



Myasthenia Gravis Association of Queensland Inc.

Messages

MARCH
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 MARCH 2024

Welcome to our March newsletter. It seems that I just turned the calendar to a new year and now we are in March already. Your management committee will certainly have a busy year with ongoing and new projects. I would like to publicly acknowledge the funding we receive from Queensland Health and their ongoing support of our association. We regularly meet with QH personnel and we always feel that we have presented information about all of the great work being carried out by our hard-working committee. Susan White, Denise Hannay and I will meet with Queensland Health representatives again in April.

Rare Disease Day was held on 29 February. I hope that everyone took the opportunity to speak with family and friends about living with Myasthenia Gravis and also touched base with another person who has MG and just asked if they were okay. Susan White, representing the MAA, and Denise Hannay from the management committee met with parliamentary personnel and representatives from Rare Voices in Canberra on that day. Being able to communicate and liaise with these people is a significant way of keeping our rare disease to the forefront of decision making. More information is contained in this newsletter.

Many thanks to members who have approached their local councils about the Myasthenia Gravis Awareness Month Lights-up Project. This activity continues to grow not only in Queensland but across other states as well. What a wonderful awareness project it is!

While the MGAQ provides much free information, we certainly still need to have members who are financial so that the association can continue to operate. The \$20 membership fee barely covers the cost of producing, printing and mailing out the newsletter 11 times a year. The association has many ongoing activities and commitments such as running face-to-face and zoom committee meetings, ensuring we provide the best two-way communication with members, continuing to produce and provide extra resources such as podcasts and brochures, being involved with research so that we have data and important information about the best treatments available, conducting meetings and get-togethers across the state – and the list goes on. So please, if you are not a current financial member, think about paying the \$20 for category A membership and/or \$20 for Carer/ Supporters and help support YOUR association.

The association has received information that postage costs will rise in April. As we post out nearly 100 newsletters each month this increase will certainly impact over a twelve-month period. If you have access to email but have not yet advised us that you are happy to receive your newsletter electronically I urge you to phone 1800 802 568 at your earliest convenience.

Stay well and focus on the positives each day.

Thanks Carol

Myasthenia Gravis Association of Queensland Inc

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Supported by



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



MYASTHENIA ALLIANCE AUSTRALIA

NEWS UPDATE

How exciting that the **Art With Heart Campaign** is under way and accepting items for the auction. As previously explained, this event is targeted towards strengthening our MG community by providing interaction as a group in a fun and positive manner. It is also very much about raising awareness of Myasthenia Gravis throughout the broader community. If we want to ask for understanding from others or acknowledgement from medical providers they need to be familiar with our condition. It is up to us to help others become better informed so that they can help us. This may result in better workplace options, better support in the general community or more informed engagement with health care providers.

What are we asking you to do to make this event effective? Firstly - please donate items or ask others if they would like to contribute. Next share the news as widely as possible. This can be done in conversation, via emails or from sharing on Facebook/Instagram etc. It is such an easy topic for sharing. We hope you will give it a try. Finally we need people to bid at the Auction when it opens in June.

You will notice in the newsletter that we are asking you to let your local politicians (State and Federal) know that you have a rare disease and that there are obstacles to getting the care needed for a rare condition. Telling your politician about the AWH campaign and referencing the MAA website really helps. Getting an appointment can take time so please persist. Pave the way to improved resources and care.

Your Committee members have been leading by example attending the **Rare Diseases Day Parliamentary lunch held in Canberra on February 29**. Natalie Windle (MAA Secretary) and Denise Hannay (MGAQ) joined me. We heard from many politicians, spoke with Minister Butler, found inspiration from the RVA Ambassadors and heard wonderful speeches from senior politicians reflecting on bi-partisan goals to improve life for people with rare conditions. The theme "Progress

Beyond Policy" is progressive and significant. Centres of Excellence are to be developed. How these might look and when they might be established is still unknown but the need to promote integrated and coordinated care across a lifespan is recognised. Sincere gratitude is offered to Dr Mike Frelander MP for his continuous and keen interest in the work of the MAA. He gave us a very warm welcome.

The MAA is delighted to announce a new Association Member benefit. The 2023 Conference Speakers have given permission for us to share the conference content to a controlled group of viewers. Therefore content is being offered via the Qld and NSW Association websites to current financial members. The content is extensive. I recommend taking nine minutes to hear Dr Stephen Reddel's closing address along with all the other amazing presentations. Please contact your Association should assistance be required.

As previously flagged, participating in research is an MAA priority. Recently, 16 Association members were selected for a priority project. We thank them very much for participating. We also say thank you to those who were willing but not suitable on this occasion. The great news is that at least two more projects are being prepared. Each time we participate in a project a report is requested. These reports will be made available. Note that it can take several months before the requested feedback becomes available. The research will be presented in many formats so do keep a look out!

Through the research opportunities it has become apparent that a significant number of patients are not confident answering particular questions about their condition. For this reason we have included a tick box graphic for you to take to your Specialist. This is an optional activity and presented to assist each individual.

Thank you for your support.

Kind regards

Susan White - MAA Chairperson.

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

CONVERSATION CONNECTION COMPANIONSHIP

MACKAY



GOLD COAST



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.org.au Member Log-in



If you need assistance call **1800 802 568** or
email info@mgaq.org.au

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

Creativity *for* Positivity

ART WITH HEART AUCTION

DONATE NOW

Art with Heart is an online auction that raises awareness of Myasthenia Gravis.

Use your “Creativity for Positivity”

Do you dabble in drawing, can you make mosaics, can you create with colours, do you nurture your knitting, can you perfect a painting, can you turn rags to riches or trash to treasure.

If your answer is yes, then donate to **Art with Heart!**

Submissions cut-off 29 May 2024

Please send a high-quality image of your donation to
treasurer@mgaq.org.au



www.myastheniaalliance.org.au

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

Website: www.mgaq.org.au



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

JUNE AWARENESS FUNCTION - GUEST SPEAKER ASSOCIATE PROFESSOR JAN SANSONI

TOPIC: Myasthenia Gravis Research:

Capturing Health Outcomes and Patient Perspectives



Associate Professor Jan Sansoni was the Director of the Australian Health Outcomes Collaboration (AHOC) and a Principal Research Fellow at the Australian Health Services Research Institute at the University of Wollongong (1997-2019). Earlier she was the inception Director of the Australian Health Outcomes Clearinghouse at the Australian Institute of Health and Welfare 1994-1997. Since her retirement in late 2019 she has held honorary appointments as an Associate Professor at both the Australian National University (ANU) and the University of Wollongong (UOW).

Associate Professor Jan Sansoni has undertaken substantial research work in patient assessment and outcomes evaluation and monitoring during her career. She was the lead author of the recently published paper (2023) concerning the national Australian survey of Myasthenia Gra-

vis patients (2022). Earlier Jan was the project manager for the national Dementia Outcomes Measurement Suite Project (Sansoni et al. 2007) and was a member of the dementia working group for the International Consortium for Health Outcomes Measurement (2014-2016) which designed an international outcomes measurement suite for dementia - building on her earlier Australian work in this field. She was heavily involved in the redesign and redevelopment of the assessment system for access to Commonwealth aged care services in Australia (Sansoni et al. 2012), and with the national field testing of a new assessment tool for aged care (Sansoni et al. 2013). She has authored many journal publications and produced numerous reports on research undertaken on behalf of Health Departments throughout Australia.

Associate Professor Janet Sansoni has been involved in the development and evaluation of patient-reported outcome measures and measurement suites for a broad range of health conditions including those associated with chronic health conditions and in the development and revision of measurement tools and indicators used in both outcome evaluation and client assessment.

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**.



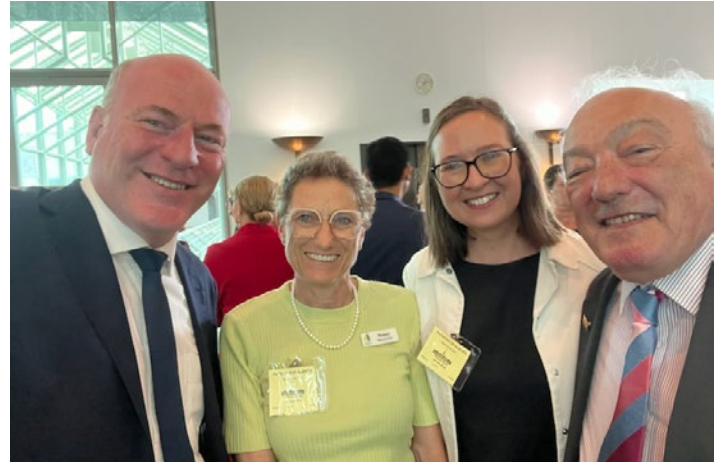
PROGRESS BEYOND POLICY

A PUSH FOR CENTRES OF EXCELLENCE

HOSTED BY RVA (RARE VOICES AUSTRALIA)



• Susan, Natalie, Louise Healy (Education and Advocacy Manager RVA), Denise (MGAQ)



• Trent Zimmerman, Susan White (MAA), Natalie Windle (MAA) and Dr Mike Freeland MP



• Denise and Susan at Parliament House



• Hon Mark Butler MP



• Susan and Lachy Beckett (RVA Ambassador)



• Dr Mike Freeland MP



• Nicole Millis (CEO Rare Voices Australia)

NOTHING About Us WITHOUT US!

KNOW YOUR MG

What type of Myasthenia do I have???

ASK YOUR SPECIALIST IF UNSURE

✓ Tick all that apply

AChR positive

Seronegative

LRP4 positive

LEMS

MuSK

Congenital Myasthenia

Ocular only

Generalised MG



This is an ongoing request to the MG community.

Please REACH OUT to your Local, State and Federal Representatives

both formally through a requested meeting or informally at a Meet and Greet event to:

- ♥ Tell them that you have a rare disease and that getting care is time consuming and hard;
- ♥ Tell them that Centres of Excellence would be ideal;
- ♥ Tell them that it is a long and chronic condition where little assistance is offered through NDIS;
- ♥ Show them the website details:
- ♥ Tell them that greater awareness is needed to improve care;
- ♥ Show them the Art With Heart flyer explaining how we are trying to help ourselves;
- ♥ Talk about the depth of work undertaken by your MGAQ and MAA committees;

www.mgaq.org.au and www.myastheniaallianceaustralia.org.au

WELCOME TO OUR NEW MEMBERS

Fran, Prospect, SA
Sheree, Melville, WA



Paul, Home Hill, QLD
Mick, Hideaway Bay QLD

Chris, Hideaway Bay QLD

Puzzlers

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

Bamboozable

POL4ICY	party party party party	WAGON		WI FE 	O F F O F F
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Sudoku

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

Word Change

chili
stall

Answers

Bamboozable 9 Answers: 1. Foreign Sides
 2. Heartland, 3. Teacup, 4. Letter 4, Exam, 5. Rectangle, 6. Headband, 7. Homesick, 8. Scary, 9. Army, 10. Spinach

What Word 3 Answers: 1. Cookie, 2. Party line, 3. Covered Wagon, 4. Back to the Future, 5. Midwife, 6. Off

Word Change 31: chili, chill, still, stall.

What Word?

Can you guess what ONE word we are describing? It is just ONE word and this can get a little tricky but fun.

Example:

Clue: Display the animal hair

"Literal" Answer: Show Fur

End Answer: Chauffeur

1. Bake the 5th letters
2. Your "ticker", nation
3. Golf ball holder, mug
4. Letter 4 exam
5. Ruined, 360°
6. Above neck, musical group
7. House, nauseous
8. Startle the 5th letter
9. 18th letter, I
10. Turn round and round, what you scratch

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

NEWS FROM AROUND QUEENSLAND

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

News from Cairns

The first Coffee & Chat for 2024 was well attended at Artview Gallery in February. Please see April newsletter for the next gathering in May.

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

News from Townsville

Our next lunch is **Saturday 20 April 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

The Mackay group joined me in welcoming Donna from MGAQ Committee for our first Coffee & Chat for 2024 whilst Donna was in Mackay visiting family. Those present enjoyed the company and the opportunity to share their MG experience. We also had a lesson on how to access the Member section and other important tabs of the MGAQ website.

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

MG Gold Coast group had their get together sharing experiences with other members on Saturday 9th March. Our next meeting will be at **10am on Saturday, 11 May at Southport Sharks Club, Corner Olsen and Musgrave Ave, Southport.** I look forward to seeing you all.

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



ALL WELCOME

**Mango Hill - Saturday 20th April at 10.30am - Coffee Club,
Mango Hill Market Place, Cnr Halpine Drive and Anzac Ave, Mango Hill
RSVP Anita on 0414 588 312**

WHAT'S ON?

What's On?	When and Where?	Topic?
June Awareness Function GUEST SPEAKER, ASSOC. PROF. JAN SANSONI	SUNDAY 9th JUNE Aspley Hornets Football Club, 50 Graham Road, Carseldine	Myasthenia Gravis Research: Capturing Health Outcomes and Patient Perspectives

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