



# Messages

MYASTHENIA GRAVIS ASSOCIATION OF QUEENSLAND INC.

**JULY 2020**

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.

## Myasthenia Gravis Association of Queensland Inc

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Founder Member, of Brisbane

## PRESIDENT'S REPORT

It is great that the whole state has had a bit of a chill in the air over the past couple of weeks. I am sure that people with Myasthenia have been very pleased to get the cardigans out of the cupboards and feel comfortable rather than suffering excessive heat.

Our Zoom "get-together" in June was a resounding success and the quality of the guest speaker, Angelo Caterino, was very, very good with his very informative information about his journey and how we can all be kind to ourselves. Many thanks to those who took the opportunity to join the Zoom meeting. **Also, remember that category A financial members can get a copy of his DVD by phoning Susan on 1800 802 568 or emailing [info@mgaq.org.au](mailto:info@mgaq.org.au)**

Nominations for our management committee for 2020/21 have now closed and I am pleased to report that we have nominations for all executive and committee members. As there were not any more than one nomination for each position, a ballot will not need to be conducted. The finalised list of

nominations will be in the August newsletter and then voted on at the AGM in September which I hope can finally be face-to-face with social distancing.

A big thank you must go to the many members who made donations, both large and small, towards the eNID project. It has been a long road but now the end, or should I say beginning, is in sight. Testing of the program is being done in earnest here in Australia and we are very much looking forward to the official launch of the project.

You will also see in this newsletter the call for members to be involved in a number of surveys in the coming months. The MGAQ has certainly become heavily involved in research and advocacy for all members and, being such a small percentage within the population, we all need to take the time to support these initiatives that can only lead to better understanding of Myasthenia and a better quality of life for all involved. Please read the information as it becomes available and look at how you can contribute to these projects.

*Cheers, Carol*

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## MYASTHENIA ALLIANCE AUSTRALIA NEWS



# MAA UPDATE

As promised, the MAA Board have remained focused on their work during the COVID isolation period and are now excited to

bring you some updates on the current projects.

### The eNID Project!

MSBase wrote to say that they are very delighted about progress on this project. They are finalising feedback from Stephen and Katherine who used the beta-version, and are currently consolidating the final corrections. They have added a COVID reporting form and imagine the project will be ready to launch within the month. This is very exciting indeed and more news will flow over the coming months. Hurray!!!

### Growing the team!

The Board is delighted to welcome Natalie to the team of workers. Natalie is a NSW team member. There is room for more workers so do call for more information if you may be interested in joining the MAA Board.

### Reaching out!

The gene therapy research work being undertaken by Amplobiotechnology is progressing. Patricio, CEO of Amplo, reached out to the MAA for an introduction to fellow patient organisations Worldwide. It is great to report that over 140 emails from the MAA have been sent and some valuable contacts for Patricio have resulted.

### Research

A key objective of the MAA is to support research. Making and maintaining contact with sufferers is a key strategy in attracting research opportunities. Evidence of our effectiveness in promoting our reach is to become obvious over the coming months as several research projects potentially come on line. The direction of the current research discussions very much involves on-line questionnaires. It is critical that we as a community, embrace this direction. If a significant response is gathered, the data becomes very useful and has the potential to lead to more detailed projects. I feel that we, the MG community, are to be 'tested' over the coming months and I am hoping for overwhelming feedback to researchers that we

are indeed very interested in advancing our care. It is recognised that there is a significant sector of the MG community who do not access on-line services. In flagging this to the researchers, they do not have an obvious solution so it is up to us to be very active in finding ways to participate. This may mean asking family, friends or local library staff to assist. For one-off opportunities, it is important that people with MG make every effort. On page 4 of this newsletter the first projects for 2020 is advertised. Allied Health services are under-utilised when it come to our patient cohort. This survey aims to identify the extent of this issue and allow conversations around gaining more help, to be started. The MAA hope you will engage with this worthwhile project and we very much thank the researchers at the University of Qld.

### Rituximab

The MAA has liaised with many key stakeholders on a regular, respectful and sustained basis, including the TGA, PBAC, Roche and the Health Minister's office. We have led many conversations around how medications for people with rare disease can be repurposed and approved for PBS support without using the traditional methods which are unachievable with small cohorts. Despite initial promising signs, MAA is concerned that meaningful discussion may have stalled. For this reason, we have asked Rare Voices Australia to now take the lead on this significant issue for rare diseases. Nicole Millis, CEO Rare Voices Australia, will be approaching all key stakeholders, including the Health Minister on our behalf. She will explain to him how the health system has fallen short and she will seek support from the top levels of government, on both sides of politics. The National Strategic Action Plan for Rare Diseases launched by the Health Minister earlier this year, highlights the need for equitable access to medicines with demonstrated clinical benefit for a rare disease, including those that are already funded for another condition. The Action Plan calls for clear processes and pathways for submitting applications for the repurposing of medicines already approved for treatment of other conditions.

*Susan White - MAA Chairperson*

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



## MGAQ Inc. podcast series

# Published & Upcoming MGAQ Podcasts

### Current List of Published and Available MGAQ Podcasts:

- **Episode 1 MGAQ Podcast Series Overview** - This provides an Overview of the planned MGAQ Podcast and Vodcast Series 1 through 5
- **Episode 2 Resilience** - This involves a discussion with Dr Angelo Contarino, a Clinical Psychologist and the current Chair of the College of Clinical Psychologists in Queensland, about Resilience. Dr Contarino talks about Resilience, what defines Resilience, strategies for how we as individuals can build our Resilience and how to apply those strategies during the current outbreak of Covid-19.
- **Episode 3 Types of MG** - This podcast discusses Myasthenia Gravis (MG) and the various types of MG.
- **Episode 4 Three Sero-negative MG'ers Discussion** - This podcast includes a conversation with three Sero-negative MG sufferers and the particular challenges they have faced together with the solutions or approaches they have adopted to help in dealing with their type of MG.
- **Episode 5 Benefits of Physical Activity & Impact of Sedentary Behaviour** - This involves a conversation with Tahlia Alsop, a trained Physiotherapist, on the benefits of Physical Activity and the impact of sedentary behaviour on MG Sufferers. Tahlia is on the UQ Academic staff where she is completing her PhD investigating physical activity and sedentary behaviour in people with MG. Tahlia was a guest speaker at the 2019 MAA National MG Conference held in Brisbane.

### New podcasts scheduled release dates:

- **5 August 2020:** MGAQ Podcasts will present the third '*My Journey with Myasthenia*' podcast. This will include a conversation with a ACHR+ MG sufferer whom discovered his MG when racing his motorcycle. In the conversation, we will discuss his robotic thymectomy and the particular journey and challenges faced in dealing with his MG.
- **19 August 2020:** MGAQ Podcasts will present the third '**Ask the Expert**' podcast. This involves a conversation with Dr Kirstine Shrubsole, a Speech Pathologist and University Lecturer, about how one's speech and swallowing is impacted by MG. As part of this podcast, Dr Shrubsole will answer the questions recently posed by many MGAQ members on the impact of MG on their abilities to speak and swallow.

Send us your questions. FreeCall **1800 802 568** Email: [podcast@mgaq.org.au](mailto:podcast@mgaq.org.au)

### A MGAQ Administered Closed Facebook Discussion Group

#### MYASTHENIA GRAVIS CARERS

Administered by the MGAQ

**Freecall 1800 802 568**

Please follow the link and join

**Myasthenia Gravis Carers at**

[www.facebook.com/groups/284865318818756](https://www.facebook.com/groups/284865318818756)

## Seeking people with Myasthenia Gravis for research



Over the coming months the MGAQ and the MAA will be emailing its members with requests to complete a number of surveys. These surveys form part of some new and important research currently taking place for persons living with MG and will cover a range of health topics.

This research is essential to the future shaping of health services; ensuring quality care and improving treatment, management and better disease understanding for persons living with MG.

The MGAQ is excited about this investment of MG research here in Queensland and more broadly across Australia. We therefore encourage all of our members to 'have your say' and support this research by sharing your knowledge, experiences and needs in the completion of these surveys. Not only will this help to ensure the best possible outcomes from this work for people living with MG but it will encourage further projects to be developed. Rare Disease is all about small numbers. Without sufficient numbers, research is not effective. This means that everyone in the MG community needs to participate!

The current offerings are survey based data collections and unfortunately these rely heavily on modern technology. Providing alternative data collection methods has been discussed but it is often not possible to change the mode. For many in our group this will mean trying much harder and working together. If possible, family and friends may be willing to assist with the technology. Local libraries can be very good at helping and by

contacting the MGAQ we may be able to help too! **We must try hard.**

Below is the current project exploring how Allied Health is utilised for our people. Delightfully, there is often a very real personal engagement from the researchers and a genuine desire to help us and to work with our community. This is very much the case with this project. Three researchers are involved. The first is **Katrina Williams**, one of only 8 Specialist Neurological Physiotherapists in Australia. Katrina is interested in Myasthenia Gravis research as she has seen that there is little research in this area. She believes it is important for people with MG to understand their conditions and see what could be done with movement and exercise to improve their daily lives. She has seen great improvements in MG people, and wants to better understand how exercise and allied health can better support patients. Working alongside Katrina is **Dr Kirstine Shrubsole**, a speech pathologist with a specific clinical and research focus on stroke care and communication disorders. Kirstine has MG and takes an active role on the MGAQ committee. Supporting these ladies is **Chloe**, a final year speech pathology student. Chloe chose this research project to challenge herself and because a friend has MG. As she learns more about the condition, she is excited to be involved and by the prospect of helping people with Myasthenia.

Now is the time for action as this current project will close on 7 August, 2020.

**Who:** Australian adults with a diagnosis of Myasthenia Gravis.

**What:** Complete an online survey (45-60 mins).

**Why:** To investigate knowledge and awareness of symptoms, and perspective on whether allied health services would assist in managing symptoms.

This research will help us develop educational and advocacy materials for people with Myasthenia Gravis to receive allied health services.

**How:** Use this link <https://tinyurl.com/MGAlliedHealth> or scan QR Code



**For further information:**

Ms Katrina Williams on 0407 550 930 or [k.williams2@uq.edu.au](mailto:k.williams2@uq.edu.au)



THE UNIVERSITY  
OF QUEENSLAND  
AUSTRALIA



*This research is supported by the Myasthenia Gravis Association of Queensland Inc.*



**The Full Recording of Dr Angelo Contarino, Clinical Psychologist from the June ZOOM Meeting is NOW AVAILABLE ON DVD!**

The DVD is available to Financial Members **BY REQUEST ONLY!**

To order your copy of the June Meeting contact:  
**Freecall 1800 802 568 or Email: info@mgaq.org.au**



**Welcome to our new members**

Tahlia, Umina Beach, QLD  
 Patricio, Albert Park, VIC  
 Katrina, St Lucia, QLD  
 Cassandra, West End, QLD  
 Pauline, Warradale, SA

Darryl, Warradale, SA  
 Kelly, Carrum, VIC  
 Tiffany, Skye, VIC  
 John, Sunnybank, QLD  
 Amanda, Salisbury, SA

**what's coming up**

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

What's On	When Is It	Where Is It?
MGAQ ANNUAL GENERAL MEETING	<b>Sunday 13th September 2020</b>	ASPLEY HORNET'S FOOTBALL CLUB, 50 GRAHAM ROAD, CARSELDINE
MGAQ CHRISTMAS FUNCTION	<b>Sunday 13th December 2020</b>	BRIBIE ISLAND

**A MGAQ Administered Closed Facebook Discussion Group**



**MYASTHENIA GRAVIS AUSTRALIA PARENTS & GRANDPARENTS**

Administered by the MGAQ

**Freecall 1800 802 568**

Please follow the link and join

Myasthenia Gravis Australia Parents & Grandparents at

[www.facebook.com/groups/821532874970222](http://www.facebook.com/groups/821532874970222)

**SUNSHINE COAST GROUP GET-TOGETHER, FRIDAY, 10 JULY**



**GOLD COAST GROUP GET-TOGETHER, SATURDAY, 11 JULY**



**A MGAQ Administered Closed Facebook Discussion Group**

**Lambert Eaton**  
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Please follow the link and join

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[www.facebook.com/groups/602254133711587/](https://www.facebook.com/groups/602254133711587/)

# MEMBERSHIP SUBSCRIPTION RENEWAL

It's that time of the year again, when Membership Subscriptions for the financial year 2020/2021 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 6/20 which tells you (and us) that you are financial to 30 June 2020. Others may show 6/21 or even 6/22 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.

**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 Myasthenic \$20**

**(or) Category E – Supporter \$20**

ADDRESS \_\_\_\_\_

And for \_\_\_\_\_ **Category D – Carer \$10**

ADDRESS \_\_\_\_\_

Mobile \_\_\_\_\_ Email \_\_\_\_\_

## news from around Queensland

### News from Cairns

For local support in the Cairns region, please contact Donna on 0414 397 462 or [donnaformosa64@gmail.com](mailto:donnaformosa64@gmail.com).

### News from Townsville

For details contact Daphne on 0400 778 637 or [daphclay@gmail.com](mailto:daphclay@gmail.com)

### News from Mackay

For more information, please contact Muriel on (07) 4954 1221.

### 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 or (07) 4973 7983.

### News from the Sunshine Coast

On Friday, 10 July, our group met for the first time since late February. Our usual venue, Kawana Bowls is again open so I thought it was time we all came out from 'under the doona'. We had a lovely lunch catching up and special thanks to Donna and Anita from the Committee for attending. For more information about the Sunshine Coast group, call Colleen on 0409 491 789 or email [colleen4551@gmail.com](mailto:colleen4551@gmail.com)

### News from the Gold Coast

Hi Everyone. I hope you are all ok and coping well with Corona and Myasthenia.

MG Gold Coast group had their get together sharing experiences with other members on Saturday, 11 July at Southport Sharks Club.

Our next meeting will be at 10am, Saturday, 19 September at Kurrawa Surf Club in Broadbeach.

I hope to see all there. Kind regards

Please keep in mind that you can call me at anytime for a chat.

For more information on the Gold Coast group, please contact Nader on 0415 834 401.



## Brisbane - Coffee & Chats are back!

Anita - 0414 588 312

Ipswich - Saturday 1st August @ 10.00am - Queens Park Cafe,  
10a Merle Finimore Ave



## Myasthenia Gravis Friends Western Australia

Come and join us for a Coffee & Chat

**SUNDAY, 9 AUGUST @ 1.30PM - ROSSMOYNE**

Rossmoyne Waters (Pelican Room) 26 Freeman Drive

Please RSVP in Facebook group comments or call 1800 802 568 and Susan will give you the phone contact.

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[www.facebook.com/groups/mgqld/](https://www.facebook.com/groups/mgqld/)