



## Myasthenia Gravis Association of Queensland Inc

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Neurologist

Founder Member, of Brisbane

# Messages

Myasthenia Gravis Association Of Queensland Inc.

## OCTOBER 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

What a wonderful experience it was to have the AGM undertaken using both Zoom and face-to-face. It certainly swelled our numbers in terms of those members able to attend the meeting with our attendance nearly doubling that from last year.

Our guest speaker after the AGM, Dr Reuben Beer, provided much interesting information in his presentation "*Recent Developments in Treating Myasthenia Gravis*". A big thank you to Reuben for his highly relevant presentation, particularly when so much is happening in terms of everyone's focus on staying healthy.

The work of the new management committee has already started with everyone trying to manage the workload from so many projects. Remember that, if you have a bit of spare time to give, it would be appreciated as every little bit of time helps. We are also looking for project managers for some smaller activities which will have a start and end date attached so people know the level of commitment required.

A big thank-you must go to the representatives from Queensland Health who made the time to meet with two management committee members prior to

our AGM. They were amazed at the work of the association and the outreach we have achieved across the state. As well as the management committee the Regional Co-ordinators work hard to ensure that both new members and the ones who have been with the association for many years are provided with opportunities to meet and chat with people with similar 'stories'.

**At this stage, things are looking good for our Christmas Get-together at the Caloundra Power Boat Club, on Sunday 12 December, 11.30am lunch sitting. Please remember to RSVP on the 1800 number so the venue can cater for any restrictions that may be in place at that time.** It would also appear that we need to send our Christmas gifts sooner rather than later and buy them when you see them as they may be gone tomorrow. I am sure that the children and grandchildren in particular have already informed you about their very long list.

Wishing everyone a safe lead up to the festive season and hope that all loved ones will be able to be together.

**Thanks, Carol**

Supported by



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

## MYASTHENIA ALLIANCE AUSTRALIA NEWS



## MAA UPDATE

Hopefully people will have received at least one notification that the “**Myasthenia Gravis Patient Reported Outcomes Survey**” **Research Project** is now ready for patient input and if they have not rushed to complete it then they are busy scheduling a time and asking for support! With an ideal target of 350 respondents, everyone must help this cause and ensure the most meaningful result.

The survey allows participants to tell of their experiences with the available range of Myasthenia Gravis treatments and also indicate if there are any resultant issues which have required additional medical attention.

This significant, highly professional and exclusively Australian research project aims to give

- insight into what treatments are being made available across Australia for Myasthenia Gravis patients; together with
- the impacts of and the patient tolerance for these treatments.

The data will be analysed promptly with the results providing invaluable information to patients when assessing choices, to clinicians when making recommendations and to government departments when prioritising access to treatment options. The data will be available to each of the researching team for on-going use. This feature will make a powerful tool for use across a range of situations and opportunities, many still to be identified.

***This project is a collaboration between Neurologist Professor Steve Vucic, an internationally recognised and award winning researcher, ANU Biological Data Science Institute, MAA and Terumo Blood and Cell Technologies as an industry partner.***

The digital survey can be found at <https://redcap-bdsi.anu.edu.au/surveys/?s=PWPFW73R73>

To make it as easy as possible for people to complete the survey it is suggested that preparations include the following -

- Allow around 45 minutes in total. A 'save and return' option is available for those who need to pause.
- Ask for support if you do not usually access technology. **Consider seeking support from family and friends.** Call **1800 802 568** to discuss or email [info@mgaq.org.au](mailto:info@mgaq.org.au)
- Making a list of ALL treatments/medications ever prescribed.
- Considering any short or long term side effects experienced as a result of the medications.
- Have your diary/calendar at hand to reflect on your past twelve months. You will be asked to report on your current MG experience and also any additional services utilised in this period.
- Read the 'Participant Information Sheet' to understand more.

Readers are aware that the MAA has been working towards this project for over 18 months and have been committed to bringing this important opportunity to our community. Please reward these workers with your time and knowledge. Thank you for your support. **Please see the flier on page 3 of this newsletter.** It can be shared in your treatment clinics and wherever else MG people may be found. Please seek out help in supporting this project.

The other exciting news is that the Federal body ATAGI (Australian Technical Advisory Group on Immunisation) has recommended a booster/supplemental Covid - 19 vaccination for those who are heavily immune suppressed. The Health Minister has indicated that this will be available from 11 October. This gives the MG community a chance to strengthen our response to the vaccine and increase our safety. It is available in the period 2-6 months post the second vaccine. The MAA strongly recommend that everyone on immune suppressing medications/treatments discuss this opportunity with their treating Doctors. Pfizer and Moderna are the vaccines preferred for this purpose but the AstraZeneca vaccine can also be considered. ATAGI also state that "Serology assaying is not currently recommended before or after the 3rd doses as variations in assays and a lack of accepted correlation of protection make interpretation difficult". More details can be found here <https://www.health.gov.au/resources/publications/atagi-recommendations-on-the-use-of-a-third-primary-dose-of-covid-19-vaccine-in-individuals-who-are-severely-immunocompromised>.

**Susan White, Chairperson**

Follow the work of the Alliance by registering at the website [www.myastheniaalliance.org.au](http://www.myastheniaalliance.org.au)

**SUPPORT** your Association by taking **MEMBERSHIP.**



Australian National University



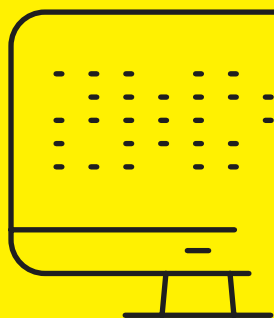
THE UNIVERSITY OF SYDNEY



Myasthenia Alliance Australia

A collaborative project

# Myasthenia Gravis Patients



## Report Side-effects Experienced from MG treatments

### ONLINE SURVEY

<https://redcap-bdsi.anu.edu.au/surveys/?s=PWPFW73R73>

Dr. Steve Vucic and the Biological Data Sciences Institute are gathering information via an online survey on the side effects of treatments used in managing Myasthenia Gravis.

Gathering this information strengthens conversation with Government, assists treating Physicians and also Researchers, and helps to understand the quality of life impacts for patients.

#### FOR MORE INFORMATION CONTACT:

Susan White  
Email

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

Study Investigator (Dr Nidhi Menon) [nidhi.menon@anu.edu.au](mailto:nidhi.menon@anu.edu.au)



Scan QR Code using your QR reader on your smartphone or tablet to complete the survey.

"The ethical aspects of this study have been approved by Australian National University Human Research Ethics Committee (Protocol 2021/269)."

"This work is supported by Terumo Blood and Cell Technologies Australia"

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



## MGAQ Inc. podcast series

# UPDATE

### ***Greetings All***

and welcome to the Podcast Teams report for the October MGAQ MessaGes newsletter. MGAQ Podcast now has around 215 total subscribers of which some 110 make regular contact with our podcasts.

Earlier this month, on the morning of Wednesday 6th October, the MGAQ published a discussion with Prof. Andrew Kornberg from the Royal Childrens Hospital in Melbourne. Dr Kornberg is paediatric neurologist and talked to us about Congenital and Juvenile Myasthenia. Dr Kornberg's podcast is a must listen to for all of us who have young children in our lives as Andrew speaks wisely about those matters most critical to young people and not just those suffering from myasthenia gravis.

Also this month, the podcast team have two very interesting new recordings. The first of these, and already completed at the time of this newsletter, involves a discussion with Dr Alex Ritchie. Dr Ritchie is a highly regarded, respiratory specialist. In this podcast, Dr Ritchie talks to us about respiratory considerations for people with MG including the role of a respiratory specialist for sufferers of myasthenia gravis, what happens in a myasthenia crisis, what one can do to sense and minimise the impacts of a crisis as well as the role of sleep with MG. Our second important recording in October is a talk with Prof Steve Vucic. Dr Vucic is an internationally recognised researcher in the field of neurodegenerative diseases and winner of the highly prestigious Gottschalk Medal by the Australian Academy of Science as well as the Eric Susman Award by the Royal Australian College of Physicians. Dr Vucic will be leading the extremely important "Myasthenia Gravis Patient Reported Outcome Survey Research" Project into the encompassing impacts of the range of treatment options provided to people with MG in Australia. This study is being undertaken by Myasthenia Alliance Australia, Sydney University, ANU Biological Data Science Institute and Terumo BCT with the objective of providing insight into what treatments are being made available across Australia for MG patients together with the impacts of and the patient tolerance for these treatments. It is our plan to make these two new podcasts available to MGAQ Listeners as soon as possible.

Finally, as has been our practice for the past six months or so, we continue to generate an audio version of the Monthly MessaGes newsletter.

We wish all our listeners stay safe in these somewhat different and challenging times.

### ***MGAQ Podcast***

## **Suggestion from Dr Podcast**

The Podcast Team are often asked by members new to MG - "Which podcast is the best place to start?" With the number of podcasts (excluding the audio newsletters) now approaching twenty, this is a very valid question. Our recommendation would be Episode 3 entitled 'Types of MG' as this discussion provides a great foundation upon which anyone of us can enhance our knowledge of myasthenia gravis. Thank you for this question!



You're invited to the  
**MGAQ Christmas Function**

to be held at  
**Caloundra Power Boat Club**  
**2 Lamerough Parade, Golden Beach**

on  
**Sunday, 12 December**

**11.30 am lunch sitting**

*For more information / RSVP - Contact Susan*

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



Hi Everyone! MG Gold Coast group had their get together sharing experiences with other members on Saturday, 18 September at Broadbeach Kurrawa Surf Club.

**Our next meeting will be on Saturday 20th of November at 10am, Southport Sharks Club**

I hope to see all there. Kind regards, Nader Amiri, Gold Coast Coordinator 0415 834 401.



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](mailto: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.**

## 'Coming Up Trumps' with Derek!

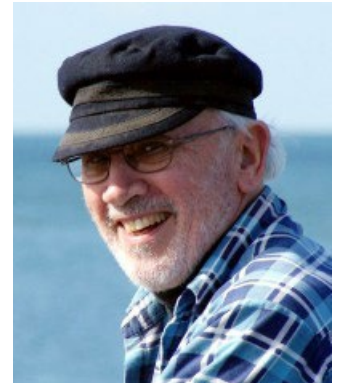
Diagnosis of MG at age 85, was a shock to me, thinking that most human ailments (vision, hearing, pacemaker, bladder, bowels, etc) had already been resolved. When driving a year ago and motor vehicles in the oncoming opposite lane ahead began jumping in front of me, as double vision kicked in, I realised that my life was about to change. I did not bargain however for the rapidly changing effects that would overtake my woodworking and workshop hobbies, and additionally render me tired and listless and dependent on a wheelie walker. 12 months to date, after experiencing the effects of the classical MG medication, I'm left with hope that the progress of this horrible affliction, has slowed.

For many years following retirement at 63, my daily dozen included 25 kms walks, gym workouts, regular ballroom dancing, wining and dining with wife Audrey, camping, fishing trips and social soirees. Also, foreign and local trips, family visits to Melbourne, accommodation of overseas family, and planned adventures that seemed to rotate regularly on our calendar. These days a trip to the local shopping centre is a major event. Lifts, travellers, and mostly level footpaths are a blessing.

Being of the stiff upper lip British Army type however, I've adjusted my daily routine to a variety of activities, most of which I can accomplish while seated. The inclined walking machine on the veranda is a challenge, but I'm closing on 5kms daily. My garage workshop is a registered Men's Shed for charitable fundraising activities, following years of involvement with The Men's Shed organisation that occupied me as President and member of 3 start-up Sheds since 2010. These days my mobile bench fit out trebles the work space, including a specialised workstation for bike repairs and restoration of donated bikes from various donors. I enjoy also, an occasional return to the wood lathe and bench saws, mindful of my slowing dexterity. Until earlier last year I'd devoted 400 hours to the construction of 2.4 m ocean kayak, reaching halfway, now sadly passed over due to energy and dexterity issues.

One particular hobby remains, driven by my lifelong love of playing most card games, American Canasta, Samba, Bridge etc., the doing of which requires holding the dealt cards in an ever-increasing shaky pair of hands (pardon the pun). A small plank of dressed aromatic cypress pine is used as an artist's palette to burn images (pyrography), with a red-hot wire tip to create artwork of any imaginable character, the more I practice, the better I become. Carefully calibrated longitudinal and horizontal saw cuts then provide for the 'holding' of the dealt hands of cards during a game in progress. These devices solve the ever-present issue of managing the cards and making discard selection.

So having solved a personal problem, I'm keen to share this idea with fellow MGAQ friends. Just email me on [djkl157@gmail.com](mailto:djkl157@gmail.com) for more information. A small donation to MGAQ will flow from proceeds. A card school can also be arranged for 2 or more players. SMS also on 0407 159 561. My hobby workshop: <https://goldenyearsmensshed.wordpress.com>



**Derek L, Clayfield, Qld.**



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## Nature is a gift

As my strength and confidence return, thanks to the right combination of medication, I am rediscovering an old love in a new way. I was always a walker. Before becoming ill with Myasthenia Gravis, I would walk 4km every morning with our trusty golden Labrador. The passing of time has brought changes for us all. Now I am walking the shorter trails with our black Labrador.

One of the trails we love follows the river in the valley below our house and circles back around to the streets that join to ours. The bush along the river, that I have known and walked for many years, was totally destroyed in the 2019 summer fires and is now regenerating. Thankfully, our house escaped harm but fourteen others in our small community were lost. The feeling I get as we walk this trail now is one of hope, excitement and anticipation as it recovers slowly but surely - a metaphor for my journey and also for our community.

I may not be able to walk the 4km that I once did but with my recently regained strength I find a new enjoyment in walking this trail more slowly. As I meander on this renewed path, I see that some of the larger trees are standing tall, but they now sway naked above the new understory as they died in the intense fire. I am glad to see however that they have become repurposed into homes for many returning birds and insects who appear to love the new hollows and fissures.

The regenerated lower canopy is now very healthy and strong and stands well above my height. The earthy aroma is now replacing the pungent ash. Small birds can be seen flitting and hopping about and I can hear the frogs calling loudly as I pass by the creek. The crisscrossing paths under the bushes confirm that the wombats and wallabies have returned, perhaps sheltering in their new homes along the river bank and amongst the fallen logs and burnt refuse hidden by the new understory.

This regeneration demonstrates nature's robust resilience. To me, nature is a gift - a big gift, and I am so thankful that the trail is still there. The bush is very changed, but then so am I, and I deeply appreciate its return. I remain inspired and encouraged by nature's tenacity. We love being able to walk these trails again.

*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.



## Welcome to our new members

Tracy, Riverhills, QLD

Phoebe, Beechboro, WA

Paul, West End, QLD

Lisa, Safety, Beach, VIC

Walter, Launceston, TAS

(Members pending until next meeting)

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

## News from around Queensland

### News from Cairns

All welcome to attend our next get together on **Saturday, 27 November at 11.00am at the Cairns RSL Club Boardroom, Cairns Esplanade**. If you are visiting Cairns at this time, you are most welcome to join us. For more information, please contact **Donna on 0414 397 462 or [donnaformosa64@gmail.com](mailto:donnaformosa64@gmail.com)**

### News from Townsville

Please note in your diary – **Saturday, 4 December**, the Townsville group will be meeting at **The Avenues Hotel, 70 Kern Bros Drive, Kirwan commencing at 12 noon. All are Welcome**. If you can come, please RSVP **Daphne on 0400 778 637 or [daphclay@gmail.com](mailto:daphclay@gmail.com)**

### News from Mackay

I have organised a lunch for the Mackay group at **11.30am on Sunday, 14 November at The Boomerang Hotel, 307 Nebo Road**. All are very welcome. Please confirm attendance by 8 November by calling **Mary on 0749 595 251**. This will be the last get together for 2021 with hope for a normal year for 2022.

### News from Bundaberg

Please join us for *Coffee and Chat* get together on **Saturday, 20 November, 10.00am at the "Spotted Dog at the Railway Hotel", 78 Perry Street, North Bundaberg**. We will be in the Canecutters room from 10.00am to 11.30am. Table has also been booked in the bistro should anyone wish to stay for lunch. 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](mailto:janpowell3@bigpond.com)**

### News from Gladstone – Wide Bay Region

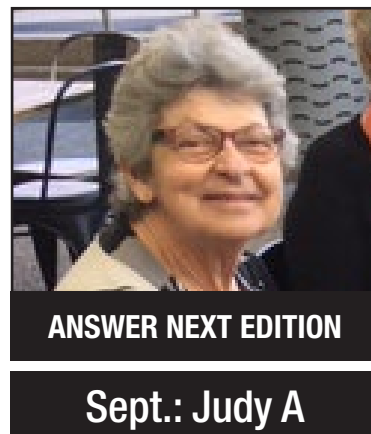
For local support in the Gladstone – Wide Bay region, call **Garth on 0408 155 954**.

### News from the Sunshine Coast

Looking forward to our next catch up on **Monday, 1 November at 10.30am, Kawana Bowls, 476 Nicklin Way, Wurtulla**. All are very welcome. For more information please contact **Vicki on 0411 146 898** or email **[avplummer@gmail.com](mailto:avplummer@gmail.com)**

### News from the Gold Coast

Our next meeting will be on **Saturday, 20 November at 10.00am at Southport Sharks Club**. I hope to see all there. Kind regards. For more information contact **Nader Amiri, Gold Coast Co-ordinator, 0415 834 401**.



### Brisbane - Coffee & Chats

**TOOWOOMBA** – Picnic Point Café, Tourist Road, Toowoomba  
Thursday 28th October @ 10.30am

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

# what's coming up

What's On	When Is It	Where Is It?
<b>MGAQ CHRISTMAS FUNCTION</b>	<b>SUNDAY, 12 DECEMBER</b>	<b>CALOUNDRA POWER BOAT CLUB 2 Lamerough Parade, Golden Beach 11.30 am lunch sitting</b>

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

**LEARNING** more about helping out is as easy as **PHONING 1800 802 568**.