



Myasthenia Gravis Association
of Queensland Inc.

MessaGes

FEBRUARY
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.



"Supporting One Another"

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PRESIDENT'S REPORT FEBRUARY 2022

We are very lucky to be living in Australia and have such a great medical system and wonderful volunteers who are prepared to just keep going to support our country when it is in need.

The information that we are getting about COVID-19 makes it appear that it will be part of our lives for a considerable time to come. An updated vaccination statement from ATAGI relating to the Omicron variant and an accompanying email from Stephen Reddel was forwarded via SMS, email and website posts in early January. Please take note of the information about the recommendation for three primary doses plus a fourth dose booster for people who are immunocompromised. Should you wish to revisit this information the link to ATAGI is:

<https://www.health.gov.au/news/atagi-statement-on-the-omicron-variant-and-the-timing-of-covid-19-booster-vaccination>

We still have quite a few members who are unfinancial. As this money is used for things such as producing and sending out the newsletter, podcasts, website updates and functions for members it is important that we have funds available to continue these services. Please take the time to check if you are financial. We only expect people to pay for the current financial year and do not ask for any unpaid fees from previous years.

Rare Diseases Day is held on 28 February to raise awareness for rare diseases and improve access to treatment and medical representation for individuals with rare diseases and their families. Please take a minute to think about the approximately 8% of the population who live with one of the 10,000 known rare diseases in Australia. Statistics show that there are a similar number of people living with a rare disease as there are people who have diabetes or asthma.

Working hand in hand, through the Myasthenia Alliance Australia, with Rare Voices Australia, the National Strategic Action Plan for Rare Diseases has provided a platform for negotiating at a national level for better treatments for people with rare diseases. A very significant example of this is the inclusion of Rituximab on the Pharmaceutical Benefits Scheme (PBS). More information about this will be forthcoming in the near future.

This year will again be a very busy one for the management committee and we look forward to continuing to provide the best possible service and support for our members.

Thanks, Carol

Myasthenia Gravis Association of Queensland Inc

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SUPPORT your Association by taking **MEMBERSHIP.**



MYASTHENIA ALLIANCE AUSTRALIA

FEBRUARY NEWS UPDATE

Welcome to 2022 and what promises to be another year of significant engagement by the MAA with our community, Government policy makers, Industry Partners, Medical Professionals and Researchers. The MAA Annual Report for 2021 is now available. For the convenience of MGAQ members it will shortly be distributed directly to you but it is easily accessible via the following link <https://myastheniaalliance.org.au/maa-2020-2021-annual-report/> or by calling 1800 802 568 for a hardcopy to be posted out.

Whilst we aim to give our volunteers a well earned rest during the family festive time, I want to express sincere thanks to each of the volunteers who make up the Queensland and NSW State Associations. When Dr Reddel, MAA Medical Advisory member, wrote to the MAA in late December about a December 24th announcement from ATAGI which was relevant to our immune suppressed people, each member of our teams made themselves available to get the information out to all the Australian myasthenia community via our range of communication methods. The entire team prioritised this need and as a result we were able to rapidly communicate this important message. I know that everyone joins me in expressing appreciation to these people who are so committed to helping others and making a difference. The MAA could not exist without the State Association Committee members. Hopefully these teams will continue to grow allowing the workload to be more widely distributed.

Thank you again to everyone who participated in the Patient Reported Outcomes survey. It has now closed and the data is currently being analysed. The responses given and the information gathered is of significance. It was pleasing to see the broad representation across all areas of Australia. The MAA look forward to sharing resulting information as we are able. Do note, that publishing recognised Medical Journal articles is usually a two year process.

Susan White, MAA Chairperson.

Follow the work of the Alliance by registering at the website www.myastheniaalliance.org.au



VICTORIAN REGIONAL MG LUNCHEON

to be held at the

**Shepparton RSL Club,
88 Wyndham Street Shepparton.
Sunday 27th March at 12 noon.**

Everyone is welcome! RSVP by Friday 25th March.

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

WELCOME TO OUR NEW MEMBERS

Olly, Southport, QLD
Helen, Deer Park, VIC
Fiona, Alphington, VIC
John, The Vines, WA

Noel, St Helens, TAS
Mark, Warner, QLD
Logan, Kallangur, QLD
Amanda, Fulham Gardens, SA

Logan's Fundraiser for MYASTHENIA GRAVIS

"This is Ashleigh. Logan is keen to support her and others as they journey with Myasthenia."

See page 5 for more details.

www.facebook.com/donate/4518817658229640/



RARE DISEASE DAY 28 FEBRUARY 2022



rare voices
AUSTRALIA®

MGAQ SUPPORTS THE "LIGHT UPS" IN
QUEENSLAND FOR RARE DISEASE DAY.

QUEENSLAND ILLUMINATIONS

Sir Albert Abbott Administration Building

Kurilpa Bridge

Story Bridge

Victoria Bridge

Reddacliff Place Steam Sculptures

City Hall Annex

MGAQ.org.au MEMBER LOG-IN

The MGAQ website has many additional features available only to financial members. These include videos of presentations from past speakers inclusive of leading specialists. All general meetings of the Association are recorded and posted.

In addition, the complete list of Podcast recordings are available too.

The contents of library materials available to members is listed and also a range of research papers the Association can help members access is given.

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 to make your request.



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

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.

200 Squats a Day for 60 Days For Ashleigh.

Logan writes -

Meet Ashleigh, recently diagnosed with Myasthenia Gravis. She is such a strong, powerful woman. An "I can do it myself" attitude and believe me when I say, she can. Seeing her lose the ability to exercise and live the way she loves and have to adapt and change for her health and wellbeing was a huge impact on her and many others with this autoimmune disease.

For myself, I am a helper, as all my clients know. So, this has been a huge challenge for me also as an outsider looking in. I've put together a charity- 200 Squats a Day for 60 Days. With a large chunk of my clients participating and helping which has been humbling. Seeing Ash's face light up at all the videos, both adults and children as they do squats has been the best thing so far in this charity event. I have put this charity together as a way for those who want to help their loved ones but don't know how, and for those with MG, to show there is hope, there are people out there that care and want to find a cure for you.

My main 3 reasons

- 1) I love this woman and want to support her, like many of you out there that know someone with MG
- 2) To raise awareness around an unknown disease that is shattering lives of those diagnosed and those around them who wish they could take it away.
- 3) To raise funds! Hopefully with a bigger following and more money we can find better medication, better preventive measures to stop those things like repetitive movement, alcohol, heat, cold etc from causing you your symptoms. The biggest focus of this is for awareness. No one knows this disease, it's time to change that.

Logan



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Our dog

When I was in my 40s, we rescued a 2-year-old Labrador. She became my buddy. Anyone who has or had a dog in their family will know what I mean. We exercised together in the morning, often walking 4 kms before work, and she always greeted me with vibrant enthusiasm at the end of the day.

She was an intelligent girl and I could walk with her off the lead. There was very little traffic around at the time, so it was safe. Whenever a car did come by, I would call out to her - "car" - and she would stand off the road and wait until it passed before resuming her sniffing and exploring.

She brought great comfort to me when I was first diagnosed with Myasthenia Gravis (MG). She would sit with me, and somehow understood that I wasn't as physically able as I once was. Of course, I was not able to continue the 4 km walks but as she had become an older dog at that stage it suited her to walk less. When I did tottled out with my walking stick, she knew to give me space, and she was satisfied with walking a short distance. As I slept and convalesced, so too, she napped.

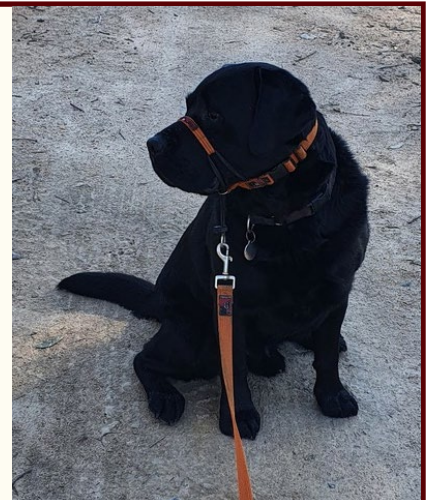
Time passed and we have now rescued another dog. I am finding it very different 20 years later! He too is a 2-year-old Labrador. He is also very intelligent and very exuberant; a loving ball of energy. He challenges me, but in the best possible way. He needs exercise, activity and engagement and I cannot just sit on the couch and sloth!

He is helping me to reestablish my muscle strength by demanding a walk each day. We are rediscovering some walks that I haven't used in a long time. It is such a joy to be back out there. We are not quite walking the 4 km of 20 years ago but I still hold the dream of being able to. I can walk 2 km on a good day and with MG this is not every day.

Our dog makes me laugh with his antics and enthusiasm for life. He has become my new buddy; my biggest motivator. Is my return to health and happiness due to the exuberance of our dog? Of course not, but by always persuading me to move he has most certainly played a big part.

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

Bamboozable

D	_SHIP	CHOICE CHOICE CHOICE	model	__, 2, 3 No No No	STORM TH
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Sudoku

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

Math Challenge

Try to fill in the missing numbers.

Use the numbers 1 through 16 to complete the equations.

Each number is only used once.

Each row is a math equation. Each column is a math equation. Remember that multiplication and division are performed before addition and subtraction.

	+		-		-		7
x		+		-		-	
	x		-		+		105
/		/		+		x	
	-		-		+		-12
-		-		-		+	
	x		-		-		-15
95		3		7		-36	

Answers

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

95		3		7		-36	
1	x	9		11	-	13	-15
-		-		-		+	
2	-	3		15	+	4	-12
/	/			+		x	
16	x	6		5	+	14	105
x		+		-		-	
12	+	10		8	-	7	7

Word Change

stare
smile

Word Change 28 Answers: stare, stale, stile, smile
Bamboozable 13 Answers: 1. Knows; 6. Thunderstorm
Decide; 2. Spacship; 3. Multiple Choice; 4. Floor Model; 5. No-one

NEWS FROM AROUND QUEENSLAND

News from Cairns

Welcome to the new year! Please note in your diary our first Coffee & Chat will be on **Saturday, 26 March at 11am at the Cairns RSL Club Boardroom.**

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

News from Townsville

Thank you to those who attended our 2021 Christmas Lunch.

Please join us for lunch at **The Avenues Hotel, 270 Kern Bros Drive, Kirwan on Saturday, 19 February at 12 noon.**

For details and if you can come, please RSVP Daphne on 0400 778637 or daphclay@gmail.com

News from Mackay

The Mackay group will not meet in March as most of the members are not venturing out socialising until things improve with the Corona virus.

We plan to set a date for April for next luncheon meet.

I would like to encourage any member who hasn't done so to check out the informative podcasts our Committee organise for us. I find the podcast very interesting.

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

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

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

News from the Gold Coast

The MG Gold Coast Group had their get-together, sharing experiences with other members on Saturday, 5 February at Broadbeach Kurrawa Surf Club. 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.



COFFEE & CHATS

Cleveland

**Crusoe Café – Thursday 10th March at 10.30am,
12/152 Shore Street West**

RSVP Anita on 0414 588 312

SUPPORT your Association by taking **MEMBERSHIP.**