



Messages

MYASTHENIA GRAVIS ASSOCIATION OF QUEENSLAND INC.

SEPTEMBER 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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Vice-President

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Dr Cecillie LANDER

Neurologist

Founder Member, of Brisbane

PRESIDENT'S REPORT

Our Annual General Meeting was held on 13 September with members joining by Zoom. This was considered necessary as four members of the management committee live outside Brisbane and, even in Brisbane and its environs, many people would have had to travel some distance. It was a new experience in terms of having members join remotely using Zoom and having a myriad of faces on the screen. Although quite a few members were tentative about using technology it all went very well and we had a great representation from across Queensland, nearly every other state in Australia and from New Zealand.

I am pleased to report that we have a full complement of members of our management committee. All positions were filled prior to the meeting and I thank all committee members for their ongoing commitment. Other business conducted was the acceptance again of BDO as our pro bono auditor, acceptance of the 2020-21 Annual Operational Plan and the decision to keep the membership fees the same.

Following the meeting our guest speaker, Dr Kirstine Shrubsole, addressed the audience about "Speech, Voice & Swallowing problems in Myasthenia Gravis: What we know and what we don't". The information she provided about speech and swallowing was very relevant. Her very interesting presentation will be available via

the website and DVD for financial members who request it.

Also discussed at the AGM was the meeting held with Queensland Health on the Friday prior to the meeting. This meeting was also held via Zoom. Some MGAQ executive members met with our contact Jodi McGrade (Principal Project Officer) and Marguerita Taylor (Director, Community Funding Branch). These meetings provide us with a wonderful opportunity to explain and show examples of all the great work that has occurred in the previous financial year as well as an outline of our plans into the future. Some highlights discussed included the Drugs to be Used with Caution pamphlet, the new Medi-alert wallet card, the podcast series and the possibility of vodcasts into the future, the MGAQ's strong commitment to eNID and its upcoming launch across Australia, the work with Rare Voices and the launch to the National Action Plan for Rare Diseases plus the ongoing push for medical services for people with myasthenia to be equitable and available to all.

The association would like to thank everyone who gave their time to attend the meeting. Our first experience with a virtual experience proved to be very successful. Remember that financial members can request a DVD copy of Kirstine's presentation.

Thanks, Carol

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MYASTHENIA ALLIANCE AUSTRALIA NEWS



MAA UPDATE

What is the latest on the quest to have more equitable access to Rituximab by seeking inclusion of this medication on the PBS for people with Myasthenia?

As discussed regularly throughout newsletters during the past two years, we have approached the Federal Government and the supporting authorities in regard to making Rituximab available to people with Myasthenia via the PBS. Our respectful and well considered approaches have resonated with the Government and with the Rare Voices Australia (RVA) organisation.

As reported by RVA, "The House of Representatives Standing Committee on Health, Aged Care and Sport, Chaired by Trent Zimmermann MP and Dr Mike Freelander MP, has commenced a Parliamentary Inquiry into new drugs and novel medical technologies. The Inquiry will include a particular focus on access to the treatment of rare diseases and conditions where there is high and unmet clinical need. Individuals and organisations are invited to make a submission addressing the terms of reference (TOR) by Tuesday 13 October 2020.

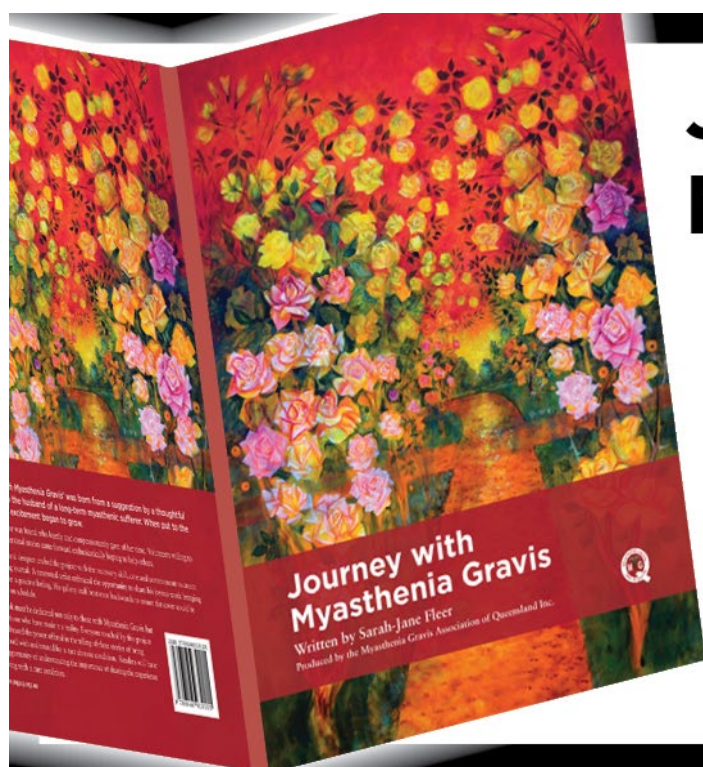
RVA encourages all stakeholders to make a submission. RVA will be providing leadership around this issue to our stakeholders and support to RVA Partners as part of our Mentorship and Education program. Guided by the National Strategic Action Plan for Rare Diseases, RVA has put together a suite of support materials to highlight the recommendations that have strong support for implementation in relation to the TOR of the inquiry. We have organised background information and a guide for each TOR."

The MAA Board will be making a submission to the Inquiry and feedback from the Myasthenia Community is welcomed.

Whilst this announcement is very exciting, it will undoubtedly involve quite a long process. Therefore the MAA Board will continue to explore options to progress this quest.

Susan White - MAA Chairperson.

Follow the work of the Alliance by registering at the website
www.myastheniaallianceaustralia.com.au



Journey with Myasthenia Gravis

A book by Sarah-Jane Fler

Raising awareness of Myasthenia is as important as always. The book demonstrates the uniqueness of each journey with the condition.

It aims to support those affected as well as their families and friends.

If you would like to purchase a copy,

Contact the Association

Free call: 1800 802 568

Email: info@mgaq.org.au

Website: www.mgaq.org.au

MYASTHENIA GRAVIS ASSOCIATION OF QLD INC. ANNUAL GENERAL MEETING SUNDAY, 13 SEPTEMBER, 2020

Election of Office Bearers for 2020-2021

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

President: **Carol Buchanan**
Vice-President: **Susan White**
Secretary: **Ron Stephen**
Treasurer: **Denise Hannay**

Committee Members:

**Donna Formosa, Rosalyn Holland,
Ian Hollingworth, Anita Jackson,
Kirstine Shrubsole and Karen Downes**

Dr Kirstine Shrubsole presented a very interesting and informative about speech and swallowing. She explained in detail how both can be affected for people with Myasthenia. She also commented on some of the results of the recent survey conducted through the newsletter and said that one thing that stood out for her was the lack of both understanding of and use of Allied Services for people with Myasthenia.

Questions from the audience also focused on the lack of comprehensive care plans and, while Kirstine agreed wholeheartedly, she said that this will be a particular focus as a result of the survey.

Many thanks to Kirstine for the information provided about how Allied Services can support people with Myasthenia.

THANK YOU TO THE PEOPLE WHO HAVE RESPONDED TO THE ZOOM MEETING
These responses will be in the October Newsletter





MGAQ Inc. podcast series

UPDATE

"Greetings" to those whom have decided to try out the MGAQ's new podcast service. We have been incredibly pleased that so many of our members have elected to join this new MGAQ membership offering.

Currently MGAQ Podcasts have nine podcasts available for Association members. A full list of these podcasts was included in the last newsletter. Two further podcasts will be published in October.

These include:

Episode 10, which will be released on October 7, where we talk with a member whom suffers from both MG and PTSD. The podcast discusses her experiences and the novel approach she has found to address her specific challenges.

With **Episode 11, to be released on October 21**, Carol Buchanan, the MGAQ President talks about our full range of Services and what objectives drive both the range and type of services the MGAQ supplies.

Having only launched this service in May this year, we are so thrilled to have:

- Over 200 members, whom have joined this service with
- More than 500 podcasts having been downloaded.

If there are other members who would like to join this service, we would love to hear from you and help in connecting is available.

Contact Dr Podcast at: podcast@mgaq.org.au

Send us your questions.

FreeCall **1800 802 568**

Email: podcast@mgaq.org.au



Dr Podcast (Mark) in action



MURIEL'S DID YOU KNOWs?

- A bearded Australian was removed from a darts match in the UK, after the audience started chanting 'Jesus!' at him, distracting the players.
- An Australian man once tried to sell New Zealand on eBay.
- In 1940, two aircraft collided in midair, in NSW. Instead of crashing, the two planes became stuck together and made a safe landing.
- The male lyrebird, which is native to Australia, can mimic the calls of over 20 other birds. If that's not impressive enough, he can also perfectly imitate the sound of a camera, chainsaw and car alarm



Myasthenia Gravis Friends Western Australia

Coffee & Chat - Sunday, 9 August



It was lovely to get together for our **WA Coffee & Chat** despite it being a very wet day. A member who came up from Denmark was happy to finally meet other MGers. We did have about six others who were unable to come, but overall it was enjoyed by those who attended.

Edna

The first American case of myasthenia gravis

Reported here is an account of the illness of Indian Chief Opechankanough (died 1644), which may represent the first recognized case of myasthenia gravis. Historical publications based on colonial correspondence with England are the sources for this article.

To my knowledge, this is the first article in the medical historical literature to mention this famous and influential Indian. Historical accounts state that Opechankanough was so weak as to be unable to walk, making it

necessary that he be carried about on a litter. Moreover, his eyelids were so weak they had to be raised by his attendants. Additionally, a hint of improvement in this weakness after rest is suggested by one historical account.

The differential diagnosis of Chief Opechankanough's weakness is discussed. The historical setting of this famous chief in Colonial America and Colonial Virginia is described, as well.

*Author information: Department of Neurology,
University of Virginia Medical Center, Charlottesville.*

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**Our hearts and
thoughts go
to all those in
lockdown**

**Chat here on one of the Discussion Forums or call 1800 802 568
your online discussion forums**



MGAQ DISCUSSION FORUM

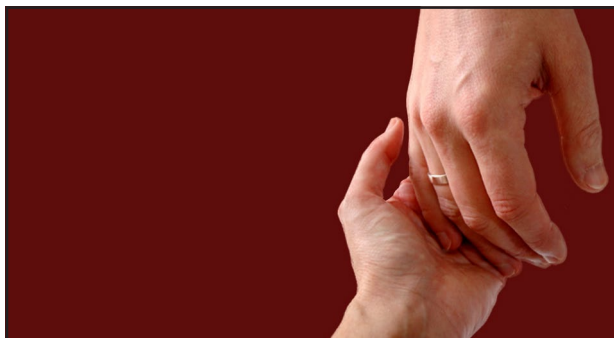
Administered by the MGAQ

Freecall 1800 802 568

Please follow the link and join

MGAQ Discussion Forum at

www.facebook.com/groups/mgqld/



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



**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

**Lambert Eaton
LEMonS
Australia**

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www.facebook.com/groups/602254133711587/

Puzzlers

Puzzles by
www.thinkablepuzzles.com
www.theteacherscorner.net

Word Search - Books of the Old Testament (2)

A C C M I T U O B I J D E I L G
 E L O A A A C E P A H N A E N E
 N T O M P D H M U X R N S I A R
 I A S G O E A F J J F O N N W I
 U Y G A N R D G A J T E I V G T
 G N S D O A O Y A H B K R H Y R
 V E R D E C B S O S R H A O C E
 B K G F N I O H A U C N A A W A
 A G O Y L F T Y B I A A M K W V
 A A J I P T S S Q X P E R A F N
 I B M Y P T W Z O J R O F A S O
 R O O Q B X A G B O Q T I B S O
 E N O F X N N N O D Z X T H M Z
 G F B Z H V A N R A T X L B T V
 L O H L D J B U R U N D I T P E
 A A I R E B I L Y R O V I I B Y

ALGERIA
 ANGOLA
 BENIN
 BOTSWANA
 BURKINA
 BURUNDI
 CAMEROON
 CAPE CHAD
 COAST
 COMOROS
 DJIBOUTI
 EGYPT
 ERITREA
 ETHIOPIA
 FASO GABON
 GHANA
 GUINEA
 IVORYKENYA
 LESOTHO
 LIBERIA
 LIBYA
 MADAGASCAR
 VERDE

Answers

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| 1 | 6 | 4 | 2 | 3 | 7 | 6 | 5 | 8 |
| 6 | 8 | 7 | 5 | 6 | 1 | 3 | 4 | 2 |
| 5 | 3 | 2 | 4 | 8 | 6 | 9 | 7 | 1 |
| 4 | 5 | 1 | 6 | 7 | 6 | 8 | 2 | 3 |
| 9 | 6 | 2 | 8 | 3 | 4 | 8 | 6 | 2 |
| 3 | 7 | 8 | 1 | 5 | 2 | 4 | 6 | 9 |
| 2 | 4 | 1 | 6 | 8 | 5 | 3 | 6 | 7 |
| 8 | 5 | 3 | 7 | 1 | 4 | 2 | 6 | 9 |
| 7 | 6 | 2 | 4 | 1 | 7 | 3 | 5 | 8 |
| 4 | 8 | 1 | 5 | 2 | 3 | 9 | 6 | 7 |

Answers:
 Word Change 26
 Reason, 6. More to it
 Ahead, 5. Within
 Grass, 4. One Step
 3. Snake in the
 Eyes, 2. Firing Line,
 1. Bags Under the
Answers
 bamboozable 32

Sudoku

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | 8 | | | 2 | | | | 7 |
| 9 | | 2 | 4 | | | 3 | 5 | |
| 7 | | | 8 | 6 | | 1 | | |
| 6 | | | 2 | 5 | | | 7 | 3 |
| | 1 | | 3 | | 8 | | 2 | |
| 3 | 2 | | | 7 | 6 | | | 4 |
| | 7 | 9 | | | 4 | | | 5 |
| | 4 | 3 | | | 5 | 7 | | 6 |
| | | | | 3 | 2 | | | 1 |

Word Change

stale

plate

Bamboozable

| | | |
|------------------------------|-------------------------|------------------------|
| iii BAGS | FIRING FIRING FIRING | GRASS |
| STEP STEP STEP STEP | REA ^{WITH} SON | MORE IT IT THAN! |

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

news from around Queensland

News from Cairns

We are back and will be meeting once again on **Saturday, 24 October at 11am at the Cairns RSL Club, Esplanade.**

It would be appreciated if you could RSVP your attendance so that we can abide by the venue's covid restrictions.

For more information or to RSVP please contact **Donna** on **0414397462** or donnaformosa64@gmail.com

News from Townsville

We had a wonderful gathering in August and am looking forward to our next lunch at **The Avenues Hotel, Kirwan** on **Saturday, 17 October at 12 noon.**

To RSVP, contact **Daphne** on **0400778637** or daphclay@gmail.com

Note: Incorrect date advertised in August newsletter.

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

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

Our next meeting will be on **Friday, 2 October at Kawana Bowls Club.** The cafe is now open again so we will gather for morning tea at 10am. Hope to see you there. For more information, call **Colleen** on **0409 491 789** or email 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.**



Brisbane - Coffee & Chats

Cleveland - Thursday 17th September @ 10.30am

Fiction Bar, 152 Shore Street West, RABY BAY

Nundah - Friday 25th September @ 10.30am

Royal Hotel 1259 Sandgate Road

Please contact **Anita** on **0414 588 312.**

RSVP is required to meet COVID-19 restrictions



WHERE IN QUEENSLAND?

Last month:

Mary Kathleen, Mt Isa

Let us know where you think it is:

Send to: info@mgaq.org.au

or post to **MGAQ, PO Box 16, Mt Gravatt, Qld, 4122**



Welcome to our new members

Joan, Redcliffe, QLD

Maurice, Tarragindi, Qld

Megan, Katherine, NT

Gloria, Tarragindi, Qld