



Myasthenia Gravis Association of Queensland Inc.

Messages

FEBRUARY
2024



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 FEBRUARY 2024

Christmas and the holidays seem to have gone in a flash and we are back into the management committee starting on or continuing particular projects.

The end of any year brings with it necessary paperwork to be done as a charitable not-for-profit organization. Reports to Queensland Health and the Australian Charities and Not-for-Profit Commission ensure that we are meeting our operational, financial and legislative requirements. We also had the opportunity in January to write a submission to the Pharmaceutical Benefits Advisory Committee (PBAC) in relation to possible future treatments for Myasthenia Gravis. With new and repurposed treatments becoming available it is important that we ensure that our 'Patient Voice' is heard across all sectors of decision making. Sincere thanks also to any of our members who made a personal submission to the PBAC. Be assured that your management committee takes every opportunity to help improve the quality of life for all members.

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.

If you have not received the 2024 log-in information for financial members please phone the **1800 number or email treasurer@mgaq.org.au**. Only financial members can access the Members Only section of the MGAQ website.

Rare Diseases Day falls on 29 February. By 'Sharing your Colours' (photos, videos and experiences) online and with friends, by shining the light on people living with a rare disease, you are supporting Rare Voices' aim to change and improve the lives of the 300 million people worldwide who are living with a rare disease. Susan and Denise from our management committee will be attending a function in Canberra, representing both the MAA and MGAQ. Attendance at this function is vitally important as it is an opportunity to speak with politicians and decision makers in person and keep Myasthenia Gravis forefront in their minds. Please make sure that, on that date, you do something to draw people's attention – make a phone call, meet friends for coffee, have the family over for a meal etc.

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



MYASTHENIA ALLIANCE AUSTRALIA

NEWS UPDATE

The MAA Team endeavoured to have some well earned downtime during the Christmas break. Naturally there were some key items requiring attention and now we are up and running for another productive and engaging year ahead.

You will see included in this newsletter that the **ART WITH HEART Awareness Campaign for 2024 is under way!**

The aim is to share with the general population and have them become familiar with the condition Myasthenia Gravis. There will be stories along the way and maybe a blog! We want people to understand that whilst 'fun-run events' and 'festivals in the sun' don't work for us there is much that we do achieve and still love to participate with in our lives. This auction event is a time for our members to showcase their talents, to share with family and friends and to start conversations in new places. It is easy to tell others about what is happening without focusing on the health issues. This event is for us! Please - everyone - let us do our utmost to make it a success. We have until the end of May to gather donations (which are already coming in from some very wonderful supporters), to tell the world that it is on. June will be the time to purchase as the Auction goes live. Purchasing is important as it shows appreciation to the people who are supporting us.

With knowledge comes greater understanding and this will lead to enhanced living for all with Myasthenia.

With significant and detailed contributions from the MAA Committee and additionally from our membership we are hoping to have presented a convincing case to the Pharmaceutical Benefits Advisory Committee (PBAC) about our desire and need to have the new treatment **Ravulizumab** PBS funded. Thank you to Natalie and Carol for the effort and skill given to making the Submissions prior to January 31st. Thank you to our members for completing the brief survey which was sent out during the Christmas period. The survey information showed that approximately half of 200 respondents do not feel well controlled with their treatments with and are not as stable as they would like to be. 40% reported a flare occurring in the past 12 months. 75% feel that the fluctuations make life difficult and that there is a significant burden associated with this condition.

The Conference Feedback strongly focused on

- the need to understand more about life with myasthenia;
- encouraging more research;
- raising more awareness generally and with the medical profession accessing new treatments.

Already the MAA is engaging with a range of marketing researchers, academics and medical researchers to work in partnership on a range of projects. MGBase is important in this work so ask your Specialist if they are participating and remember to keep a look out for opportunities to share your experiences. This will happen through a range of surveys, personal interviews etc.

The MAA Board is working hard to ensure that our community is heard and to drive the initiatives we all want. I thank my team for their continued commitment to the wide range of projects and connections that have resulted from 10 years of volunteer work. **The MAA are ALWAYS seeking out additional**

MAA UPDATE continues page 3

MAA UPDATE continued from page 2

help. We provide lots of support and a warm welcome. It is not necessary for Board members to have the condition so why not raise the idea with family and friends about giving some time and making a difference. **Call 1800 802 568 for more information.**

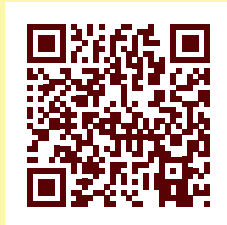
Once again, we will be in attendance at the **Canberra Parliamentary Event hosted by Rare Voices Australia to celebrate Rare Diseases Day - February 29!** This is a time to talk with politicians and to identify our ongoing needs.

Reminder - everyone should be registered at www.myastheniaalliance.org.au

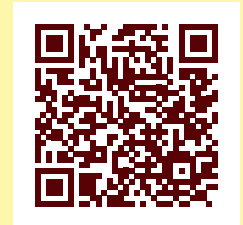
Keep cool and stay safe in this heat. Kind regards
Susan White - MAA Chairperson.

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

Scan to apply for
Membership or to
renew your existing
Membership



Scan to make a
donation to the
Myasthenia Gravis
Association of Qld Inc.



MGAQ Inc. PODCASTS

COULD THIS BE YOUR NEW WORLD?

Greetings All

The MGAQ Inc is after a new leader for our Podcast series. Can you see yourself creating our Podcasts? The role comes with all the equipment provided plus tuition from our current Dr Podcast.

What you see in the photo is what you will receive..

Do you think this volunteer activity could be a new interest for you or a family member?

If so Dr Podcast would be very grateful as equipment must go due to downsizing of current premises.

Please contact Dr Podcast at
podcast@mgaq.org.au



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

Creativity *for* Positivity

ART WITH HEART AUCTION

DONATE NOW!

Renowned artist and Myasthenia Gravis Warrior, Lyn Church, initiated the first auction successfully two years ago, and we're back for another impactful event! Lyn likes to paint mainly in oils and on location. This becomes challenging as she needs to paint quickly before the natural scenery changes too much. It's pretty tricky when your vision is double, your arms are weak and you wobble when standing. In Lyn's words: "Never give up! Even though we suffer from this rare condition we are strong and we can achieve"



Submissions: Submissions cut-off 29 May 2024

Auction Live 1st to 29th June 2024

Donations: Send a high quality image of your donation to treasurer@mgaq.org.au or via message on [facebook.com/mgqld](https://www.facebook.com/mgqld)

www.myastheniaalliance.org.au



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

What did the volunteers say about their experience at the MAA Conference.

I had attended the 2017 MAA MG Conference in Sydney and the opportunity to be able to travel to the 2023 MG Conference was another great chance to listen to the experts and hear about the advances in treatments and what is offered to MG sufferers. I'm also very interested in the technical aspects of the condition, so listening to all the details was something I very much enjoyed.

Another important part of the conference was being able to meet and talk to other MGers and hear their stories. It's surprising how many people have had the same journey with MG. Since being diagnosed in 2013 and having time to adjust to the condition, it was great to listen to newly diagnosed MGers and try and help them understand what they are going through.

Thanks to all the volunteers from the MAA to make this happen and to the specialists giving their time so freely. **Greg (MG)**

As a carer/support person, the conference always has some more information for me to help with Greg and his MG. Thanks to the MAA committee and the speakers. **Maria (Support)**

The MG conference was a great opportunity to meet others with MG and learn about their journeys. I valued being able to share our research about allied health access with the MG community. I am proud of the work I have done to raise the profile of MG in the research space beyond the medical focus. Thank you to the conference organisers for a great event. **Kirstine**

It was wonderful last October to attend the MAA conference as a representative of the MGAQ and MAA committees. This was my first MAA conference and I was impressed with the quality of the presentations and I learnt so much about MG and future directions for treatments. The neurologists who presented and attended the conference were so happy to chat, listen and share their wealth of knowledge. It was fantastic to meet others with MG and listen to their experiences of living with MG. I was pleased to hear how researchers are working towards improving treatments for those of us MG'ers who struggle to control our symptoms. What I loved about the conference was knowing I wasn't alone in my experiences of living with MG.

I look forward to attending the next MAA conference. **Lisa**

BECOME INVOLVED - MAKE A DIFFERENCE

For membership payments and donations, the MGAQ account details are:

BSB: 124032

A/c: 10263772

SUPPORT your Association by **VOLUNTEERING.**



rare voices
A U S T R A L I A

RARE DISEASE DAY

THURSDAY 29 FEB. 2024

Rare Disease Day is the globally co-ordinated movement for Rare Disease Day working towards equity in social opportunity, healthcare and access to diagnosis and therapies for people living with a rare disease.



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

Brisbane City Council - 28 February

The Story Bridge, Victoria Bridge

City of Logan - 28 February

Wine Glass Water Tower, Hillcrest, Jacaranda Tower, Underwood

Telfer Street Tower, Shailer Park

NOTHING About Us **WITHOUT US!**

Sero-Negative

How does this Make Things More Difficult?

*Break out session with Dr. Stefan Blum Summary
Myasthenia Alliance Australia – Conference 2019.*

10% of the diagnosed Myasthenia Gravis population are termed Sero-Negative.

The quandary for Doctors is how do they make this diagnosis before treatment begins. Therefore, the Doctor may be appearing to be hesitant.

Testing for Sero-Negative Myasthenia Gravis is not clear cut. The blood tests to detect the MG antibodies have quantitative cutoff levels to be termed a positive result. This may not be at a suitable level for the individual being tested and is designated negative. Also, the way the blood test is conducted through the protein binding may change results.

Other pathways are then investigated to rule out any other causes for the symptoms.

After the main blood tests (Anti-MUSK, AChR) were done a few people in the group commented they also did not get conclusive diagnosis from Nerve conduction tests also. The new blood test LRP4 is available but has to be sent overseas for testing and at a cost. There was an inconclusive discussion whether it was warranted to be retested at a later date.

The next diagnostic intervention is a positive response to Mestinon in the reduction of symptoms. Dr Blum said for him that is a strong indication for the diagnosis of Sero-negative MG as Mestinon does not work for other diseases. The Tensilon test is not really used anymore as it can have major side effects, has to be done in a hospital with emergency equipment and it needs to be a 3-syringe blind test.

There was interactive discussion on the frustration people felt when going through the diagnosis process and this was very impacting to them. Due to this uncertainty, prolonged process of diagnosis and the beginning of treatment and sometimes the feeling of not being believed posed the question of did it lead onto psychological problems for these patients? Discussion termed it is a hard path for people and one has to deal with it in some way.

The last discussion was that lifestyle factors are very important to be considered in conjunction with treatment. It is important to be as healthy in your lifestyle as you can be physically and mentally that is appropriate to the individual.

This resource and many others are available from the MGAQ Information Officer on
FREECALL
1800 802 568

Puzzlers

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

Bamboozable

LIP	LIP	MINUTES MINUTES MINUTES MINUTES MINUTES	BACK	MINUTES MINUTES MINUTES MINUTES MINUTES	Life LIVE LIVE	▲ 1. thing 2. thing 3. thing	MOGOTION MOGOTION MOGOTION	COAST
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Sudoku

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

Number Block

Try to fill in the missing numbers.
The missing numbers are integers between 0 and 12. The numbers in each row add up to totals to the right. The numbers in each column add up to the totals along the bottom. The diagonal lines also add up the totals to the right.

							30
1			10	6	2		36
	8	6	5				32
1		12	7		1		41
11	3	5	5		1		27
8		6		11	1		39
7	2	0	6	7	11		33
39	40	37	38	37	17		48

Answers

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

39	40	37	38	37	17		48
7	2	0	6	7	11		33
8	8	6	5	11	1		39
11	3	5	5	2	1		27
1	10	12	7	10	1		41
11	8	6	5	1	1		32
1	9	8	10	6	2		36
30							

Word Change

pouch
peace

Word Change 29 Answers: pouch; peach; peace
Bamboozable 11 Answers: 1. Tulips; 2. Back in five minutes; 3. One Life to Live; 4. First Thing in the Morning; 5. Go Through the Motion; 6. The Coast is Clear

CONVERSATION CONNECTION COMPANIONSHIP

WESTERN AUSTRALIA



RECIPE CORNER

My favourite Tuna Sandwich filling

INGREDIENTS

- 425g canned tuna in oil
- $\frac{3}{4}$ cup whole egg mayonnaise
- $\frac{3}{4}$ cup diced celery
- 5 Tablespoons finely chopped dill pickles
- 2 Tablespoons Dijon mustard
- 3 Tablespoons finely chopped fresh dill
- $\frac{1}{3}$ cup finely sliced shallots
- Salt and Pepper to taste

METHOD

Put all the ingredients in a bowl. Mix well with a wooden spoon, breaking up the tuna, celery and dill pickles. Season with salt and pepper.

Good for ribbon sandwiches or spread on your favourite cracker biscuits.



NEWS FROM AROUND QUEENSLAND

Please remember to bring empty Mestinon bottles to all MGAQ gatherings to support Chloe's art project.

News from Cairns

Please join us for a **Coffee & Chat** at Artview Gallery, 220 Toogood Road, Bayview Heights, **Saturday 24 February at 10.30am.**

For more information, please contact **Donna on 0414 397 462.**

News from Townsville

Our next lunch is **Saturday 17 February Sports Club at 12 noon, 159 Bamford Lane, Kirwan.**

Please RSVP to **Daphne on 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

The Sunshine Coast group will meet on **Monday 8 April at Kawana Club at 10.30am, 476 Nicklin Way, Wurtulla** for informal Coffee & Chat. All are welcome to attend.

For more information please contact **Michael on 0447 887 652.**

News from the Gold Coast

Hi Everyone. MG Gold Coast group had their get together sharing experiences with other members on Saturday, 13 January at Southport Sharks Club. Our next meeting will be at **Saturday 9 March 10.00am at Southport Sharks Club.**

It was decided to always have our Gold Coast meeting at Southport Sharks Club due to parking problems at Kurrawa Surf Club, Broadbeach. I look forward to seeing you all.

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

WELCOME TO OUR NEW MEMBERS

Roslyn, Brunswick VIC

Geoff, Ferney Hills QLD



COFFEE & CHATS

IPSWICH - Saturday, 16th March at 10.30am

Queens Park Café, 10A Merle Finimore Avenue, Ipswich

ALL WELCOME!

RSVP Anita on 0414 588 312

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