



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

Internet: www.mgaq.org.au

COMMITTEE MEMBERS

President

CAROL BUCHANAN

Vice-President

SUSAN WHITE

Secretary

RON STEPHEN

E: info@mgaq.org.au

Treasurer

DENISE HANNAY

E: treasurer@mgaq.org.au

Committee

ANITA JACKSON

DONNA FORMOSA

ROSALYN HOLLAND

IAN HOLLINGWORTH

KIRSTINE SHRUBSOLE

KAREN DOWNES

Newsletter Editor

GREG BREADEN

E: MGAQ.editor@gmail.com

PATRON

DR CECILIE LANDER

Neurologist

Founder Member, of Brisbane

Messages

Myasthenia Gravis Association Of Queensland Inc.

AUGUST 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

It takes everyone to do the right thing in order to stop the spread of this pandemic which, unfortunately, will probably be a part of our lives well into the future. The MGAQ feels for all people with Myasthenia and their families and hope that everyone stays well, even if it means staying at home, not visiting family, etc.

I 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 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 Annual General Meeting is on Sunday, 12 September, commencing at 10.00am sharp. The venue is Aspley Hornets Football Club, 50 Graham Road, Carseldine. WE ARE STILL LOOKING FOR PEOPLE TO NOMINATE TO BE A MEMBER OF THE MANAGEMENT COMMITTEE SO THAT WE HAVE A FULL COMPLEMENT OF PEOPLE ON THE COMMITTEE. WE WILL ALSO

ACCEPT NOMINATIONS FROM THE MEETING ON THE DAY. The committee ensures that all people are comfortable with any projects in which they are involved and allow time for people to get to know the workings of the committee.

ANYONE WHO IS ATTENDING THE AGM, EITHER IN PERSON OR VIA ZOOM, MUST REGISTER PRIOR TO THE EVENT. Please either phone 1800 802 568 or email info@mgaq.org.au before 08 September. The club has managed the Covid restrictions well every time we have used that venue. However, remember that, with the current lockdowns in Brisbane and environs, the meeting may be held by Zoom only.

Our guest speaker after the AGM is Dr Reuben Beer who will speak about 'Recent Developments in Treating Myasthenia Gravis'. Dr Beer's areas of interest include general neurology, multiple sclerosis, headache and migraine, myasthenia gravis, and immune mediated neurological disorders. We certainly look forward to his presentation. If the meeting is by Zoom his presentation will still go ahead

A focus for the MGAQ is 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.

Thanks, Carol

Supported by



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

MYASTHENIA ALLIANCE AUSTRALIA NEWS



MAA UPDATE

I am so excited to share with you that the On-Line Survey Project has made significant progress in the past month. The survey is drafted, the technology is ready for testing, the advertising materials have been prepared and the ethics application has been submitted. *Now we wait!*

Please - don't stop reading don't disengage don't think this isn't for youdon't think that you won't have time!

The team behind this project is very skilled and very experienced. This opportunity to define the impact of our treatment options is important to the MG community in so many ways and information from the project will flow quickly.

I CAN HEAR PEOPLE SAYING

- I don't do technology so this is not for me
- I am tired of taking on-line surveys
- I am too busy
- I am too old to be bothered.

Our community needs everyone to participate. We do not want any demographic or any situation missed. Every individual history is important. Our community will benefit. Let's help ourselves and those coming after us.

For people who don't have access to technology or find it tiring, it is time to ask for help. Maybe a family member can assist, perhaps taking a cake into a neighbour would do it, local libraries can help, for some people their health care workers make things happen or there may be an "MG buddy" at the end of a phone waiting to help out. We need to work as a community on this project. The MAA is a partner in this project and this means that our MG Community has an obligation to make this a success.

More information will follow once approval has been finalised. **Please do make contact on 1800 802 568 or info@mgaq.org.au** if you have ideas for supporting others who may have difficulty contributing.

Susan White, Chairperson

Follow the work of the Alliance by registering at the website www.myastheniaalliance.org.au

ANNUAL GENERAL MEETING GUEST SPEAKER

SPEAKER: Dr Reuben Beer (BPharm, MBBS, FRACP)

TOPIC: ***Recent Developments in Treating Myasthenia Gravis***

Dr Reuben Beer (BPharm, MBBS, FRACP) is a consultant neurologist at the Mater Hospital in Brisbane, Australia. Dr Beer completed a fellowship in multiple sclerosis and neuroimmunology at the Princess Alexandra Hospital and the Mater. He was a qualified pharmacist prior to completing his postgraduate degree in medicine at the University of Queensland. Dr Beer completed specialist neurology training in southeast Queensland.

Dr Beer is currently undertaking a PhD examining advanced imaging characteristics in multiple sclerosis. He has published several peer-reviewed scientific articles on myasthenia gravis and antibody mediated neurological disorders. He has also presented research at national and international neurological conferences.

Dr Beer's areas of interest include general neurology, multiple sclerosis, headache and migraine, myasthenia gravis, and immune mediated neurological disorders.

AGM and Zoom Meeting details Pages 7 & 8

SUPPORT your Association by taking **MEMBERSHIP.**



MGAQ Inc. podcast series

UPDATE

Greetings All

The podcast team has been very lucky in having as a guest Dr Andrew Kornberg. Dr Kornberg is a Paediatric Neurologist and is the Director of both Neurology at Royal Children's Hospital Melbourne (RCH) and the National Muscular Dystrophy Centre at the Howard Florey Institute. Andrew has major clinical and laboratory research interests in immune-mediated neurological syndromes. He gave us his insight into the diagnosis and treatment considerations of children with myasthenia gravis. He also spoke on the special recommendations he gives parents who are making very complicated decisions and managing issues such as schooling. Please keep a lookout on your podcast access point for Dr. Kornberg's podcast.

The latest Monthly Newsletter continues to roll out for our listeners. We do hope you are enjoying them. Remember you can access any or all of the previous podcasts directly from the email or should you not wish to receive further podcast emails, then you can also unsubscribe directly from there.



WE NEED YOU!

The Podcast team require your help

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, please email podcast@mgaq.org.au.

Remember, if you would like to be added to the MGAQ Podcast Subscriber List, simply email me, Dr Podcast, at the following address podcast@mgaq.org.au and just say "Add me to the Subscriber List". That's all any member needs to do and when we publish each new podcast, you'll get an email.

We wish all our listeners safe and well in Lockdown Times.



Welcome to our new members

Gloria,
Killarney, Qld

Robert,
Chevron Island, Qld

Maria,
Murrumbeena Vic

Marina,
Murrumbeena Vic



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.

Acknowledging their strength and resilience helps me

My father-in-law Sam lived to be 87 years old, but for his strength and resilience he would not have made it that far. Sam was a prisoner of war, captured by the Japanese in Singapore in 1942 and taken to Burma. Along with thousands of fellow Aussies, he worked on the railway for three and a half years. Some worked to their death. Sam however, made it home.

Many years later, dealing with his demons, Sam and his wife Betty wrote and published his story. The book became an incredible gift to the family. Like many young soldiers who went off to war in the early 1900s, Sam had no idea what he would have to call upon to survive. Reading about the trauma that they all endured, always brings me to tears, but it also shows the incredible stamina of the human spirit that is revealed in adversity. In order to survive Sam would concentrate only on what was in front of him at that moment, and that would get him through that day. And then he would do it again the next day. A powerful lesson.

We all have family stories of survival through adversity. We can reflect on them, and the difficult times in the past, for inspiration. Our ancestors did the hard yards. They made the tough decisions and they made it through. If they could do it, I certainly can. We all can. In acknowledging their strength and resilience, we recognise that we share in these qualities and can bring them to our current experience.

Many times, during my ten-year journey with Myasthenia Gravis, I have depended on this attitude. Each day is different on this journey. Some days I am more able than others. Some days I decide to take a step back and rest so I can go again the next day but resilience, stamina, and constancy help me focus on day-to-day tasks, one step at a time. If I look at the whole task, I can feel overwhelmed, by taking one step at a time the task can be completed.

Our lives always deliver challenges but I know I can draw on the strength I have gained from my family's stories and my personal experiences to cope with whatever may come along. Whether it be surviving the worst bushfire season in living memory, living with Covid 19 and the unparalleled alteration to our way of life, or dealing with the day-to-day challenges of a chronic disease, in drawing on this knowledge, I not only survive, I thrive; and in doing so, help my loved ones recognise that they can too.

Helen T

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.



MURIEL'S DID YOU KNOWs?

- The Australian Thorny Devil is one of the longest-lived lizards of its size in the world, with a lifespan of up to 20 years
- The Kangaroo and Emu were chosen to be the two animals on the Australian Coat of Arms because they can't walk backwards, reflecting a forward-thinking culture
- 17 of the world's most poisonous snakes can be found in Australia
- Australia is home to around 1,500 types of spiders, 4,000 types of ants and 350 types of termites

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

RSVP ARE 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 **POSTPONED** at the Cairns RSL Club Boardroom, Esplanade. If you are visiting Cairns, you are most welcome to join us. For more information, please contact Donna on 0414 397 462 or donnaformosa64@gmail.com

News from Townsville

Townsville MG lunch dates for 2021. Saturday, 2 October, Saturday, 4 December at The Avenues Hotel, 70 Kern Brothers Drive, Kirwan commencing at 12.00 noon. All Welcome. If you can come, please RSVP Daphne on 0400 778 637 or daphclay@gmail.com

News from Mackay

Thank you to Muriel for organising our social lunches prior to COVID-19. Interested people in the Mackay district are invited to attend our next get-together lunch on **Sunday, 12 September**. We are hoping that we can join in on the MGAQ AGM "Zoom" session and are therefore looking for a suitable venue. For more details, please call Mary on 4959 5251.

News from Bundaberg

For more information, please contact Denise on 0431 571 399

News from Hervey Bay – Wide Bay Burnett Region

For more information, please contact Jan on 0429 622 438 or janpowell3@bigpond.com

News from Gladstone – Wide Bay Region

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

News from the Sunshine Coast

For more information please contact Vicki on 0411 146 898 or email avplummer@gmail.com

News from the Gold Coast

Our next get-together is **18 September at Kurrawa Surf Club**. For more information, contact Nader Amiri, Gold Coast Co-ordinator, 0415 834 401.

Brisbane - Coffee & Chats



CALAMVALE – Coffee Club, 668 Compton Road, Calamvale – Wednesday 25th August @ 10.30am

BANYO – Putia Pure Food Kitchen, 4/17 Royal Parade, Banyo – Thursday 26th August @ 10.30am

IPSWICH – Queens Park Café, 10a Merle Finimore Avenue, Ipswich – Saturday 4th September @ 10.30am

MANGO HILL – Coffee Club, Cnr Anzac Avenue & Halpine Drive, Mango Hill – Thursday 16th September @ 10.30am

Please contact Anita on 0414 588 312.

what's coming up

What's On	When Is It	Where Is It?
AGM AND GUEST SPEAKER DR REUBEN BEER	SUNDAY, 12 SEPTEMBER 10.00 AM	ASPLEY HORNETS FOOTBALL CLUB 50 GRAHAM ROAD, CARSELDINE QLD 4034

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

Best **CARE** for all Australians is our **GOAL!**

MY MG JOURNEY STORYTELLERS



LAUREN



BRIDGET

As part of the MGAQ's 30th Year celebration, we asked our young people to write a story about their experience with Myasthenia. It was a good opportunity for both Lauren and Bridget to share with us their journeys with MG and give us an idea of the troubles as well as the strengths our younger MG stars have experienced and developed along the way.

AGENDA FOR THE ANNUAL GENERAL MEETING

of the

MYASTHENIA GRAVIS ASSOCIATION OF QLD INC.

to be held on

SUNDAY, 12 SEPTEMBER, 2021

at the

Aspley Hornets Football Club, 50 Graham Road, Carseldine
10.00 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 13 SEPTEMBER, 2020**
5. **BUSINESS ARISING FROM MINUTES**
6. **PRESIDENT'S ANNUAL REPORT**
7. **TREASURER'S REPORT**
8. **ELECTION OF MANAGEMENT COMMITTEE 2021/2022**
NOMINATIONS:

PRESIDENT	Carol Buchanan
VICE PRESIDENT	Susan White
SECRETARY	Yvonne Hornby-Turner
TREASURER	Denise Hannay
COMMITTEE MEMBERS (6)	Anita Jackson, Donna Formosa, Roslyn Holland, Karen Downes, Kirstine Shrubsole
9. **APPOINTMENT OF AUDITOR** *Notice of Motion - Auditor:* That this meeting agrees to the appointment of BDO Australia Ltd as Auditors for the year 2021/22
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, 8 September 2021
and tell Susan if you are attending in person or via zoom.

MYASTHENIA GRAVIS ASSOCIATION OF QUEENSLAND INC. 2021/2022 ANNUAL GENERAL MEETING

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

Sunday, 12 September 2021

**ASPLEY HORNETS' FOOTBALL CLUB,
50 GRAHAM ROAD, CARSELDINE**

10.00AM SHARP

**As our Annual General Meeting will practise Social Distancing,
RSVP is essential by Wednesday, 8 September 2021.**

FREECALL 1800 802 568 or EMAIL info@mgaq.org.au

Guest Speaker: Dr Reuben Beer (BPharm, MBBS, FRACP)

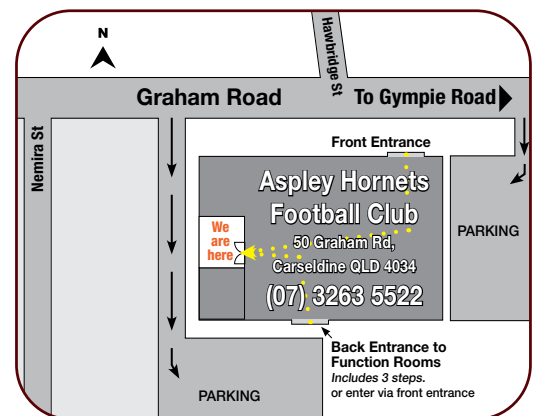
Topic: 'Recent Developments in Treating Myasthenia Gravis'

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/95133946193?pwd=dWpRZlFiell4MTZQVzVXQmV1SWI0dz09>

Meeting ID: 951 3394 6193

Password: 041998



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
by Wednesday, 8 September 2021 and tell Susan if you are attending in person
or via zoom or if you need help.**