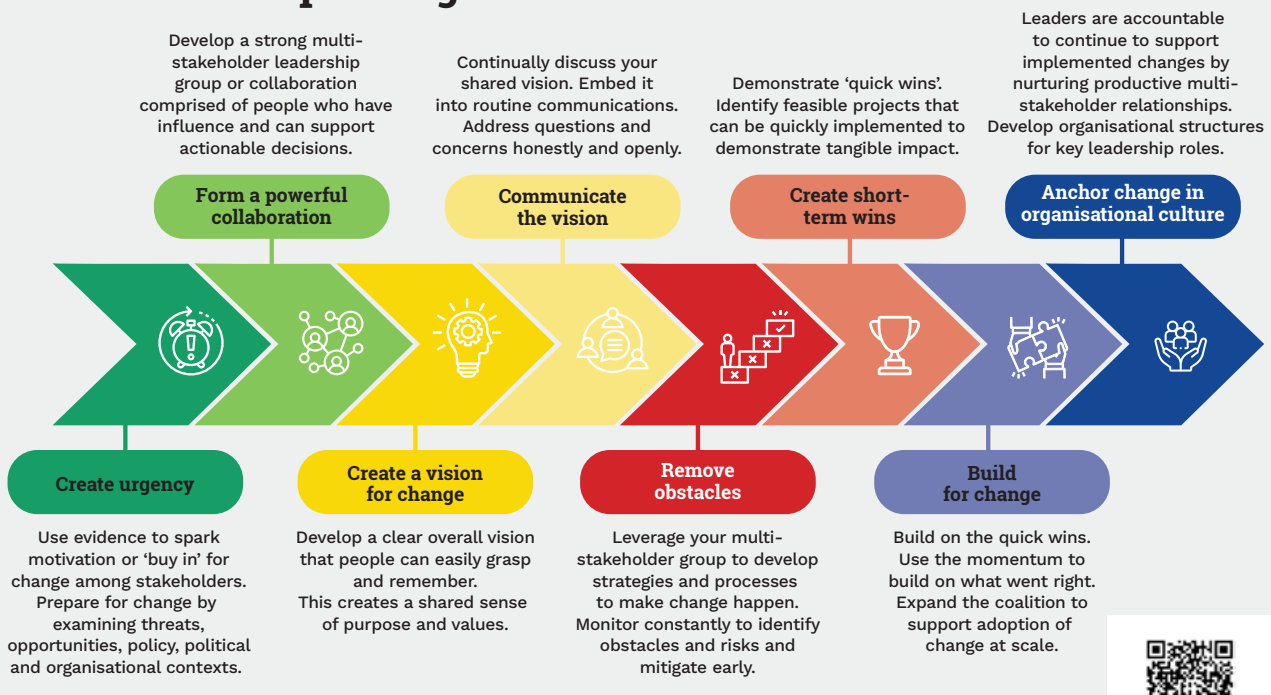
Understanding the roles and responsibilities of each stakeholder is integral to effective collaboration.

A tangible example of this complex collaboration is the Australian Government's National Strategic Action Plan for Rare Diseases (the Action Plan). The Action Plan is the first nationally coordinated effort to address rare disease in Australia.¹

Often championing change are rare disease organisations. Kotter's 8-step change model below depicts how all stakeholders can create change. Action on rare diseases is everyone's responsibility.



Kotter's 8-step change model²



Scan the QR code for more information.

1. Australian Government Department of Health. National Strategic Action Plan for Rare Diseases. Canberra; 2020. Accessed <https://www.health.gov.au/resources/publications/national-strategic-action-plan-for-rare-diseases> on 11 October 2023.
2. Kotter JP. Leading change, with a new preface by the author. Boston (MA): Harvard Business Review Press; 2012. Accessed <https://www.kotterinc.com/methodology/8-steps/> on 11 October 2023.

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.

Gift to Myasthenia Gravis Association of Queensland, in memory of Mr. Robert H. "Bobby" Day, 85, of Jena, Louisiana, USA.

Bobby Day was born on July 18, 1938, in Trout, Louisiana, and died of seronegative myasthenia gravis on Monday, June 3, 2024, at St. Frances Cabrini Hospital in Alexandria, Louisiana.

He is survived by his wife, Nelia, three children and their spouses, six grandchildren, and his very special dog, Charlie.

Mr. Day grew up in Jena, Louisiana and graduated from Jena High School. He then joined the Army National Guard and graduated from Northwestern State University with a degree in history. He taught history and was an assistant football coach (American gridiron) at Jena High School for 5 years. He then worked as a personnel manager and industrial engineer at Belden Incorporated, where he retired after 25 years. He was the President of the LaSalle Parish School Board for many years.

The memorial gift was made to MGAQ by Bobby's brother-in-law, Ben and his wife Cyn D, who live in Burleigh Heads, QLD. The donation was made through their Shaw-Fisher Charitable Endowment which is part of the Australian Philanthropic Services Foundation. Bobby was a good and kind man, with many friends. You would be hard pressed to find a man who loved his family more than Bobby did his. He would certainly be delighted that this donation will go to support Aussies suffering from myasthenia gravis and their families.

Scan to apply for
Membership or to
renew your existing
Membership



Scan to make a
donation to the
Myasthenia Gravis
Association of Qld Inc.



NEWS FROM AROUND QUEENSLAND

News from Cairns

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

News from Townsville

Townsville MG lunch is on **Saturday, 17 August 2024, 12 noon** at **Kirwan Sports Club, 159 Bamford Lane Kirwan**. For more information please contact **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

For local support, 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

The Sunshine Group will meet on **Monday, 5 August at 10.30am** at **Kawana Club, 476 Nicklin Way Wurtulla**. All visitors to the area are also welcome.

For more information please contact **Michael** on 0447 887 652.

News from the Gold Coast

Hi Everyone, MG Gold Coast group had their get together sharing experiences with other members on **Saturday, 13 July** at **Southport Sharks Club**. **Our next meeting will be at 10am on Saturday, 7 September at the same venue**. I hope to see you all there. Visitors are welcome.

For more information, please contact **Nader** on 0415 834 401.



COFFEE & CHATS

RSVP Anita on 0414 588 312

IPSWICH – Saturday, 3 August at 10.30am

Queens Park Cafe, 10A Merle Finimore Ave, Ipswich

– All Welcome!

WHAT'S COMING UP

What's On?	When Is It?	Where Is It?
Conversation, Connection, Companionship MGAQ AGM	Sunday 15th September 2024 Doors open @ 10am for 10.30am start	Hornets Football Club, Graham Road Carseldine
MGAQ Christmas Function	Sunday 10th November 2024	Southport Sharks Club, Gold Coast

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



ANNUAL GENERAL MEETING ELECTION OF OFFICE BEARERS SUNDAY, SEPTEMBER 15, 2024

CALL FOR NOMINATIONS FOR THE MANAGEMENT COMMITTEE 2024/2025

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 held each second Saturday of the month excluding January, April and October. They are a mixture of Zoom and in-person meetings. Attendance is expected for the 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 2024/2025.

Nominations **MUST** be received by **EMAIL info@mgaq.org.au** or by **POST to PO Box 16, Mt Gravatt QLD 4122**, by the close of business on **Friday, 2 August 2024**.

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 **Wednesday, 11 September 2024**.

Should there be no nomination for a particular position, nominations will be called at the AGM to be held on Sunday, September 15, 2024.

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:.....

