



Myasthenia Gravis Association of Queensland Inc.

Messages

DECEMBER 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 DECEMBER 2022

It is hard to believe that this is our final newsletter for 2022. The next one will be printed and distributed in February next year.

The catchcry that **"Patient Voices Matter"** is starting to be heard by all levels of government. Committee members, Susan and Denise, attended a high level summit in Sydney along with members of Rare Voices Australia. Please read the MAA report for more information.

Further evidence of the hierarchy taking notice of our associations is the work being done in relation to the availability of Mestinon 180mg and Mestinon 60mg. Lots of phone calls and emails have resulted in processes being put in place to secure this medication for people with Myasthenia. It also alerted the medical profession with the fact that this is a very serious issue as this medication cannot be substituted by another. Many thanks to the MAA for taking a leadership role in this and I hope that all people with Myasthenia who take Mestinon now feel comfortable with accessing same. If you have any issues please call the freecall number 1800 802 568.

The MGAQ funding from Queensland Health will continue into 2024 and we thank them most sincerely for their ongoing support. Our committee is

always most proud to present our activities report and evaluation of same to Queensland Health and I know they appreciate all the work we do with such a small committee.

By now people who bid and won will have received their Art with Heart auction items. It was such a nice surprise to open the box and find such a beautiful item. My bowl will certainly be on the Christmas table.

Many current and past management committee members, people with myasthenia, carers, families and friends, past and present, have contributed to this association in many ways and I wish to acknowledge all the support received over such a long period of time.

The committee will now take a break and resume activities in February. Their work throughout this amazing year is much appreciated by me. I wish them a well-deserved rest and a happy Christmas. The management committee also wishes everyone a Christmas filled with family, love, laughter and, most importantly, good health. I am sure that families will really appreciate the fact that we can all get together and show the love and appreciation that we have missed over the past few years.

Thanks, Carol

Myasthenia Gravis Association of Queensland Inc

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



MYASTHENIA ALLIANCE AUSTRALIA

NEWS UPDATE

Thank you to Natalie Windle (MAA Secretary) and Glenda Bidner (MAA Board Member) for their frequent and persistent enquiry with the both the TGA and the Pharmaceutical companies (iNOVA and Medsurge) as the MAA pursues a resolution to the issues surrounding supply of Mestinon Timespan and the 60mg tablets. Please see Page ... of this newsletter for the latest update or visit www.myastheniaalliance.com.au. All updates are shared across a wide range of platforms as the MAA tries very hard to keep all Australians informed. Your feedback helps us to understand the issues being experienced so please keep in touch.

It was an absolute privilege to attend the Rare Voices Australia (RVA) 2022 National Summit which was hosted in Sydney. Denise Hannay supported me representing the MGAQ. Both organisations partner with RVA whose work is exciting and progressive. The RVA team now has nine members and this team is achieving significant outcomes, is building deep and effective relationships and is actively seeking to grow understanding of the issues faced by the rare disease community.

The diverse backgrounds of attendees demonstrated broad representation from the Medical Profession, Government, Industry and Patient Groups. There were many very small organisations such as the MAA and MGAQ but also more developed organisations, some with significant staff. It was good to network, to learn and to reflect.

Dr Mike Freeland MP, who is a keen supporter of the rare disease sector, attended in person and opening messages came from both The Hon. Mark Butler MP, Minister for Health and Aged Care and Shadow Minister, Senator Anne Ruston.

The MAA was asked to present a case study sharing our journey to success with Rituximab achieving PBS listing for Myasthenia Gravis. This demonstrated how a medicine has been repurposed in line with Action 2.4.3.3 of the National Strategic Action Plan for Rare Disease which was launched in Feb 2020. It truly was an honour to be an invited speaker and the subsequent feedback was heartwarming.

Overall, the three days demonstrated a clear vision a willingness and committed purpose to achieve a strong future for this sector. A great deal more needs to be achieved but the Myasthenia community does not stand alone.

(A copy of the Action Plan is now available through the MGAQ Library Resource.)

The MAA Annual Report is soon to be published and will be widely shared. Please take the time to read this report and learn about the diverse engagement of this patient support organisation.

I thank the MAA Board for their commitment, hard work and support throughout 2022. I wish the Myasthenia Community, inclusive of patients, family, supporters, carers and interested health professionals, a Christmas season which is joyful, contented and healthy.

Best regards

Susan White - MAA Chairperson



• Susan White on the Q & A Panel



• Susan White with Amanda from RVA and Denise from MGAQ



• Susan White presenting the MAA Case Study at the RVA National Summit.

If you are not already registered with the Alliance please go to www.myastheniaalliance.org.au

PATIENT Voice Matters

MGAQ CHRISTMAS FUNCTION - DEC. 12

Club Southside 76 Mount Gravatt-Capalaba Rd, Upper Mt Gravatt



- Some of the committee members at the December meeting.



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

MY JOURNEY WITH THE MGAQ COMMITTEE

Hi, my name is Denise and I am in my seventh year as a member of the MGAQ Management Committee, all in the role of Treasurer.

In 2016, the MGAQ was calling for a new treasurer, so I travelled to Brisbane to meet the then committee with the late Graeme Peters as President, to see what the committee did, to see if I would fit in, and also for them to meet me. In the four years since my diagnosis, I had not met another person with MG. I instantly felt that I had met my other family, people who understood and felt me, that I had come home... As everyone sat down around Shirley's dining room table, to get down to the monthly business and share in a beautiful homemade morning tea, I was sold. *Such a revelation!* I have been on other major management committees, but this was different, very personal and with the focus on the members wellbeing and what could be done to improve their lives.

Thus began my journey as a member of this amazing committee. The huge amount of work and projects that the committee undertakes for the MG community has grown exponentially over this time and it has evolved into a highly strategic and active organization. All of this on a voluntary basis, without an office, with people from all over the state, such a cohesive body, all with the same goal, to help improve the lives of people with Myasthenia and their families.

This has been and still is a very rewarding experience for me personally. To have met so many like-minded people, making lifelong friends and having the satisfaction of doing something worthwhile. I have learnt new skills, learnt to extend myself, been involved in two MG national conferences, helped implement and streamline our accounting system and membership data base, been involved in many other projects, recently the Art the Heart Auction. I have also had the privilege to attend the recent Rare Voices Australia (RVA) National Summit as a representative of the MGAQ, and so much more. Just being



involved with the everyday running of the association, attending nine meetings a year, interacting with members, working with my fellow committee members, being part of an incredible team – such a fulfilling experience.

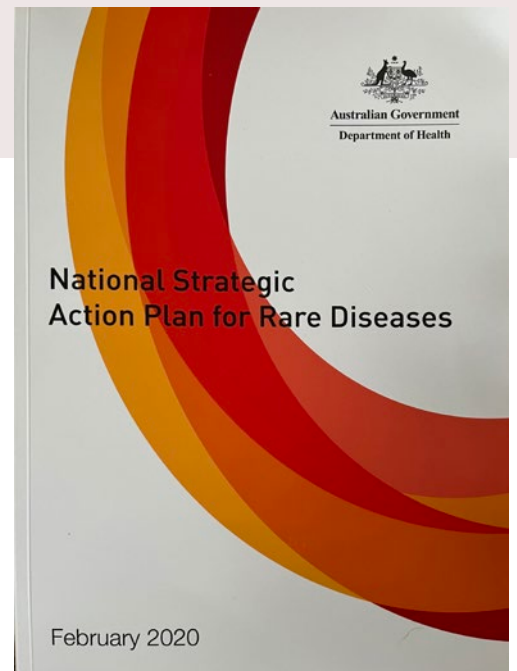
I would like to recommend to anyone who would like to become involved in some way with the MGAQ, either as a committee member or as a support person to help with projects. If you have any skills or enthusiasm that you would like to share with us, it would be greatly appreciated. We are continually growing and have so much more to do, but all members of the committee have MG to varying degrees, and we need more help so that we are able to continue to give the MG community the best possible representation. Thank you for your interest.

NEW LIBRARY RESOURCE AVAILABLE TO MEMBERS

This document is the framework that directs the future strategic actions for Australians with a rare disease. There are four supporting pillars to this policy. It is well worth taking a look.

In the usual way this Library item will be posted out and members are required to pay the return postage.

Please call 1800 802568 or email info@mgaq.org.au if you would like to take advantage of this opportunity.



WELCOME TO OUR NEW MEMBERS

CHARLES, BANYO QLD

JEANETTE, BAYVIEW HEIGHTS QLD

SONIA, HERMIT PARK QLD



COFFEE & CHATS

RSVP Anita on 0414 588 312

IPSWICH

Saturday 28th January - 10.30am
Queens' Park Cafe,
10A Merle Finnimore Avenue, Ipswich

MANGO HILL

Thursday 2 February - 10.30am
Coffee Club, Mango Hill Market Place,
Cnr Anzac Avenue & Halpine Drive

SUNSHINE COAST DECEMBER



PATIENT Voices Matters

GOLD COAST DECEMBER



RECIPE CORNER

Jo Zampieri's Christmas Cake

Serves: 15-20

Prep time: 10 minutes (+24 hours soaking time)

Cook time: 60-90 minutes



1 ½ serves per portion

Ingredients

1kg mixed dried fruit
500-750mL orange juice, no added sugar
1 cup wholemeal self-raising flour
1 cup self-raising flour
1 teaspoon all spice

Method

SOAK fruit overnight in 500mL of orange juice in the fridge.
PREHEAT oven to 160°C conventional/140°C fan-forced.
ADD flours to the fruit and juice mixture and stir until combined.
POUR in more orange juice if the mixture is too dry.
SPRINKLE in allspice and place mixture into a lined 20cm baking tin.
BAKE in oven for 1-1½ hours or until a skewer comes out clean.



Discretionary Food

Recipe courtesy of www.qcwacountrykitchens.com.au

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

MAA UPDATE ON MESTINON SUPPLY - DEC '22

The MAA continues to stay abreast of the Mestinon supply shortage issue and is in regular contact with government and industry stakeholders. The latest update for Timespan (180mg) and 60mg is below.

- Timespan (180mg): **Section 19A approval is extended to 31 May 2023** (previously approved until 30 November 2022) and this is **listed for subsidy under the PBS**. This means you should pay what you normally pay for your Mestinon Timespan script. Medsurge Healthcare is currently assisting with the import and supply of this product. **Please get your scripts in so that your Timespan can be ordered.**
- 60mg: **Section 19A approval has now been confirmed to 31 May 2023**, however the PBS subsidy is not yet confirmed but we understand an application is pending. iNova Pharmaceuticals is currently assisting with the import and supply of this product.

A reminder that Section 19A aims to reduce the impact of the shortages of the usual Mestinon products brought into Australia.

Please ensure you take information provided by the MAA updates with you to your pharmacist to assist with the process.

Thank you for continuing to support each other as a patient community and if you have any concerns or feedback please contact us:

Email info@myasthenia.org.au or call (02) 4283 2815

Email info@mgaq.org.au or call 1800 802 568

SHEPPARTON, VICTORIA DECEMBER



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

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.

The Committee have thoroughly enjoyed Helen's contributions throughout 2022 and express our sincere thanks.

My mind's eye

Using my mind's eye or visualisation (having a clear picture in my imagination or memory) is a skill I first consciously developed in my late teens. We all have this ability, and with practice I became adept at the technique and continue to experience the benefits.

I used visualisation very early in my diagnosis with Myasthenia Gravis (MG). When I was unable to walk due to muscle weakness, I would visualise myself walking with our dog. This exercise helped me to 'get out of the house' and enjoy what I knew so well. All I had to do was close my eyes and I was there. I could 'see' every street, the curves of the road, the potholes to miss, the trees, the view of the green rolling hills and all aspects that I would normally have enjoyed if I was physically walking there. As a bonus I could use my other senses too and 'hear' the crunching of the gravel beneath my feet, the wind in the trees, and 'feel' the sun on my face.

The use of visualisation or mental rehearsing by athletes has been noted in many scientific journals. The articles report that visualisation is not that different to the actual physical rehearsal in the way in which it helps an athlete prepare for their sport and get the most from themselves. Other research suggests that visualisation can strengthen muscles. (Source: www.verywellfit.com Do visualization exercises help build strength? By Elizabeth Quinn, August 13, 2020). I did not necessarily feel an improvement in my muscle strength from using visualisation, but it did have a favourable effect on my mental health.

More recently, visualisation was especially useful during the pandemic lockdowns. I had a lot of fun revisiting innumerable beautiful places all over the world without the danger of catching Covid19, and without the cost! Closing my eyes and imagining myself elsewhere helped me get past the 'four walls syndrome' that was rife during that time.

So, being a dreamer does help. Using my understanding of the power of the mind's eye I can re-encounter old or envisage new experiences. Visualisation has helped me navigate my MG journey and has been very beneficial in our current climate, giving me both relief and distraction from existing conditions. It has been entertaining and fun and most importantly, beneficial to my mental health. Maybe it even helps tone my muscles too. I'll keep my eye on that research!

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.

PUZZLERS

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

Sudoku

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

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

Word Change

grate
blame

Answers

Word Change 28 An-
swers: grate, grade, blade, blame

Commonym Answers:
1. they are caught
2. they are tossed
3. they are popped
4. they have caps
5. they have tongues
6. they have anchors
7. they are magazines
8. they have lanes
9. they lift
10. they have checks

Bamboozable 30 An-
swers: 1. Total Mess;
2. Paint by Numbers;
3. Four Part Harmo-
ny; 4. Poison Ivy; 5.
Tilt a Whirl; 6. Internet.
Site.

Word Search - Books of the Old Testament

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

DEUTERONOMY
ECCLESIASTES
ESTHER
EXODUS
EZRA
GENESIS
JOB
JOSHUA
JUDGES
LEVITICUS
NEHEMIAH
NUMBERS
PROVERBS
PSALMS
RUTH

Bamboozable

MESS +MESS +MESS	paint276 paint514 paint693	ha rm on y
IpoiseV	WHIRL	teNrr net sight

Commonym (1)

What's a commonym you ask? A commonym is group of words that have a common trait in the three words/items listed. For example: the words; A car - A tree - An elephant.. they all have trunks. These will make you think!

1. A Ball - A Fish - A Cold
2. A Ball - A Salad - A Coin
3. A Cork - A Question - A Balloon
4. A Bottle - A Baseball Player - A Mushroom
5. A Bell - Mouth - A Shoe
6. A Tug of War - The Nightly News - A Boat
7. Seventeen - Time - People
8. A Basketball Court - A Highway - A Bowling Alley
9. Fog - A Jack - A Body Builder
10. A Hockey Game - A Restaurant - A Bank

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

NEWS FROM AROUND QUEENSLAND

News from Cairns

It has been a pleasure to see people back at our regular get-togethers this year and welcome those who are new to the myasthenia journey. Our thoughts and prayers are with all who have had health challenges and life challenges this year and look forward to seeing you all again in 2023.

We farewell Paul as he heads back to New Zealand and wish him all the best in the cooler climate.

Please mark in your diaries **Saturday, 18 February at 11.00am, Cairns RSL Club** as the first get-together for 2023. If you will be visiting Cairns at this time, you are also welcomed to come along.

For more information please call/text **Donna on 0414 397 462**.

News from Townsville

Townsville members had a lovely Christmas lunch on 3 December and beautiful gifts were exchanged. Thanks to Shirley for organising this activity. Our next lunch is on **Saturday, 4 February 2023 at Sports Club, 159 Bamford Lane, Kirwan at 12 noon**. RSVP/more information call **Daphne 0400 778 637** or email 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

Sunshine Coast group enjoyed each other's company at the recent gathering on 5 December. I am looking forward to more coffee and chats with you in 2023. I would like to wish everyone a very Merry Christmas and a happy new year.

For more information, please contact **Vicki on 0411 146 898** or email avplummer@gmail.com

News from the Gold Coast

Hi Everyone. MG Gold Coast group had their get together sharing experiences with other members on Saturday, 3 December at Southport Sharks Club. **Our next meeting will be at 10am on Saturday, 11 February at Southport Sharks Club**. I hope to see all there.

I take this opportunity to wish everyone a merry Christmas and a happy new year.

For more information, please contact **Nader Amiri, Gold Coast Coordinator 0415 834 401**.

*The Myasthenia Gravis Association of Queensland Inc.
Committee would like to wish everyone a*



*Merry
Christmas* and a safe
and happy
New Year!

MessaGes will take a break over January and looks forward to resuming in February 2023. Thank you to all contributors during 2022.