



# Messages

MYASTHENIA GRAVIS ASSOCIATION OF QUEENSLAND INC.

**AUGUST 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

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

Ron STEPHEN

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

#### Treasurer

Denise HANNAY

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

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Anita JACKSON

Donna FORMOSA

Rosalyn HOLLAND

Ian HOLLINGWORTH

Kirstine SHRUBSOLE

Karen DOWNES

#### Newsletter Editor

Greg BREADEN

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

#### PATRON

Dr Cecillie LANDER

Neurologist

Founder Member, of Brisbane

## PRESIDENT'S REPORT

What unusual and disturbing times in which we are now living. Unfortunately, it takes everyone to do the right thing in order to stop the spread of this pandemic. We feel for all people with Myasthenia and their families, but particularly those in Victoria and parts of New South Wales who are in lockdown.

I would again remind members who receive the newsletter directly from the Association via hard-copy or by email that, if you have not yet renewed your membership, please do so before **30 September** if you wish to continue receiving your copy of the newsletter directly as well as being able to access other information produced by the association. If you are not sure of your membership status, please email to [info@mgaq.org.au](mailto:info@mgaq.org.au) or contact our **1800 802 568 support line**. Our association needs to make a concerted effort to attract all people who are eligible to be members to do so as members who are not financial cannot gain access via the website to all publications, videos etc. that are produced for those who pay their yearly membership.

Our AGM usually provides us with a wonderful opportunity to meet other members as well as formalise the work of the association for the year. Following the AGM there is a short meeting to confirm our Annual Operational Plan and membership fees.

**The Annual General Meeting is on Sunday, 13 September, commencing at 10.15am sharp.**

**The venue is Aspley Hornets Football Club, 50 Graham Road, Carseldine.**

**Anyone who is attending, either IN PERSON or via ZOOM, MUST REGISTER PRIOR TO THE EVENT.**

**Please either phone 1800 802 568 or email [info@mgaq.org.au](mailto:info@mgaq.org.au) before 9 September.**

The club has assured us that they can cater for the numbers with safe social distancing.

A focus in my report at the AGM will be the need for 'helpers' for the management committee. We are not asking people to be on the committee and have to attend meetings but rather offer to help with projects in which they may have an interest or ones that they think they can do to support the ongoing operations of the MGAQ. The number of high-level projects and activities in which we are now involved is very time consuming and thus many of the ongoing established practices are taking time away from the innovative, progressive priorities we are endeavouring to achieve to help our members. Everything we do must be positive for the myasthenia community.

Stay safe well and we hope to be able to meet some members at the AGM.

**Cheers, Carol**

**Supported by**



**Queensland Government**

**Ausenco**

**MYASTHENIA ALLIANCE AUSTRALIA NEWS****MAA UPDATE****The eNID project - What is it? Where are we at?**

There has been steady conversation about the eNID project for four years now so I imagine that many are now a little lost in regard to the details.

eNID stands for "electronic Neuro-Immunology Database". It is a way for the Specialist Doctors to gather detailed and progressive information about a patient's history when managing this chronic condition over many years. The combined database has the potential to explore treatment and disease trends using de-identified information. As myasthenia is a rare disease and the number of patients each Neurologist may see during their working lives can be small, utilising modern technology allows them greatest access to information.

Multiple Sclerosis patients are familiar with this programme and it is because of this that the Myasthenia community have been offered the opportunity to access this technology also. Financially, this offer has been a significant gift to our small cohort. MSBase, a Melbourne based not-for-profit organisation have developed the technology to manage the large volumes of data involved. Thanks to engagement with MS-Base by our leading Specialists, Dr. Katherine Buzzard, Assoc. Prof. Stephen Reddel and Dr. Stefan Blum, and with support from the Myasthenia community, a unique platform has been created within MSBase for people with Myasthenia. The complexity of operating this database and then incorporating a second condition should not be underestimated and the challenges have resulted in time delays. To make this data most valuable, information is to be collected extensively. For MS patients, this means worldwide participation. For myasthenia, the focus is initially on the Australian and New Zealand patient base.

There has been great excitement over the past months as Dr Buzzard and Dr Reddel have allocated a significant amount of their time to getting the 'coding' underway and fine tuned. IE - what are the critical questions; how are the trends displayed; how does the technology handle these requirements. The project is now ready for testing in the clinics and this is happening at a selection of sites. It is hoped that a wider uptake will occur after a launch around October this year. Neurologists wishing to participate will need to make application and seek the necessary ethics approval but Dr Buzzard is hoping that 500 patients will be registered by the end of the year. The MAA will keep you informed regarding progress at each step. We are very confident that this new technology will support best practice medicine for people with Myasthenia and be able to support discussions with government in regard to care plans for our community.

**Suffering in Silence! [www.cslbehring.com/suffering\\_in\\_silence](http://www.cslbehring.com/suffering_in_silence)**

The Economist Intelligence magazine conducted a survey across the Asia Pacific region to better understand care for people with rare diseases. It was sponsored by CSL and reported on in a webinar discussion with key speakers from Australia, Singapore and Hong Kong. A White Paper was subsequently produced. Accessing this discussion has proved very insightful for the MAA Board. The data showed how challenging it is to recognise and comprehensively treat rare diseases. Government approaches vary greatly though there is an appetite to find solutions and provide improved coordinated care. The significant role of support organisations in bringing forward best practice policies and services was clear. It will be patient based discussion which will bring awareness, education and care plans. For the MAA to be most effective, we will need to build strong relationships with all parties who offer our community care and governing policy. Communicating effectively will be critical and having meaningful data will be an important part in these conversations. The MAA are keenly exploring the ways in which data can be effectively and efficiently gathered. This will occur in a range of methods and will include surveys completed by the Doctors and also by the patients. Partnering by as many people diagnosed with MG as possible will bring the greatest results for us all.

**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.
- **Episode 6: ACHR Positive, Generalised & Thymectomy** - This podcast includes a conversation with a ACHR positive MG sufferer who 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.

### New podcasts scheduled for release on the dates noted below, includes:

- **19 August 2020:** 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.
- **2nd September 2020:** MGAQ Podcasts will present the fourth '**Ask the Expert**' podcast. Originally presented as a Zoom Presentation and now available through this podcast, this story discusses the MG journey of Dr Angelo Contarino or as he describes, his Metropolis Journey. Whilst not initially considered to have Myasthenia Gravis, Angelo was subsequently diagnosed as sero-negative which many years after was confirmed as sero-positive. The conversation covers the challenges of Angelo's journey including the changes in medication, his conventional thymectomy, the impacts on his life and how he managed these difficulties.
- **2nd September 2020:** MGAQ Podcasts includes as a standalone podcast, the Question and Answer session following Dr Angelo Contarino's '**My Journey with Myasthenia**' discussion.

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



## Mango Hill Coffee and Chat



On Tuesday 14th July, we met at the Coffee Club at Mango Hill Market Place. Great catch up with good coffee and also very glad to welcome our new members. Had many laughs so was good to get rid of the cobwebs from ISO. Looking forward to our next catch up.

## IPSWICH COFFEE AND CHAT

On Saturday 1 August, we met at the Queens Park Cafe in Ipswich. Great catch up with good coffee and cake even though we all live in a Hotspot and we ventured out and practised our distancing. Many laughs were had as well as discussions and we farewelled Vicki as she is moving to Mooloolaba. Looking forward to our next catch up.

**For more information about the Coffee and Chats in Brisbane, call Anita on 0414 588 312.**

## Seeking people with Myasthenia Gravis for research

**LAST CHANCE!**  
**CLOSING AUGUST 22**

**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.*

## Welcome to our new members



Leanne, Werombi NSW  
Robert, Mindarie WA  
Monique, Thornlands QLD  
Kenneth, Lindisfarne TAS  
Christine, Lindisfarne TAS  
Katherine, Noosaville QLD  
Carolyn, Beecher QLD



## your online discussion forums



### MGAQ DISCUSSION FORUM

Administered by the MGAQ

**Freecall 1800 802 568**

Please follow the link and join

MGAQ Discussion Forum at

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



### 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](http://www.facebook.com/groups/284865318818756)



### 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)



### LAMBERT EATON LEMonS AUSTRALIA

Administered by the MGAQ

**Freecall 1800 802 568**

Please follow the link and join

Lambert Eaton LEMonS Australia at

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



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

## 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

Looking forward to our next lunch gathering at The Avenues Hotel, Kirwan on Saturday, 22 September at 12 noon. **Covid-19 rules apply.** To RSVP, 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

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

Our next meeting will be at 10am, Saturday, 19 September at Kurrawa Surf Club in Broadbeach. Of course, should there be any changes due to Covid-19 restrictions I will be in touch with our members by email/SMS. **For anyone else that is not sure, please contact Freecall 1800 802 568.** Please keep in mind that you can call me at anytime for a chat. Kind regards, Nader 0415 834 401.



### WHERE IN QUEENSLAND?

Last month:

**Majestic Theatre, Pomona**

Let us know where you think it is:

Send to: [info@mgaq.org.au](mailto:info@mgaq.org.au)  
or post to MGAQ, PO Box 16,  
Mt Gravatt, Qld, 4122



## Brisbane - Coffee & Chats

Cleveland - Thursday 17th September @ 10.30am

*Fiction Bar, 152 Shore Street West, RABY BAY*

Please contact Anita on 0414 588 312.

**RSVP is required to meet COVID-19 restrictions**

# 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

# AGENDA FOR THE ANNUAL GENERAL MEETING

of the



## MYASTHENIA GRAVIS ASSOCIATION OF QLD INC.

to be held on

**SUNDAY, 13 SEPTEMBER, 2020**

at the

**Aspley Hornets Football Club, 50 Graham Road, Carseldine**  
**10.00 am for 10.15 am sharp**

Lunch is available at the venue with a varied and reasonably priced menu.

Tea and coffee will be available prior to the meeting.

Everyone Welcome – **RSVP is essential to meet COVID-19 restrictions**

1. OPENING
2. APOLOGIES
3. CONFIRMATION OF QUORUM
4. MINUTES OF THE PREVIOUS AGM HELD AT SOUTHERN CROSS SPORTS CLUB ON 15 SEPTEMBER, 2019
5. BUSINESS ARISING FROM MINUTES
6. PRESIDENT'S ANNUAL REPORT
7. TREASURER'S REPORT
8. ELECTION OF MANAGEMENT COMMITTEE 2020/2021  
**NOMINATIONS:**  

PRESIDENT	Carol Buchanan
VICE PRESIDENT	Susan White
SECRETARY	Ron Stephen
TREASURER	Denise Hannay
COMMITTEE MEMBERS (6)	Donna Formosa, Rosalyn Holland; Ian Hollingworth; Anita Jackson; Kirstine Shrubsole; Karen Downes;
9. APPOINTMENT OF AUDITOR **Notice of Motion - Auditor:** That this meeting agrees to the appointment of BDO Australia Ltd as Auditors for the year 2020/21
10. GENERAL BUSINESS:  
**Notice of Motion- Bank Authority:** That the signatories for the Bank of Queensland accounts will be the President, Vice President, Treasurer and Secretary.  
**Notice of Motion – Annual Operational Plan:** That the membership accepts the Annual Operational Plan (AOP) as presented.
11. CLOSE

NOTE – the AGM will be followed by a short general meeting to confirm membership fees.

**RSVP is required to meet Covid-19 restrictions.**

Ring our FREECALL 1800 802 568 by Wednesday, 9 September 2020  
and tell Susan if you are attending in person or via zoom.



Myasthenia Gravis  
Association of  
Queensland Inc.

## 2020/2021 ANNUAL GENERAL MEETING

**Attend AGM either in Person or Via Zoom – Your choice!**

**Sunday, 13 September 2020**

**ASPLEY HORNET'S FOOTBALL CLUB,**

**50 GRAHAM ROAD, CARSELDINE**

**10.00AM FOR 10.15AM SHARP**

**As our Annual General Meeting will practise Social Distancing,**

**RSVP is essential by Wednesday, 9 September 2020.**

**FREECALL 1800 802 568 or EMAIL [info@mgaq.org.au](mailto:info@mgaq.org.au)**

**Guest Speaker:** Dr Kirstine Shrubsole, Speech Pathologist

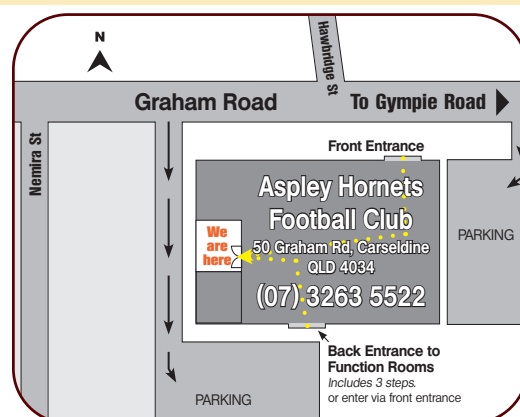
**Topic:** "Speech & Swallowing problems in Myasthenia Gravis: What we know and what we don't"

### DIRECTIONS:

Take Graham Road directly off Gympie Road (M3 and A3 access).

Hornet's Club venue located south side of Graham Road.

Suitable for access via the Gateway.



### Join AGM Zoom Meeting

<https://zoom.us/j/92085121972?pwd=Y0lVZDIBSCtNOXQ5Z3hiM3lxcWpGUT09>

**Meeting ID: 920 8512 1972**

**Password: mgaq2020**



***Need help? Instructions can be emailed on downloading zoom or joining the zoom meeting***

**Ring our FREECALL 1800 802 568 or EMAIL: [info@mgaq.org.au](mailto:info@mgaq.org.au)**

**by Wednesday, 9 September 2020 and tell Susan if you are attending in person or via zoom or if you need help.**