



Myasthenia Gravis Association of Queensland Inc.

# MessaGes

NOVEMBER  
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.

## PRESIDENT'S REPORT NOVEMBER 2022

With all the Christmas decorations and gifts everywhere in shops and advertising coming through in all forms of technology, it seems that another year is nearing the end. No doubt everyone will be very aware of what they are spending this Christmas as the level of uncertainty seems to not be getting any better.

Denise, our treasurer, is still trying to find out if people who are not up to date with their membership still want to remain as financial members of the MGAQ. If you receive any inquiries from her about this, please take the time to either reply to her email or phone 1800 802 568 so that she can make the appropriate changes. Keeping an up-to-date list of members is vitally important.

Accolades must go to our treasurer, Denise, for the many hours she put into organising the Art with Heart Auction. While its prime focus was to raise awareness of Myasthenia Gravis within the community, it was also a fundraiser to support the work of the Myasthenia Alliance Australia. As it was the first year this event has been held, it was a resounding success. We look forward to bigger and better next year.

Our meeting with Queensland Health in September was once again very positive. It is such a delight on the part of the MGAQ executive team to hear that Qld Health were amazed at the work of the asso-

ciation and the outreach we have achieved across the state. They were also particularly impressed with the support materials we have developed for our members. Positive comments were also received about the quality and range of guest speakers we have and the extent and range of podcasts we now have for financial members.

The catchcry that "*Patient Voices Matter*" is starting to be heard by all levels of government and pharmaceutical companies. The MAA has been working hard speaking with relevant individuals and companies in an effort to ensure that the shortage of Mestinon will be addressed in the near future. People will be kept informed through webpages, email and SMS messages.

**Our MGAQ Christmas Function to be held at Club Southside, 76 Mount Gravatt-Capalaba Rd, Upper Mt Gravatt on Sunday, 11 December 11.30 am.**

**For more information or to RSVP please Email: [info@mgaq.org.au](mailto:info@mgaq.org.au) or Freecall 1800 802 568.**

As it is our last event for the year we hope that as many as possible make the effort to attend.

Just when we thought the Covid situation was looking more positive we have another two variants. Let's hope that all our members get to spend another Christmas with family and friends.

**Thanks, Carol**

### Myasthenia Gravis Association of Queensland Inc

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#### COMMITTEE MEMBERS

**President:** CAROL BUCHANAN

**Vice-President:** SUSAN WHITE

**Secretary:** YVONNE HORNBY-TURNER

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**Treasurer:** DENISE HANNAY

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# MYASTHENIA ALLIANCE AUSTRALIA

## NEWS UPDATE

Included in this newsletter are two very important items. The first, which is found below, gives members information in regard to the Mestinon shortages that are currently happening. The MAA have been actively reaching out for the past weeks raising concerns, explaining difficulties and requesting a plan for management of this situation. The team will continue to do so and we hope to be able to provide more information in the weeks ahead. The information will be shared in all the usual ways.

The second item is on **page 3** and gives the first feedback from the **‘Patient Reported Outcomes Survey’** research project which closed January 2022. Once again, a big thank you to all those who participated in this lengthy survey. Please note the “Next steps: What will we do with this data?”

**Best regards**

**Susan White - MAA Chairperson**

If you are not already registered with the Alliance please go to  
**[www.myastheniaalliance.org.au](http://www.myastheniaalliance.org.au)**

## MESTINON SHORTAGE

There are ongoing supply issues for some forms of Mestinon (particularly Timespan 180mg and 60mg) in Australia. We appreciate this can be concerning for MG patients who take Mestinon continuously and/or regularly. Please see recent updates below and your state associations (MGNSW and MGAQ) and the MAA will keep you as updated as we can.

Mestinon Timespan 180mg is available under Section 19A, with Medsurge Healthcare using suppliers in the USA. Patients only need their regular prescription to obtain Mestinon Timespan from their pharmacy. **A price can be more clearly determined once the stock arrives.**

For Mestinon 60mg, patients need to visit their doctor and ask them to complete a Special Access Scheme (SAS) form and submit this to the Therapeutic Goods Administration (TGA). Once this is approved, it will be returned to the doctor to then pass on to the patient. The patient will submit this to their pharmacist, who will use this approval number to order the medication (each script will be processed and ordered separately). **The pharmacy will be advised of the cost of the medication and will inform the patient.**

Please visit the TGA website <https://apps.tga.gov.au/shortages/search/Details/pyridostigmine-bromide> regularly as this will help confirm the need for Mestinon for MG patients.

More information on Section 19A approvals to address medicine shortages is available at <https://www.tga.gov.au/safety/shortages/database-section-19a-approvals-import-and-supply-medicines-address-medicine-shortages>, and more information on the SAS available here <https://www.tga.gov.au/resources/resource/forms/special-access-scheme>.

# THANK YOU!

## Myasthenia Gravis (MG) Australian Survey 2022

### A Summary for Participants

#### Study objective: What did we hope to achieve?

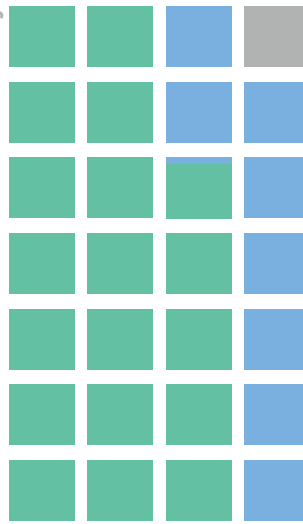
Generate evidence required to advocate for people living with MG to have timely and equitable access to better health service, better funding, and more reimbursement pathways.

#### Study design: How did we collect the data?

Surveyed MG patients electronically about quality of life, personal histories with MG, and the financial and clinical aspects of living with MG.

**280** Respondents **Average Age 60.5**

**67.5%** Female **32.1%** Male **0.4%** Nonbinary



Average **2.9 years** from first symptoms to diagnosis

1.5 Years Male

3.6 Years Female

**50%** from capital cities | **50%** from regional areas

### Participant Experience With MG

Most were limited in daily tasks and activities



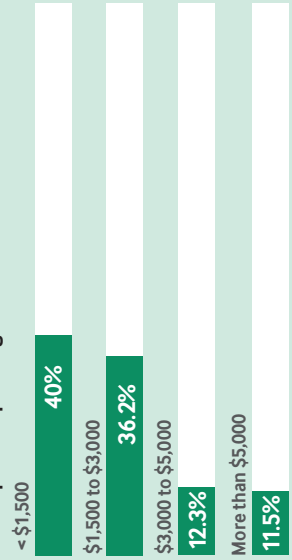
During the past 12 months:



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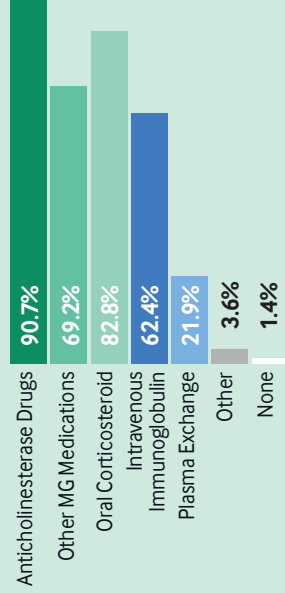
**48%** required additional medical intervention

Those who required additional intervention reported out-of-pocket spending:

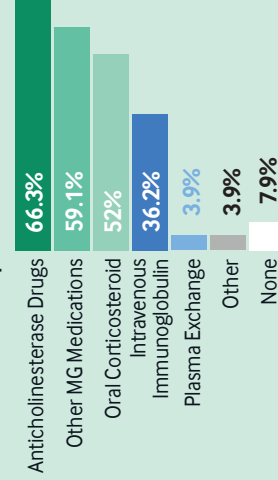


Participants reported their treatments used, currently or in the past

All current and previous medications and procedures\*



Current medications and procedures\*



**33.7%** reported that their thymus had been removed

Next steps: What will we do with this data?

- Share it with neurologists in clinical conference
- Publish it later in 2022
- Use it in dialogue with the Minister of Health as part of a larger effort to improve treatment options

\*These categories are not mutually exclusive.



## TOOWOOMBA COFFEE & CHAT

# Puzz1ers

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

### Word Search

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

**BAMBOOZABLE Answers:** 1. Keeping You Out of Trouble; 2. Foreign Movie; 3. A Little Rough Around the Edges; 4. Too Little, Too Late; 5. Double Your Money Back; 6. Start of Something Big.

### Bamboozable

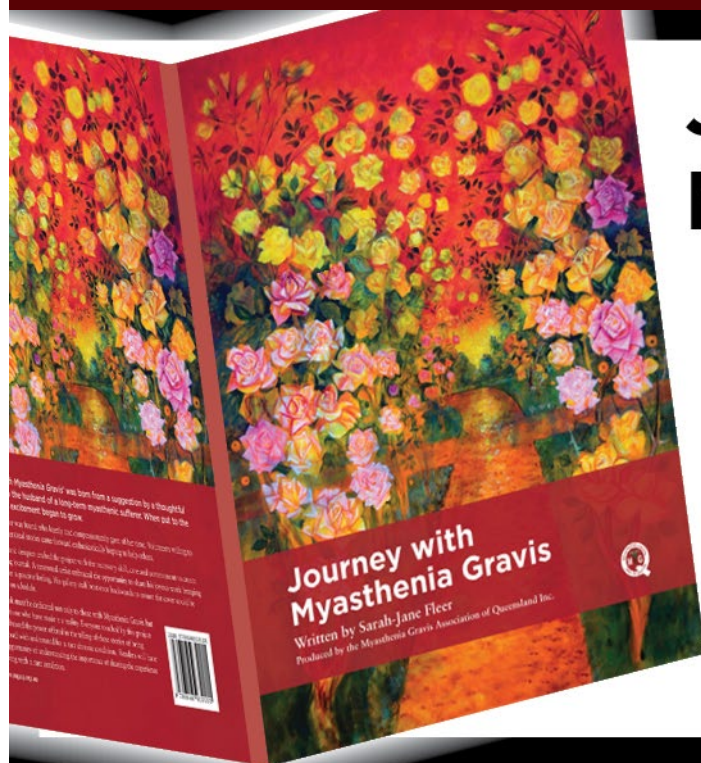
TRO BLE TRO BLE TRO BLE	MOV 4 IE	rough rough rough
LATE LATE	YENOMRUOY YENOMRUOY	SOMETH BI

### WORD SEARCH

#### Famous Female Singers

BLIGE	MADONNA
CAREY	MCENTIRE
CASS	NICKS
CLOONEY	PARTON
CROW	REDDY
DION	RONSTADT
ESTEFAN	ROSS
FLACK	SIMON
FRANKLIN	STREISAND
HILL	SUMMER
HOUSTON	TURNER
JACKSON	TWAIN
LAUPER	WARWICK
LOPEZ	WINEHOUSE
LOVE	WOMACK





# 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)**

## RECIPE CORNER

### Spinach, Ham and Egg Rollups

Serves: 4 (makes 16 small rolls)

Prep time: 10 minutes    Cook time: 0 minutes



1 serve per portion

#### INGREDIENTS:

- 4 hard boiled eggs, peeled
- 2 tablespoons mayonnaise
- 2 teaspoons Dijon mustard
- 4 pieces rectangular flatbread (e.g. mountain bread) 2 tablespoons hummus\*
- 120g leg ham, lean, shaved
- ½ Lebanese cucumber, cut into long strips
- 1 ½ cups baby spinach leaves

#### \*Hummus

- 400g can chickpeas, drained and rinsed
- ½ lemon, juiced
- 1 small garlic clove
- 2 tablespoons olive oil
- ½ teaspoon ground cumin



#### METHOD:

BLITZ hummus ingredients in a food processor until smooth.

PLACE eggs in a bowl. Add mayonnaise and mustard and mash with a fork.

SPREAD a thin layer of hummus over the flatbread.

ARRANGE ham in a row across the bottom third of each piece of flatbread.

SPOON egg mixture evenly across ham layer.

TOP with a row of cucumber strips and spinach leaves. Roll up firmly.

SLICE each roll into 6 pieces when ready to serve.

Recipe courtesy of [qcwacountrykitchens.com.au](http://qcwacountrykitchens.com.au)

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



## Myasthenia Gravis Friends Western Australia Coffee & Chat - **Sunday, 20 Nov.**

Venue: **Austria Club, 46 Staniland Street, Orange Grove**

Date: **Sunday, 20 November at 2.30pm**

For more information, please contact Annette on 0413 855 077.



### VICTORIAN REGIONAL MG LUNCHEON

to be held at the

**Sunday 4 December at 12 noon.**

**Shepparton RSL Club, 88 Wyndham Street Shepparton.**

Everyone is welcome! RSVP by Friday 2 December.

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

## WELCOME TO OUR NEW MEMBERS

KAREN, MOUNT LOUISA NSW

ROSS, SEVEN HILLS QLD

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

to be held at

### Club Southside

76 Mount Gravatt-Capalaba Rd, Upper Mt Gravatt

on

**Sunday, 11 December**  
**11.30 am**

*For more information / RSVP - Contact Susan*

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



**SUPPORT** your Association by **VOLUNTEERING.**

## 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.**

### Changing of the Guard

I have newly become a grandmother. The joy and amazement that this little one brings to our lives is incomparable. Recently too though, our Mum passed away. Some describe these as the 'highs and lows' of life, but can they be seen differently? It is wonderful that Mum got to experience great-grandmother-hood, even if from a distance. They lived three states apart, but Mum continually delighted in seeing how 'Z' changed and grew in the six months that she knew her.

Isn't it remarkable how new life can bring total delight and a renewed zest for life? Even in the sadness of loss I have used this energy to help me focus. I have been reflecting on the sixty years that I shared with Mum, recalling the fun things that we did, what she taught me, and all that we enjoyed. There are numerous skills, talents and loves that Mum passed on to me and they continue to fuel my appetite for life.

Mum was an avid gardener, and it was where I found my love of gardening (be it so, I still call myself an amateur). She was also a very skilled sewer and knitter and taught me to knit when I was six years old. She made 'Z' one of her first outfits. It was a set of knitted pants and cardigan, complete with booties and a hat, in red – my favourite colour.

Mum always made sure I experienced art. She took me to amateur theatre performances and to the city to see art exhibitions and installations. My love of art and beauty comes from experiencing these with her. No doubt I will now get to indulge our granddaughter in these as she grows, and in this way, I get to honour Mum all over again as I share her loves with a new generation. A kind of "changing of the guard" if you like.

I choose to see the positive in both the highs and the lows of life. As it has been stated, how can we know joy without tears, light without dark or happiness without sadness? I certainly know and appreciate health and wellness after experiencing the extremes of unwellness. And so, I go on rediscovering old loves with renewed enthusiasm and with much gratitude to our new granddaughter and to our Mum.

**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.





## NEWS FROM AROUND QUEENSLAND

### News from Cairns

Please join us at the **Cairns RSL Boardroom, Esplanade** on **Saturday, 26 November at 11.00am** for our regular catch up. Please note change of date.

If you are visiting Cairns, you are also welcome to come along. This will be our last gathering for 2022. For more information please call/text **Donna on 0414 397 462**.

### News from Townsville

Thank you to everyone who attended our lunch in October. The December lunch is at **Sports Club, 159 Bamford Lane, Kirwan** on **Saturday 3rd December at 12 noon**.

As this is our Christmas lunch, you are invited to bring a gift (\$15-\$20) and we will exchange gifts. Looking forward to your company. Family members are also welcome. Please RSVP to **Daphne on 0400 778 637** or email [daphclay@gmail.com](mailto:daphclay@gmail.com)

### News from Mackay

For more information, please contact **Mary on 07 4959 5251**

### News from Bundaberg

For more information, please contact **Denise on 0431 571 399**.

### News from the Sunshine Coast

Please join us for our next Coffee and Chat on **Monday, 5 December at 10.30am - Kawana Club, 476 Nicklin Way Kawana**. All are welcome.

For more information, please contact **Vicki on 0411 146 898** or email [avlplummer@gmail.com](mailto:avlplummer@gmail.com)

### News from the Gold Coast

Our next meeting will be at **10am on Saturday, 3 December at Southport Sharks Club**. I hope to see all there.

Kind regards Nader Amiri, Gold Coast Coordinator **0415 834 401**.



## COFFEE & CHATS

RSVP Anita on 0414 588 312

### WELLINGTON POINT

**Thursday, 1 December at 10.30am, Farmhouse Restaurant & Coffee Shop  
625 Main Road, Wellington Point**

# YOU'RE INVITED

SEE PAGE 6

What's On?	When Is It?	Where Is It?
<b>MGAQ CHRISTMAS FUNCTION</b>	<b>SUNDAY, 11 DECEMBER 11.30</b>	<b>Club Southside, 76 Mount Gravatt- Capalaba Road Upper Mt Gravatt</b>

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