



Messages

MYASTHENIA GRAVIS ASSOCIATION OF QUEENSLAND INC.

MAY 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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PRESIDENT'S REPORT

As I write this newsletter article I am very aware of the trying circumstances under which we are all trying to cope. As the weeks continue to grow, the incidences of infection seem to have reduced and stayed low except for a few 'hot spots' as they are being referred to by our state and national leaders. I am sure we are all very grateful to the essential workers who continue to work long hours as well as support the community.

In this newsletter you will find important information to help support your ongoing wellbeing. Queensland Health have provided a website that is constantly being updated for vulnerable people. Also, Associate-Professor Stephen Reddel has provided some very informative and useful information about "**Getting the Most from Your Telemedicine Consultation**". Please take the time to read this, particularly as Stephen wrote and sent it to us for distribution to all.

Membership subscriptions for the financial year 2020/2021 are now due. The envelope in

which your newsletter is enclosed will advise you when your membership expires. 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. If you are unfinancial, please take a minute to phone or email to advise whether or not you wish to retain your membership and thus receive all information from the association. We do not expect anyone to pay back fees for membership and the costs have remained the same as last year.

Because of social isolating restrictions we will be having our **June get-together via technology**. Our guest speaker, **Dr Angelo Contarino** will speak on the topic "**My Metropolis Journey with MG**". Further details about joining in are in this newsletter.

Stay safe and keep well during this difficult time.

Thanks, Carol

Supported by



**Queensland
Government**

Ausenco

MYASTHENIA ALLIANCE AUSTRALIA NEWS

MAA UPDATE

Whilst life is currently a little changed, work still progresses for the MAA in regard to its key projects.

MAA Medical Advisory Board key Specialist, A/ Prof. Stephen Reddel, has written an article which is included in this newsletter assisting people to get the most out of having a Telehealth consultation. We thank him very much for his cheerful and encouraging assistance.

A/Prof. Stephen Reddel and Dr. Katherine Buzzard have been busy beta testing and working with the programme designers in relation to the eNID project. Progress is being made sure and steady.

A survey has been advertised on the MAA website to garner information from people with Myasthenia in regard to the type of facility used to

access treatment and to understand how widely immune suppressive therapy has been utilised and also if Rituximab was a treatment option. These results will hopefully assist Government in understanding how our community accesses their treatment.

It is a very short survey taking only a couple of minutes and will be available for participation for only a few more days. At the time of writing the participation rate has been great and the results are as hoped. If you would like this opportunity to communicate with the government, act quickly by going to www.myastheniaallianceaustralia.com.au

Stay safe.

Best regards Susan White

IMPORTANT MAA SURVEY

The MAA continue to pursue the opportunity for more equitable access by the Myasthenia community to the treatment option, Rituximab/MabThera.



As this drug is currently only available through a select group of major hospital pharmacy budget (at no or little cost to the individual) or by direct funding from individuals (at very significant costs) it is not an achievable treatment option for many people with Myasthenia. The MAA Board aim to understand more about this issue in our community and urge people to complete the following very short survey.

It will take less than 60 seconds to complete!

Thank you in anticipation.

<https://myastheniaallianceaustralia.com.au/important-maa-survey/>

Those people who do not use a computer, seek family help to complete the very short survey.

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

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 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 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 _____



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.

A Member writes:

My name is Dorothy and I will be 77 years of age in May. I live on my own and was diagnosed with MG in 1997. My condition stabilised in time and with careful management I lived a fairly normal life.

In August 2019 things changed and I was struck down with little warning. I began to feel unwell collapsed into my bed. I covered myself with my doona and experienced a type of shivering attack but I felt neither hot nor cold. I phoned for help which soon arrived. The next thing I was aware of was being in the emergency department at the local hospital. I was told my temperature was 40.7oc

I felt very nauseous which continued for a fortnight, I couldn't eat and was given liquid supplements. I lost 10kg in this time. I was transferred to Toowoomba Base Hospital

and given every inconceivable test plus a PET scan. Blood samples went to Brisbane daily. Nothing conclusive so it was put down to a virus. Discharge was out until my temperature went below 37.5°C, this took four (4) weeks as the "thing" had to run its course.

After discharge I remained unwell, so I consulted a neurologist who organised many blood tests (two of which cost \$250.00). The tests showed a rise in antibodies in my blood. A plasma exchange was discussed, but due to the current coronavirus, a hospital visit was deemed risky, so I am starting medication today in the hope things settle down. My local GP is to closely monitor me at the moment with future appointments with my neurologist. MG is certainly a strange bedfellow.

JUNE 2020

International Myasthenia Gravis (MG) Awareness Month

June 8 & 9, 2020

With Queensland taking a particular focus on 8 June.

International Myasthenia Month aims to raise awareness about this rare auto-immune disease.

Brisbane is contributing to MG Awareness Month, with the Brisbane City Council lighting up both the Story Bridge and the Victoria Bridge in the Teal colours of recognition.

This will occur on the evenings of 8 and 9 June 2020.



Myasthenia Gravis Association of Queensland Inc.

JUNE MEETING

June 14, 2020
10.00am AEST

The Myasthenia Gravis Association of Queensland Inc. and Synergy Video

SYNERGY VIDEO
growing your audience

are inviting you to a scheduled Zoom meeting - June 14 2020 @ 10am AEST



Guest Speaker – Dr Angelo Contarino, Clinical Psychologist
His talk is **“My Metropolis Journey with MG”**

Join Zoom Meeting

<https://zoom.us/j/92373172881?pwd=NFIQbHFNS1dHd2NUT0N3L2ErVTVHZz09>

Meeting ID: 923 7317 2881

Password: MGAQ2020

As a participant you do not need to download the software you can simply jump on straight from your web browser.

If you have not used Zoom before. If you would like to, please feel free to download the Zoom App for your Android or Apple device.



A full set of instructions can be found here to help you get setup and test your system for the meeting

<https://support.zoom.us/hc/en-us/articles/201362193-Joining-a-Meeting>

During the meeting everyone will be muted and your video will be turned off (except for the speaker) If you would like to ask a

question please use the chat function - please follow these instructions, relevant to the device you are viewing on

<https://support.zoom.us/hc/en-us/articles/203650445-In-Meeting-Chat>

For any technical support during the meeting please call Brett Greig 0405 351 983

SYNERGY VIDEO
growing your audience

We encourage you if you are not a regular Zoom user to please join the Zoom test meeting
<https://zoom.us/test> (please join with computer audio if prompted)

If members cannot participate on the day, the event will be recorded and made available to members via the MGAQ website, emailed link or in the usual format of a DVD if requested.

For more information about the June Meeting, please contact Susan, Freecall 1800 802 568 or email: info@mgaq.org.au



Getting the Most from Your Telemedicine Consultation

The author is A/Prof Stephen Reddel (Neurologist NSW). He is a member of the MAA Medical Advisory Board and we sincerely thank him for his guidance at this time.

G'day folks, hope you're all safe and snug hunkered down at home in these times of isolation. COVID-19 has been pretty dreadful but so far Australia has done well and we hope that continues into the winter months where transmission of respiratory infections increases, so keep doing the right thing to help. Personally I've also got the COVIDSAFE infection tracking app and would recommend it to you and your family, you definitely want to know if anyone in your family has been exposed. And while COVID-19 has been terribly disruptive we should always try to make the most of it, and hopefully use the opportunity to make things better.

I have been doing telemedicine for about 7 years, but until recently we have not been allowed to do this sanctioned by medicare other than for rural patients, so I have some ideas about what works and what doesn't work. But this is a work in progress, so expect a learning curve. Do set this up with the doctor's staff, and remember to update any personal details with them if required, and make sure there is a referral.

TECHNICAL STUFF

(this can be a bit daunting but almost everyone can make it work, so don't give up):

Video is better than a call. We prefer to see people's smiles, or not, and their droopy eyelids and anything else. So if possible use video, be it laptop, tablet, smartphone or relative's smart phone. Remember a desktop computer generally has no camera unless specifically installed via USB. Check it all works with a test run to somebody else. Remember the doctor may be struggling with IT too, the hospitals can be particularly re-

strictive, and very occasionally the doctor could be a minute or two late. But at least by computer you can read my handwriting.

Methods vary by doctor, but include:

- where we connect by common server, such as Zoom, so you have to accept the invitation and click on a link to start. Do this a few minutes before the appointed time, so you can check everything works, and troubleshoot it with time if it doesn't. You often need to touch the screen or wave the mouse pointer around to see the start video and start microphone settings. More than two people can login more readily, so this is good if a family member / carer would like to also join but is somewhere else, like sunbaking on Bondi beach (just joking).
- **Device to device**, by Skype or Whatsapp video call. Note facetime is Apple only, so we don't tend to use that as a sole means. The quality is not quite as good but it's a bit simpler. The doctor may prefer to use a dedicated skype name login for professional purposes for privacy. As Whatsapp uses the mobile phone number, again they would typically use a practice specific phone if using Whatsapp.
- **Telephone call**. When in doubt it works, so leave it on and readily available. I often find I have to call to explain a few technical things the first time, and the practice secretaries may also need to call.

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- **Email** – check your email and have it on, instructions are usually via that means, and information can be sent out during the consultation if things are super-efficient.

MYASTHENIA STUFF

How's it all going. Make some brief notes of things to discuss including how you are feeling, but remember this is not a social chat!

- Are there things that are due, or should be – like blood tests or bone density?
- What prescriptions do you need?
- Here's the interesting bit – do your own myasthenia gravis composite (MGC) severity score modified for tele (secretly it uses some Quantative MG bits, but it is good enough). This is how we measure MG (including for eNID-MG). Do the following before the telemedicine
 - Lie on your back. How long can you lift your leg off the bed at about 45 degrees - try for 100sec. Record the time. If one hip (or shoulder below) is dodgy use the better one.
 - Still on your back. How long can you lift your head off the bed at about 45 degrees – try for 120sec. Record the time.

- Sitting now. How long can you hold your arms outstretched (90 degrees, but can be more forward or to the side). Try for 240sec and again record the time.
- Breathing, swallowing, chewing (chewy bread or steak) and talking - are they normal, mildly not quite right, or more severely affected?
- Eyes can be checked by the doctor on video.

PRACTICAL STUFF

If you like to take someone along to an in-person consultation, do the same for telemedicine. Share the link if needed.

- Have there been any side effects of medications?
- Or any other serious things since last consultation, particularly infections, cancers including skin cancers, or operations?
- Or things that are going to happen, such as operations? Are you pregnant? Lads, if you ticked yes, this is going to get ugly.
- Any changes to your medications?
- What's next, including next appointment, and in-person, telemedicine, or to be determined.
- Maybe use this as a checklist, it could make things efficient

Stay safe – Stephen Reddel

KEEPING UP TO DATE WITH THE LATEST INFORMATION ABOUT COVID-19

Queensland Health continues to keep our association informed about how to access the most up to date information in relation to COVID-19. They have provided us with a website that is most relevant to vulnerable people within the community. Once you access this website please scroll down for the latest information.

<http://www.mbsonline.gov.au/internet/mbsonline/publishing.nsf/Content/Factsheet-TempBB>.

Both the Australian and Queensland Governments are regularly reviewing and updating the information on all their websites to ensure the general public has the most current advice.



Welcome to our new members

Correction from April Newsletter

Kevin D is from Denmark WA not SA

NEWS FROM AROUND QUEENSLAND

I would like to say that on behalf of all the Regional Co-ordinators, we miss our regular get-togethers and will return as soon as COVID-19 restrictions have been lifted and it is safe to do so. However, in the meantime remember you can always phone your regional co-ordinator if you would like to have a chat.

Cairns:

Donna on 0414 397 462 or donnaformosa64@gmail.com

Townsville:

Daphne on 0400 778 637 or daphclay@gmail.com

Mackay: Muriel on (07) 4954 1221

Hervey Bay – Wide Bay Burnett Region:

Jan on 0429 622 438 or janpowell3@bigpond.com

Gladstone – Wide Bay Region:

Garth on 0408 155 954 or (07) 4973 7983

Sunshine Coast:

Colleen on 0409 491 789 or email colleen4551@gmail.com

Gold Coast: Nader on 0415 834 401

Brisbane: Anita on 0414 588 312

If you would like a chat, pick up the phone and call your local regional Coordinator.



WHERE IN QUEENSLAND?

APRIL: Wallaman Waterfall

Thomas B. was correct.

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



What I do on an Isolation Day!

Rebecca

**Jigsaw Puzzles
and
Story Writing**



Completed a 6,000 word story about my husband's Norfolk Island ancestry.

Isaac Tarr - in a nutshell; a marine from the First Fleet flagship, Sirius, wrecked on Norfolk Island 19 March 1790. We attended NI for the 230th anniversary of its fate with the reef. Isaac settled on the island for 4 years then returned to NSW and took up a grant of land at Parramatta.

Send your Isolation Day picture to:

PO Box 16, Mt Gravatt 4122, Qld or info@mgaq.org.au