



Myasthenia Gravis Association  
of Queensland Inc.

# MessaGes

MARCH  
2022

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.



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

## PRESIDENT'S REPORT MARCH 2022

My first thought in writing this newsletter is about all of our members, their families and friends who are having to go through this terrible rain that does not seem to be moving off the coast at all. The Aussie spirit is alive and well when you hear of the amazing work being done by the Mud Army, the SES and first responders, defence force personnel and those who are just looking after their neighbours. Our heartfelt thanks must go out to everyone who has helped in any way, big or small. Hopefully, the insurance companies will move in quickly so people can be reassured about the future. Please remember that, if you feel that life is getting on top of you, there is a variety of agencies to which you can talk.

You will have noticed the new format for our newsletter. We are endeavouring to use the same picture on all of our major publications so that it is easily recognised by members and others as an MGAQ publication. Many thanks to our editor, Greg, for his continued support and creativity.

I hope that everyone took the opportunity on Rare Disease Day to talk with someone about Myasthenia Gravis, how you manage it and what symptoms affect you the most.

**Please circle 12 June on your calendar for our get-together in Brisbane.** The guest speaker will be **Louise Healy** from **Rare Voices Australia** whose presentation will be available via **Zoom**. If you do not know how to use Zoom, just ask one of your younger family members who are sure to be familiar with it! More details will be provided in upcoming newsletters.

It is hoped that everyone took very careful notice about the ATAGI information and the supporting introduction from Dr Stephen Reddel about the need for people who are immunosuppressed to consult with their doctor and/or specialist about what is best for them in terms of ensuring the best protection from Covid. Information about this was provided in the February newsletter.

The members of the management wish everyone well and hope that you are getting the support you need if you have had to cope with this ongoing weather event.

Thanks, Carol

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





## MYASTHENIA ALLIANCE AUSTRALIA

# MARCH NEWS UPDATE

The MAA Board sends sincere thoughts to the many members experiencing our extreme summer weather. The flooding rains are incredible and have caused such loss and devastation for many people whilst the prolonged heat in the west and north has also been a challenge. I don't think there is anyone who has not been touched in some way. This all brings stress and exhaustion. Suffering from Myasthenia or not, we ask that you please keep safe, care for yourself and accept help when it is offered. In regard to medications, please plan ahead and keep stocked up.

With such a challenging start to the year the MAA hasn't even found time to have a formal meeting yet. This has not stopped the work however and I bring you a couple of snippets with the promise of more details next month.

1. It remains positive that Rituximab for patients with Myasthenia will complete the PBS listing process. Regrettably we are advised, that it is a more complex process than usual and it is still being worked through. I have been assured that, whilst completion is still some time away, the Myasthenia community should remain positive. Not exactly the news I had wanted to bring you this month but still very optimistic. Regular follow ups continue.
2. **Well done us!!!** After some initial challenging work for the analysts in validating the survey responses, the Australian Myasthenia Community has provided a fantastic **280 contributions to the Patient Reported Outcomes Survey!** The data analysts are now working diligently to understand, correlate, delve into and quantify the information we provided. It was a very large survey providing a broad spread of information and so the work is involved. Results are being cross referenced and compared against previous reports. More information will be shared as opportunities arise.

**Susan White, MAA Chairperson.**

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



Please join us on  
**Sunday, 20 March at  
12.30pm**  
Matthew Flinders Hotel,  
667 Warrigal Road,  
Chadstone  
**RSVP: Robyn on 0421 980 929**



## MGAQ Inc. podcast series

### LIST OF MGAQ PODCASTS

Available to Members at [www.mgaq.org.au](http://www.mgaq.org.au)

#### SEASON 1

Episode 1:	MGAQ Podcast Series Overview.....	12 minutes
Episode 2:	Resilience - MGAQ 'Ask the Expert' Podcast.....	20 minutes
Episode 3:	Types of MG - MGAQ 'My Journey with Myasthenia'.....	17 minutes
Episode 4:	3 Sero-negative MG'ers Discussion - MGAQ 'My Journey with Myasthenia' Podcast.....	21 minutes
Episode 5:	Benefits of Physical Activity & Impact of Sedentary Behaviour - MGAQ 'Ask the Expert' Podcast.....	19 minutes
Episode 6:	Sero-positive, Generalised & Thymectomy - MGAQ 'My Journey with Myasthenia'.....	22 minutes
Episode 7:	Impact of Myasthenia on Speech & Swallowing - MGAQ 'Ask the Expert'.....	27 minutes
Episode 8:	From Sero-negative to Sero-positive - MGAQ 'My Journey with Myasthenia'.....	26 minutes
Episode 9:	From Sero-negative to Sero-positive Q&A - MGAQ 'My Journey with Myasthenia'.....	25 minutes
Episode 10:	Suffering from both MG & PTSD - MGAQ 'My Journey with Myasthenia'.....	26 minutes
Episode 11:	A discussion on the objectives, content & range of MGAQ Membership Services.....	20 minutes
Episode 12:	Is more merrier? - MGAQ 'My Journey with Myasthenia'.....	24 minutes
Episode 13:	Getting the best MG outcome when you live in a regional setting. An MGAQ 'Ask the Expert' Podcast.....	26 minutes
Episode 14:	Understanding LEMS, MG's very rare cousin - MGAQ 'My Journey with Myasthenia'.....	31 minutes

#### SEASON 2

Episode 16	Covid 19 Vaccination Discussion Paper with Karen & Susan.....	29 minutes
Episode 17	Improved mobility by getting the most out of our feet, ankles and lower limbs.....	26 minutes
Episode 23	Congenital & Juvenile Myasthenia - an MGAQ 'Ask the Experts' Podcast.....	19 minutes
Episode 25	MGAQ Audio Newsletter - October 2021.....	29 minutes
Episode 26	Respiratory considerations for MG Sufferers - MGAQ 'Ask the Expert' Podcast.....	27 minutes
Episode 27	MG Patient Reported Outcome Survey - Lead Researcher Prof Steve Vucic.....	12 minutes
Episode 28	MGAQ Audio Newsletter - November 2021.....	25 minutes
Episode 29	MGAQ Audio Newsletter - December 2021.....	19 minutes

The MGAQ website has many additional features available only to financial members including the complete list of Podcast recordings.

Access to the member only area is provided with receipt of membership payment. Don't miss out – call 1800 802 568 or email [info@mgaq.org.au](mailto:info@mgaq.org.au) to make your request.



### VICTORIAN REGIONAL MG LUNCHEON

to be held at the

**Sunday 27th March at 12 noon.**

**Shepparton RSL Club,**

**88 Wyndham Street Shepparton.**

Everyone is welcome! RSVP by Friday 25th March.

For all bookings, please call/text Pauline 0419 332 260.

With more people **VOLUNTEERING**, more **PROJECTS** can be undertaken.

## ANY ACTIVITY IS BETTER THAN NONE

### **Myasthenia Researcher Tahlia writes:**

“Moving more and sitting less has important health benefits for everyone, including for people with myasthenia gravis. It is recommended that adults engage in 150-300 minutes of moderate-intensity or 75 minutes of vigorous-intensity physical activity per week (or an equivalent combination), and limit the amount of time spent sitting. Importantly, any activity is better than none and even small increases in any intensity of physical activity has proven health benefits. Although exercise is one part of physical activity, physical activity describes any bodily movement where our bodies are expending energy above what it would usually expend at rest – this includes activities like walking, gardening or even doing chores around the house.

However, there can be challenges with knowing what to do and how to do it when it comes to being physically active, especially when managing the symptoms of MG. Allied health professionals with expertise in physical activity (such as physiotherapists and exercise physiologists) can support people with MG to develop individualised programs that fit their goals and lifestyle. You can find out more about how people with MG can use exercise to improve strength, mobility and daily function, the role of allied health professionals, and how to access them in the MGAQ’s new information sheet which will be available in the April Newsletter.

**Kind regards, Tahlia Alsop** BHLthSci (Hons), MPhty, GradCertClinRehab

### **MURIEL'S DID-YOU- KNOWS**

- Australia is home to the world’s largest cattle ranch – which is bigger than the entire country of Belgium
- Australia is the 6th largest country in the world in terms of land area
- Australia’s dingo fence is longer than the Great Wall of China
- The Nullarbor Plain is home to the longest straight road in the world, at 146km long
- Australia is the only continent in the world without an active volcano



## **Journey with Myasthenia Gravis**

A book by Sarah-Jane Fleer

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**

**Freecall: 1800 802 568**

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

**Website: [www.mgaq.org.au](http://www.mgaq.org.au)**

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

## MEMBERS' FORUM

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.**

### My Reading Group

Some time ago, when I was out on my daily tottle with my trusty walking stick and Labrador (the one that walked off the lead), I met up with a neighbour who was also walking her dog. We would often stop to have a quick chat. We talked about things we were doing, or books we were reading. On this occasion she asked me if I would like to join her and two others, each month to talk about novels. Excited about the opportunity of sharing my love of literature I agreed to join them. It was one of the best decisions that I have made.

We didn't really know each other very well before we started meeting, only really to wave a polite hello in the street, but our monthly visits changed that. We have read many books together over the time, and had many enjoyable chats and lively discussions about authors and writing. It has broadened my view of novelists and different styles of writing and I have devoured the opportunity to share in another's view of the world; both theirs' and the authors'.

Five years on and our group has changed and morphed. So much has happened worldwide with Covid19, and locally with the fires, but in all that time we have always managed to meet monthly. During lock down we started to meet on Zoom and continue to now, as we all navigate Covid19 and our 'new normal'.

I've discovered so much about myself by being part of this group. Obviously, we each have a love of reading and literature, but uniquely each person brings so much more to our meetings. We listen and encourage each other in all our endeavours. I have never really considered writing myself; that was until I met these three women. With their enthusiasm for all things literature, they encouraged me to write. I'm still developing my skills (aren't we all) but I am having so much fun discovering this new aspect of myself. That is really what writing is about for me.

What new thing/hobby/endeavour have you taken on lately?

*Helen T*

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*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.



# Puzzlers

Puzzles by  
[www.thinkablepuzzles.com](http://www.thinkablepuzzles.com)  
[www.theteacherscorner.net](http://www.theteacherscorner.net)

## Sudoku

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

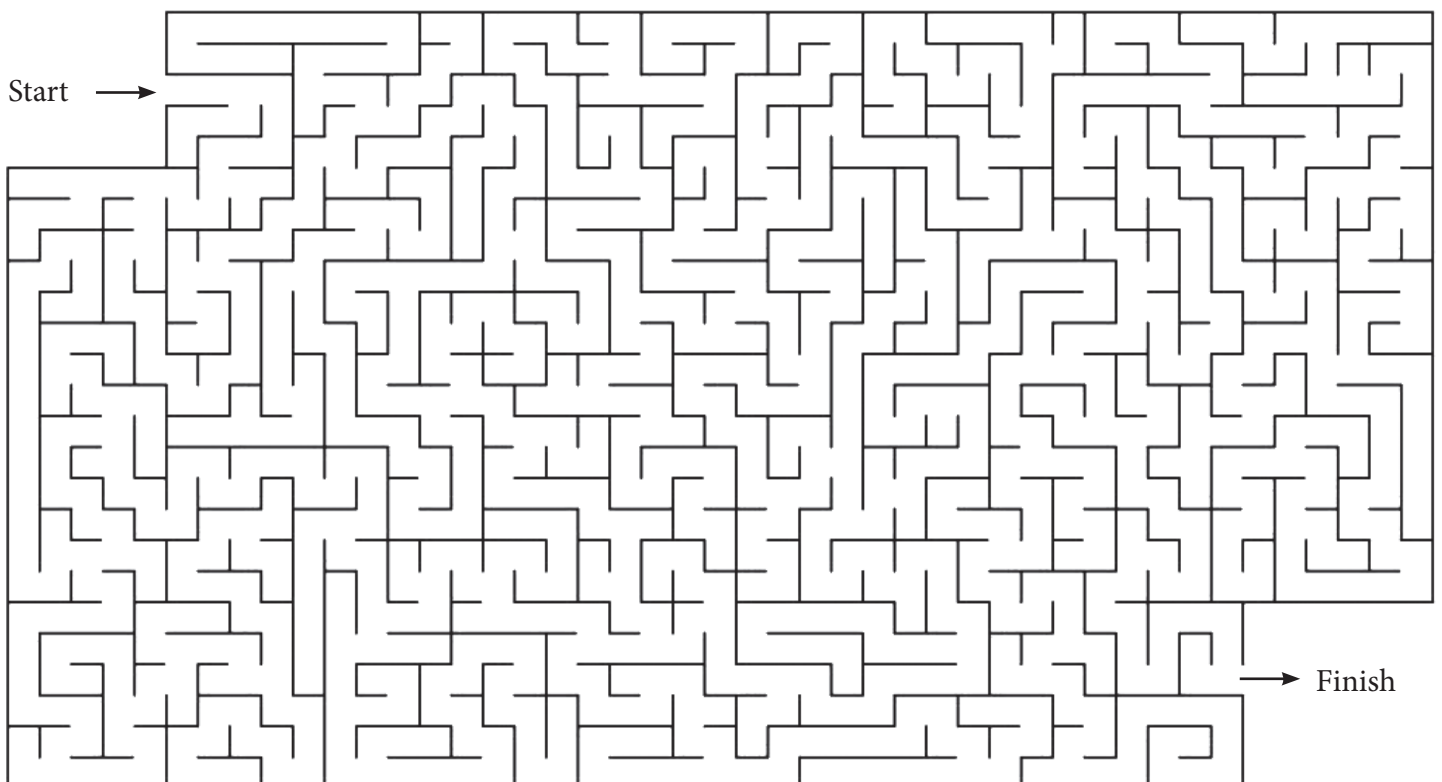
Bamboozable 16: 1. One step forward, two steps back; 2. Double or nothing; 3. Peppermint twist; 4. Forefathers; 5. Enroll; 6. Addresses.

## Bamboozable

STEP 93T2 93T2	OR OR Ø	PEPPERMINT
FATHER FATHER FATHER FATHER	NZZZZN	dress dress + dress

## Answers

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



## NEWS FROM AROUND QUEENSLAND

### News from Cairns

Please join us for our first Coffee & Chat in 2022, **Saturday, 26 March, Cairns RSL Boardroom at 11am**. Some will stay for lunch afterwards at 12.30pm. If you are visiting Cairns at this time, you are most welcome to join us.

For more information, please contact Donna on 0414397462 [donnaformosa64@gmail.com](mailto:donnaformosa64@gmail.com)

### News from Townsville

Thanks for attending our February lunch. **Saturday, 30 April at 12 noon** is set for the next luncheon at **Kirwan Sports Club, 159 Bamford Lane**.

Family members are welcome. Please note change of venue. I look forward to your company and I will let you know if covid conditions change.

For details and if you can come, please RSVP Daphne on 0400 778 637 or [daphclay@gmail.com](mailto:daphclay@gmail.com)

### News from Mackay

For more information, please contact Mary on 0749 595 251.

### 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](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

Please join us on **Monday, 11 April at 10.30am** for a Coffee and Chat at **Kawana Club, 476 Nicklin Way**. All 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 at **10am on Saturday, 9 April, at Southport Sharks Club at 10am**. I hope to see all there. Kind regards. For more information contact Nader, Gold Coast Co-ordinator, 0415 834 401.

## WELCOME TO OUR NEW MEMBERS

Michael, Cleveland QLD

James, Willetton WA

Beverley, Carlton VIC



## COFFEE & CHATS

RSVP Anita on 0414 588 312

### IPSWICH

– **Queens Park Café –**  
**Saturday 26th March at 10.30am**  
**10a Merle Finimore Avenue, Ipswich**

### MANGO HILL

– **Coffee Club –**  
**Thursday 7th April at 10.30am**  
**Cnr Halpine Drive & Anzac Avenue, Mango Hill**

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