



## Myasthenia Gravis Association of Queensland Inc

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### COMMITTEE MEMBERS

#### President

Carol BUCHANAN

#### Vice-President

Susan WHITE

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#### Treasurer

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Donna FORMOSA

Rosalyn HOLLAND

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#### PATRON

Dr Cecilie LANDER

Neurologist

Founder Member, of Brisbane

# Messages

MYASTHENIA GRAVIS ASSOCIATION OF QUEENSLAND INC.

**AUGUST 2019**

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

The third Myasthenia Alliance Australia (MAA) Conference held in Brisbane last weekend was absolutely fabulous. The quality of the speakers' presentations was excellent and the feedback from the break-out groups was overwhelmingly positive. It was wonderful to see the new friendships being made and the terrific discussions being held. A big thank you to the myriad of people who devoted an enormous amount of time and effort to making this conference such a success.

Do not forget the **Annual General Meeting on Sunday, 15 September, commencing at 10.15am sharp. Please also note the venue is Aspley Hornets Football Club, 50 Graham Road, Carseldine.** Following the AGM there will be a short meeting to confirm our Annual Operational Plan and membership fees.

Our AGM provides us with a wonderful opportunity to share conference information and experiences. Management committee members who attended our conference will lead discussions in small groups, sharing information about the guest speakers and some of the break-out sessions. We welcome all other conference participants to be involved by contributing to these discussions.

I would again remind members who receive the newsletter directly from the Association via hard-copy or 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 and 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 now cannot gain access via the website to all publications, videos etc that are produced for those who pay their yearly membership.

### **The association really needs both a Secretary and a Minutes Secretary.**

The role of the **SECRETARY** would evolve as the person becomes familiar with the operations and responsibilities of the association. If someone is prepared to take on this role, there will be plenty of support and the number of 'jobs' to be done will be handed over slowly so that the person can get their head around one responsibility before being faced with others. **Please see page 3 for further details.**

A second person, the **MINUTES SECRETARY**, would involve attending (or teleconferencing) the eleven meetings each year and ensuring that the minutes and agenda are prepared and distributed in a timely manner. **Please see page 3 for further details.**

Another 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. Everything we do must have a positive for the myasthenia community.

*Thanks, Carol*

**Supported by**



**Queensland Government**

**Ausenco**

## MYASTHENIA ALLIANCE AUSTRALIA NEWS



### Conference 2019 - Wrap Up.

After months of planning, the Conference was a huge success! Such a lot of energy and conversation went into reaching out across Australia with New Zealand captured

as well. The result was **147 registrations** and **full capacity for our volunteer team**. The room looked great, the energy reverberated and the presentations came quickly. It was a very special day for people with a rare disease to come together and realise that they were not alone. Much learning, sharing and connecting happened, although another several hours would have been useful - if only anyone would have had the stamina!!

Feedback from the day reflected the warmth and generosity offered by this **amazing group of Specialists** who shared their knowledge and compassion. Conversation from these Doctors included helping us to understand how Rituximab works, why there is a tightening guideline to IVIg prescriptions and why patients should not be fearful, what is Therapeutic Plasma Exchange and can it be a possible option for some patients. New therapies were hinted at and included subcutaneous IVIg for home administration, bone marrow transplant in Myasthenia and gene therapy research. All these are a way off for now, but it was reassuring to think of possibilities for the future.

**Stephen Reddel** reported that the **eNID project** will progress and VIC, NSW and QLD will participate in the initial trials. The generous financial contribution from the MG Community was recognised and was clearly a determinant in the project progressing. He spoke of the importance of **growing the MAA and the State Associations**. Gathering data is critical to progress. The Queensland Patient Survey has again been analysed and its value is clear. This project is on-going and people were recruited on the day.

**Nicole Millis, CEO of Rare Voices** and key speaker, was described as an 'inspirational person'. She gave of her time to attend, to listen, to encourage and to provide solutions around how challenging objectives involving government policy change can be pursued. The MAA and MGAQ felt the **strength of the partnership they share with Rare Voices**.

The Presenters all received their **gift bags from Enjo**. It was wonderful when Dr James Morton, leading Haematologist, swung his bag high and announced that **"my wife loves this stuff"**! He congratulated us on this thoughtful gift.

Our young, vibrant Physiotherapists from UQ were on hand to firstly explain why we must **keep moving and maintain as much fitness as possible** to avoid many secondary conditions. Kristen from the Body Refinery then developed the conversation showing

us how this can be achieved via a **rehabilitation programme with a physiotherapist**. Interestingly, when attendees gathered at the break out session were quizzed, no one in the room had ever participated in such a programme. Naturally she urged people to seek out this on-going support.

The Conference bag had some great gifts in it. Anita, MGAQ Committee member, lovingly made **150 hand sown teal lapel ribbons** to be worn for Myasthenia Awareness. An exclusive MAA pen and a handy key chain in teal with Myasthenia Gravis on it kept the surprises coming. A special highlight was a new **'Drugs to be Used with Caution' flyer** which reached the printing presses just days before the conference. Our sincere thanks to Dr Blum for making this happen. Its value was discussed during a break out session, but more information on this will follow.

**Dr Cecilie Lander, MGAQ Patron**, was on hand from 8am until pack-up to support the day. Her assistance and good cheer was fabulous. **Grace Grace, Qld State Education Minister**, provided her encouragement via a welcoming note highlighting the value of being informed and of learning.

Exciting support for the work of the MAA came from various attendees on the day. These conversations will be followed up over the coming weeks. Many **ideas flowed** regarding what more can be done.

People with the more unusual forms or experiences of Myasthenia were connected on the day. It is keenly hoped that these conversations can be supported and progressed to develop into more meaningful outcomes.

Some great questions came from the audience and it was very pleasing to see a focus on good nutrition and a healthy gut. **Prof McCombe was clear that ALL junk food is out!** This is an area that the MAA/MGAQ is keen to explore further.

Let's not forget the **bubbly team of Greeters!** This chirpy group of five fellows gathered people up as they wandered into the main hospital entrance and delivered them safely to the registration desk. No extra charge was made for the happy banter included with the walk through.

Susan's crazy crooked balloons! I took some teasing over these. The MAA letters atop the tall columns never ended up sitting straight - oh well!

Sincere thanks to all who supported this day. The volunteers gave so much and the attendees put in a big effort to share in the day. **Everyone did their best and made the day such a success.**

Do enjoy the photos which follow.

**Susan White, MAA President**





## Myasthenia Alliance Australia – Conference 2019 Conference Wrap-Up



• Dr Cecilie Lander, Carol Buchanan and Susan White.



• Assoc. Prof. Stephen Reddel and Lara from Enjo.



• Question Time with the Panel of Experts.



• Dr Stefan Blum with a conference attendee.

### URGENT – POSITION VACANT ON EXECUTIVE.



Legislatively, we **MUST** have a secretary for the association. This person does not have to be highly skilled as the hand-over of responsibilities will be staggered with much support from other committee members. We are looking for someone who is prepared to accept responsibility, meet required timelines and is prepared to communicate in a timely manner with other members of the committee via phone calls and email.

**Please phone 1800 802 568 or [info@mgaq.org.au](mailto:info@mgaq.org.au) as soon as possible if interested.**

### MINUTES SECRETARY URGENTLY NEEDED.



The job would entail attending the meeting, writing and distributing the minutes, emailing people to remind them of their commitments from the previous meeting and that they need to write and distribute their reports for the next month's meeting.

Then, prepare and distribute the agenda for the next meeting.

**To register your interest, contact**

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





• Enjoying lunch Queensland style.



• MAA team of Greeters.



# Positions Available

## To support the MGAQ Organisation

**Meeting Host** - Make a home available to host up to 11 attendees at monthly committee meetings. Meetings held every 2nd Saturday of the month (except January) from 8.30am-3.30pm. Requirements include 35 minute access to airport, landline facility (no significant costs), reasonable parking access. Not necessarily a Committee person. Back-up venues available if needed.

**Additional Committee Members** to come on board, learn about the Association, offer support as suitable and then find their particular point of interest. Commitment requires email participation and availability in person or via teleconference every 2nd Saturday of the month (except January) commencing at 9.00am. Attendance at most but not all meetings is required.

To register your interest or find out more, contact:

**Freecall:**

**1800 802 568**

**Email:**

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



# Myasthenia Gravis Association of Qld Inc.

## LENDING LIBRARY

The committee has established a lending library of MG and related information resources. The collection is small, but is expanding over time.

Loans of material are available to financial members of the Association and the loan period is 1 calendar month. Postage out is paid by MGAQ and return postage is the responsibility of the member.

**To request a loan, please contact John on (07) 3293 4655 or Email: [jam3740@bigpond.com](mailto:jam3740@bigpond.com)**

### BOOKS IN LIBRARY

#### Attacking Myasthenia Gravis

Ronald E Henderson MD – *Easy Reading*

#### Living a Healthy Life with Chronic Conditions

#### Myasthenia Gravis & Myasthenic Disorders

Collection of Medical Papers –

*Very Technical*

#### Rare Voices the Australian Experience of Living a Rare Disease

Megan Fookes ex-Director

“Rare Voices Aust” – *Personal stories*

#### Journey with Myasthenia Gravis

Sarah-Jane Fleer Produced by MGAQ – *Personal stories*

#### Depression the Way Out

Neil Nedley MD – *Easy*

#### I Dropped my Chicken Soup

Rebeka Huggins Stories about Multiple Sclerosis – *Easy*

#### Living Well with Autoimmune disease

Mary J Shomon – *Easy*

#### Myasthenia Gravis “Manual for the Nurse”

USA National MG Foundation –  
*Some-what Technical*

#### Beyond Blue National Depression Initiative

Stories of Hope and Recovery  
(DVD - Vol 1 / Vol 2)

### A SELECTION OF DVDs IN LIBRARY - **More titles available**

Katrina Williams

**MG. Physiotherapy and Exercise.**

Dr Jean Foster

**MG. Getting the Most out of Your Doctor.**

Rebecca Elkington

**MG. Information on Good Nutrition.**

Dr C M Lander

**MGAQ 20th Anniversary Guest Speaker.**

Ms Justine Joppich

**Commonwealth Dept Human Services, Centrelink Benefits.**

Dr Jennifer Nitz

**Preliminary Report MG Pilot Exercise Effect.**

Dr Stefan Blum

**Some Interesting Results from the MG Survey.**

Dr Sharon Pandey

**Health in Retirement.**

Prof Cindy Gallois

**Living with Chronic Illness.**

Dr Rob Henderson

**Thymoma other Information on MG.**

Nicole Millis

**“Rare voices Aust” What it is and how it can help MG.**

Prof Cindy Gallois

**Communicating with health professionals, strangers & friends.**

Judy Burrows

**Importance of Getting to Know Your Pharmacist.**

Zoe, Winner of the Kath Ross Memorial

Scholarship

**“On Her Journey with MG”.**

A/Prof Stephen Reddel

**The Many Myasthenias.**

Katerina Williams

**MG Therapeutic Exercise for Life.**



The Committee has, with the guidance from a solicitor, developed new Rules (Constitution) for the MGAQ.

People with an email address will receive one that way.

People who receive the newsletter by mail should contact **Freecall 1800 802 568** and request one if they want to peruse it.

This document will be presented for adoption at the AGM.



## NEWS FROM AROUND QUEENSLAND

### News from Cairns

We will meet again on **Saturday, 21 September** and **Saturday, 7 December** at the **Cairns RSL Club, Esplanade** at **11.00am**. If you are visiting Cairns, you are most welcome to join us. For more information, please contact Donna on 0414 397 462.

### News from Townsville

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

### News from Mackay

For information for the Mackay region, please contact Muriel on (07) 4954 1221.

### News from Gladstone – Wide Bay Region

For local support in the Gladstone – Wide Bay region, call Garth on 0408 155 954 or (07) 973 7983.

### Hervey Bay – Wide Bay Burnett Region

Coffee & Chats are a good opportunity to connect with people in your area. All are welcome.



**Tuesday, 17 September at 10.30 am**

**Coffee Club, Stocklands, 6 Central Avenue, Pialba**

Contact Donna 0414 397 462

### 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 MG meeting will be on **Saturday, 24 August**, in **Kurrawa Surf Club** in **Broadbeach**. I will miss seeing you all due to overseas travel but our member Angela Brosnan (0427 752 956) will be there to greet you. I look forward to seeing you all again in the following meeting get together on **26 October** in **Southport Sharks Club**. Cheers Nader GC coordinator 0415 834 401.

### News From Brisbane

Coffee & Chats are a good opportunity to connect with people in your area. All are welcome.



**Cleveland Sunday, 22 September at 2pm**

**Fiction Bar, 152 Shore Street West, Raby Bay**

**Nundah Sunday, 13 October at 3pm**

**The Royal Hotel, 1259 Sandgate Road**

**Ipswich Friday, 25 October at 10am**

**Queens Park Café, 10A Merle Finimore Avenue**

**Burpengary Sunday, 10 November at 2pm**

**The Coffee Club, 164-166 Station Road**

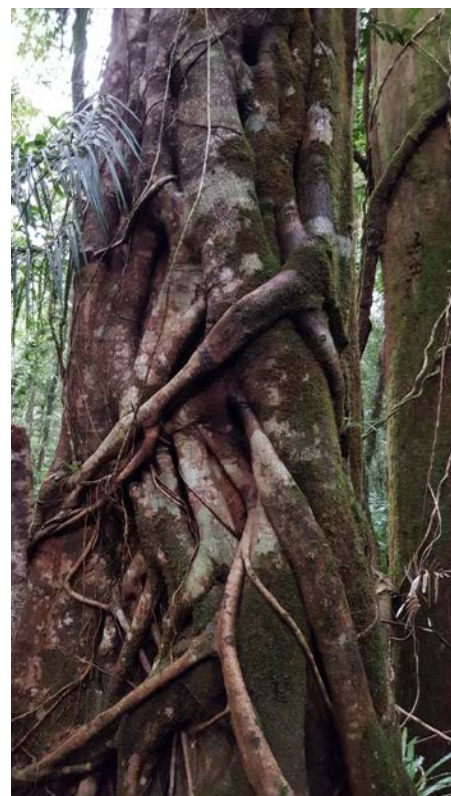
For more information, Contact Anita on 0414 588 312

### WHERE IN QUEENSLAND?

Let us know where you think it is:

### July Edition: Weipa

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



## Welcome to our new members

Kirstine  
Lota  
Queensland

Terry  
Newtown  
Queensland

# AGENDA FOR THE ANNUAL GENERAL MEETING

of the



## MYASTHENIA GRAVIS ASSOCIATION OF QLD INC.

to be held on

**SUNDAY, 15 SEPTEMBER, 2019**

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.

*Bring yourself and whomever else you wish to bring along – the more the merrier*

1. **OPENING**
2. **APOLOGIES**
3. **CONFIRMATION OF QUORUM**
4. **MINUTES OF THE PREVIOUS AGM HELD AT SOUTHERN CROSS SPORTS CLUB ON 9 SEPTEMBER, 2018**
5. **BUSINESS ARISING FROM MINUTES**
6. **PRESIDENT'S ANNUAL REPORT**
7. **TREASURER'S REPORT**
8. **ELECTION OF MANAGEMENT COMMITTEE 2019/20**  
**NOMINATIONS:**  
 PRESIDENT Carol Buchanan  
 VICE PRESIDENT Susan White  
 SECRETARY  
 TREASURER Denise Hannay  
 COMMITTEE MEMBERS (5) Ian Hollingworth, Anita Jackson, Rosalyn Holland, Donna Formosa, Dee De-Almieda
9. **APPOINTMENT OF AUDITOR** *Notice of Motion* - That this meeting agrees to the appointment of BDO Australia Ltd as Auditors for the year 2019/20
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 - Rules (Constitution) of the MGAQ:* That the membership accepts the updated Rules of the MGAQ which were completed under the guidance of a solicitor and meet the Australian Charities and Not-for-Profit Commission guidelines.
12. **MAA 2019 MYASTHENIA GRAVIS CONFERENCE RECAP:**  
 Susan White will give an overview of the Conference, followed by Q&A in discussion groups.
13. **CLOSE**

NOTE – the AGM will be followed by a short general meeting to present the Association's Annual Operational Plan 2019-2020

**RSVP - Ring our FREECALL 1800 802 568 and tell Susan if you are coming, how many and if you are staying for lunch. Please let Susan know by Monday, 9 September, 2019**



## Myasthenia Gravis Association of Queensland Inc.

# 2019/2020 ANNUAL GENERAL MEETING

**When** **Sunday, 15 September**  
**10.00am for 10.15am sharp**

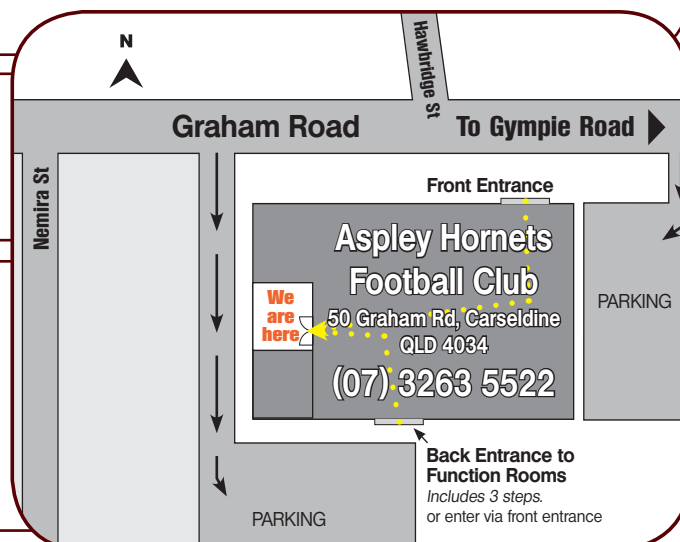
**Where** **Aspley Hornets Football Club,**  
**50 Graham Road, Carseldine**  
Lunch is available at the venue with a varied and reasonably priced menu.  
Tea and coffee will be available prior to the meeting.

**Conference Recap** **2019 Myasthenia Alliance Australia (MAA)  
National Myasthenia Conference**

Susan White will give an overview of the Conference, followed by Q&A in round-robin discussion groups.

**What do I need to bring** Yourself and whomever else you wish to bring along – the more the merrier.

**How do I get there** 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.



**RSVP** Ring our **FREECALL 1800 802 568** and let Susan know numbers attending and if you are staying for lunch.  
**Please RSVP by Monday, 9 September 2019.**  
Also call if you require help with transport.