



## Myasthenia Gravis Association of Queensland Inc

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### 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)

#### Committee

Anita Jackson

Donna Formosa

Roslyn Holland

Karen Downes

Kirstine Shrubsole

Craig Streatfield

#### Newsletter Editor

GREG BREADEN

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#### PATRON

DR CECILIE LANDER

Neurologist

Founder Member, of Brisbane

# Messages

Myasthenia Gravis Association Of Queensland Inc.

## SEPTEMBER 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

What a wonderful experience we again had with using Zoom to allow members from near and far to join our AGM as well as having a group of people meet in person for the meeting. While many people who would normally travel from within the Brisbane area joined via Zoom, we also had people from all over Queensland and other Australian states. The total number of 56 attendees was outstanding and those who joined via zoom really embraced the technology.

As well as the election of office bearers for 2021-22 other business included the acceptance again of BDO as our pro bono auditor, acceptance of the 2021-2022 Annual Operational Plan and the decision to keep the membership fees the same.

Welcome Yvonne Hornby-Turner who nominated prior to the closing date and to Craig Streatfield whose nomination was accepted from the floor. We are sure that they both will bring a level of expertise and skills to the committee.

The management committee takes this opportunity to thank our two outgoing members, Ian and Ron. We have been, and still are, very fortunate to have a computer whiz such as Ian who has been responsible for adding to and upgrading our website and other technology. Ian has offered to continue in this role as a Project Officer for the MGAQ. Ron was our Secretary and worked hard to understand and be involved with everything

that this position requires. We thank both Ian and Ron for their valued contribution to the MGAQ.

As we have one less member we welcome people to come to our meetings, see the types of activities in which we are involved and decide if you feel that becoming a member of this dynamic, hard-working group is something which might interest you. Everyone has particular strengths and interests and we endeavour to link people to what they feel is important or of interest to them. Everyone can contribute in some way to enable us offer the very best for our members. Our guest speaker, Dr Reuben Beer, provided much interesting information in his presentation "Recent Developments in Treating Myasthenia Gravis". Some people on Zoom even managed to post questions for Dr Reuben Beer during his presentation which he kindly answered, along with those from the in-person attendees, at the end of his talk. A big thank you to Reuben for his highly relevant presentation.

We are still hopeful that people can come together for our usual Christmas lunch but we all know that the "wait and see" attitude is now a part of our life. The association will keep everyone informed.

Once again, thanks to all the members who made our AGM so successful and particular congratulations to those who managed a new skill by using Zoom.

**Thanks, Carol**

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

## MYASTHENIA ALLIANCE AUSTRALIA NEWS



## MAA UPDATE

Members across Australia are facing a wide range of extra challenges due to the Covid pandemic. Our thoughts and hopes go to each person with a particular focus on those in NSW and Victoria.

We hope that everyone has now either received a vaccination or has spoken with their Specialist about the choices available to them.

For your reference, access to the Discussion Paper, made available in March 2021, regarding Covid 19 vaccinations and Myasthenia and prepared by A/Prof Stephen Reddel can be found here <https://myastheniaalliance.org.au/update-to-discussion-paper-regarding-covid-vaccination/>

A hard copy version can be sent out if requested. Please email: [info@mgaq.org.au](mailto:info@mgaq.org.au) or phone **1800 802 568**.

*Stay safe, stay well.*

**Susan White, Chairperson**

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



## MGAQ Inc. podcast series

## UPDATE

**Greetings All**

As advised in the August MGAQ MessaGes newsletter, the podcast team has recorded a discussion with Dr Andrew Kornberg. A/Prof Andrew Kornberg is a paediatric neurologist with considerable neuro-muscular experience and particular knowledge about children suffering from congenital or juvenile myasthenia. The focus of our discussion with Prof Kornberg was this specific topic and the challenges for and with children with MG. The podcast will become available to members on the morning of Wednesday 6th October. Prior to this date, the podcast subscriber list will be updated so that all current members will have access to this wonderful discussion with Dr Kornberg.

As has been our practice for the past six months, we continue to generate an audio version of the Monthly MessaGes newsletter. We do hope that you are enjoying them. Please feel free if you see ways that we can add to this or our other podcast services, do let us know. In line with this objective, we are asking all members to advise... **"What is the special little thing you do to help yourself in doing an activity you enjoy on a day your symptoms are playing up?"**

If you would like to share your special hint, and in doing so potentially helping other members, please email [podcast@mgaq.org.au](mailto:podcast@mgaq.org.au).

We wish all our listeners stay safe in these somewhat different and challenging times-

**SUPPORT** your Association by taking **MEMBERSHIP**.

# MYASTHENIA GRAVIS ASSOCIATION OF QLD INC. ANNUAL GENERAL MEETING SUNDAY, 12 SEPTEMBER, 2021

## Election of Office Bearers for 2021-2022

The following were elected to the Management Committee until the 2021 AGM:

President: **Carol Buchanan**  
 Vice-President: **Susan White**  
 Secretary: **Yvonne Hornby-Turner**  
 Treasurer: **Denise Hannay**

Committee Members:  
**Anita Jackson, Donna Formosa**  
**Roslyn Holland, Karen Downes**  
**Kirstine Shrubsole, Craig Streatfield.**

The 2021 MGAQ Annual General Meeting was hosted at Aspley Hornets Football Club on Sunday 12 September. For the first time members were able to attend in person or participate via zoom. This proved a successful formula in this COVID world, with 25 people attend in person and a further 31 people attend via zoom. Carol's President's Report was presented, showcasing the varied, diverse and supportive work that has been accomplished this year. The Annual Operational Plan (AOP) was presented as was the Treasurer's Report, showing the strong position the MGAQ is in financially.

We farewelled Ron and Ian from the committee and thank them immensely for their contribution. Ian continues in a Project Officer role as our IT person.

The election of office bearers saw Yvonne come on board in the role of secretary and Craig, both join our wonderful committee. We warmly welcome them both.

Our guest speaker, Dr Reuben Beer (BPharm, MBBS, FRACP) gave a very informative presentation on 'Recent Developments in Treating Myasthenia Gravis'. Reuben spoke clearly and in detail on where the different treatments will target and what treatments we may expect in the future. Dr Beer then answered questions from both the floor and from the zoom audience. This very interesting presentation was extremely well received, and everyone was appreciative of Reuben's time. Paid up financial members will be able to access this presentation on the Member's page of the MGAQ website [www.mgaq.org.au](http://www.mgaq.org.au)

or a DVD can be requested by calling Susan on 1800 802 568.

Lunch was then enjoyed by those who stayed on and used the time for a much needed catch up.

Denise



**AGM Guest Speaker Dr Reuben Beer**







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](mailto: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.**

## Expressing appreciation has flow-on effects

I find all manner of things to appreciate in my life. Myasthenia Gravis has required me to 'slow down' and take a quieter pace to allow my body to heal. This has gifted me more time with my family who have been a pillar in my recovery. The other mainstay has been our garden and it has become my oasis and my sanctuary. In nature I breath more easily and deeply, and the healing from this is evident.

My family bring me joy in unexpected ways. It is often the little things that make the most difference. A couple of weeks ago my 18-year-old niece wrote me a heartfelt letter. It was unforeseen and therefore even more poignant in its meaning. As a class assignment she was asked to write a letter of gratitude to someone she felt had contributed significantly to her life and she chose me. I had not really considered how my journey might affect the learnings of others. Her letter reminded me of the integral part we all play in each other's lives.

As our area recovers after the fires of late 2019, the birds have slowly returned to our garden. I enjoy watching them come and go. We currently have the Currawongs here, they come down from the mountains every year when it is too cold there, and sing their mighty calls to us before moving back in spring. The Kookaburras too, bring me much amusement and mirth. I love their contagious laughter and I can't help but join in. There really is no other bird call like it in the world. I wonder if the person who said 'laughter is the best medicine' ever heard the Kookaburra?

I find I participate more actively as I regain my strength and balance. I am so aware of how expressing appreciation for all I have has flow-on effects. Sometimes unexpected effects. The happiness I share is what is important. I measure my achievements in love and joy, not in how much I get done in a day or how many belongings I might have; and that brings me peace.

*Helen T*

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*About the Author:* I was diagnosed with Myasthenia Gravis in 2012. I live on the Far South Coast of NSW with my Husband and our big black Labrador. I enjoy creative endeavours like painting, crochet and knitting, reading and watching old movies, and writing.



## Welcome to our new members

Tanya, Manunda QLD

Mike, Daisy Hill QLD

Derek, Clayfield QLD

Catherine, Carnegie VIC

Julie, Bellbird NSW

**SUPPORT** your Association by **VOLUNTEERING.**



**RSVP IS 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, 2 October at 11.00am at the Cairns RSL Club Boardroom, Cairns Esplanade.** If you are visiting Cairns at this time, you are most welcome to join us. For more information, please contact **Donna on 0414397462 or [donnaformosa64@gmail.com](mailto:donnaformosa64@gmail.com)**

### News from Townsville

We will be meeting in Townsville on **Saturday, 2 October and Saturday, 4 December at The Avenues Hotel, 70 Kern Brothers Drive, Kirwan commencing at 12 noon.** All Welcome. If you can come, please RSVP to **Daphne on 0400 778637 or [daphclay@gmail.com](mailto:daphclay@gmail.com)**

### News from Mackay

How wonderful it was to be able to attend the MGAQ Annual General Meeting and listen to Dr Reuben Beer's presentation via zoom. Thank you to the MGAQ committee for making it possible to include the regional areas and to Mark for the simple instruction of connecting to zoom.

A date is yet to be advised for our November get-together. For more information, please call **Mary on 07 4959 5251.**

### News from Bundaberg

If you are in the Bundaberg area and would like to meet up with others, please contact **Denise on 0431 571 399.**

### News from Gladstone – Wide Bay Region

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

### News from Hervey Bay – Wide Bay Burnett Region

If you are in the Hervey Bay area and would like to meet with others, please contact **Jan on 0429622438 or [janpowell3@bigpond.com](mailto:janpowell3@bigpond.com)**

### News from the Sunshine Coast

Looking forward to our next catch up on Monday 4th October at 10.30am – Kawana Bowls, 476 Nicklin Way, Wurtulla. All Welcome. For more information, please contact **Vicki on 0411 146 898 or email [avplummer@gmail.com](mailto:avplummer@gmail.com)**

### News from the Gold Coast

Our next get-together is **18 September at Kurrawa Surf Club, Old Burleigh Road, Broadbeach.** For more information, contact **Nader, Gold Coast co-ordinator, 0415 834 401.**



### **Brisbane - Coffee & Chats**

**CLEVELAND – Crusoe Café, 12/152 Shore Street West, Cleveland  
Thursday 23rd September @ 10.30am**

Please contact Anita on 0414 588 312.

# what's coming up

What's On	When Is It	Where Is It?
<b>MGAQ CHRISTMAS FUNCTION</b>	<b>SUNDAY, 12 DECEMBER</b>	<b>CALOUNDRA POWER BOAT CLUB 2 Lamerough Parade, Golden Beach 11.30 am for 12 noon</b>

Please note that due to COVID-19 Government Guidelines and Restrictions, the advertised event may change.

**LEARNING** more about helping out is as easy as **PHONING 1800 802 568.**