Myasthenia Gravis Association of Queensland Inc.

MessaGes

MAY 2024

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 MAY 2024

I frequently seem to be writing about being vigilant about your health. Covid is still with us to a lesser degree but an early start to the influenza season is another concern. Just keeping on top of things is a real chore sometimes but it is something we all must do.

June is a special month in the Myasthenia Gravis 'world' and it continues to be especially significant for Queensland. The MGAQ theme of **"Lights Up for Myasthenia"** continues to gain momentum. Please take the time to see the page in this newsletter for the various towns and the buildings and landmarks that will be lit up on various dates. If you can manage it I am sure a drive to look at these in your local area will prove well worthwhile. If you are able to take a photograph of these structures the committee would appreciate an emailed copy of same. Remember to try to wear a teal-coloured ribbon next month so that people might ask you the meaning behind it.

If you live in Brisbane or environs I urge you to attend the get-together on **Sunday, 9 June** with our guest speaker **Assoc. Professor Jan Sansoni speaking on *"Capturing Health Outcomes and Patient Perspectives"*. The venue for this June Function is Hornet's Football Club, Graham Road, Carseldine.** Further details are in this newsletter.

I cannot stress too strongly the importance of being a financial member of the MGAQ. Your association really relies on membership fees to fund the many and varied booklets, pamphlets, flyers etc that are readily available to all. Also, being a financial member gives you access to the Members Only section of the website. You will find a wide collection of valuable resources such as podcasts and videos plus the very informative presentations given by renowned speakers at the recent MAA Conference.

Three members of the management committee met with two members of the Community Funding Branch of Queensland Health. I must thank these representatives of Qld Health for the time given and the high level of interest shown. I am pleased to advise that the MGAQ has received approval of funding for a five (5) year term from 1 July 2024 to 30 June 2029. They also stated:

"The Department acknowledges that the demand for community services remains high and there is a continuing business need, and a community expectation, for the delivery of community services."

The **Myasthenia Alliance Australia's "Art with Heart"** is now live. Please go to the MAA website and take the time to look at the wonderful auction items waiting for people to bid for them. Please also take a few minutes to discuss this with your family, phone friends and bring it up in conversation. This awareness campaign will benefit you and others with Myasthenia.

Stay well

Thanks Carol

Myasthenia Gravis Association of Queensland Inc

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

MYASTHENIA ALLIANCE AUSTRALIA

NEWS UPDATE from Natalie Windle, MAA Secretary

RARE DISEASE ROUNDTABLE WITH THE MINISTER FOR HEALTH AND AGED CARE, HOSTED BY ALEXION

MAA advocacy work focuses on enhancing available treatment options and ensuring the best outcomes are achieved for each person living with Myasthenia Gravis in Australia. This includes engaging and collaborating with a range of stakeholders, especially government and politicians.

As the MAA Secretary and MGNSW President, I recently attended a rare disease roundtable in Sydney with the Minister for Health and Aged Care, the Hon. Mark Butler MP.

I was very honoured to represent the Myasthenia Gravis patient community and contribute to the discussion as a person with lived experience of a rare disease. This involved sitting alongside a diverse group of experts including clinicians, researchers, industry, and other advocates.

The roundtable was a fantastic example of people coming together to discuss **shared outcomes for rare disease patients** such as **timely and equitable access** to medication and treatments, and **ways to improve primary care.**

The discussion was very open, honest and respectful. We also talked about patient engagement in the **Health Technology Assessment (HTA) process and HTA reform**. This helps inform the MAA's current advocacy work providing feedback to the HTA reform program and engaging with the HTA process for new treatments being considered by the Pharmaceutical Benefits Advisory Committee (PBAC).

The patient voice matters and this was such a valuable opportunity to have our voice heard. Thank you to Minister Butler for his time and engagement, to Alexion Pharmaceuticals for facilitating this event, and to the Co-Chair of Parliamentary Friends of Rare Diseases, Dr Mike Freelander MP.

If you're interested in following the MAA, make sure you're subscribed at:

https://myastheniaalliance.org.au/subscribe/

If you want to know more about how you can contribute to this important work, please contact us via the state association partners:

MGAQ: call 1800 802 568 or
email info@mgaq.org.au

MGNSW: call (02) 4283 2815 or
email info@myasthenia.org.au

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ROUND TABLE ATTENDEES

MAA UPDATE continued from page 2

MAKE A SUBMISSION TO PBAC ABOUT A NEW COMPLEMENT INHIBITOR TREATMENT, ZILUCOPLAN

A new treatment for generalised MG, **Zilucoplan (brand name Zilbrysq ®) is on the agenda for the next Pharmaceutical Benefits Advisory Committee (PBAC) meeting.**

Make a personal submission highlighting the lived experience as a MG patient by completing the online form here: **https://ohta-consultations.health.gov.au/ohta/pbac-july-2024** by Wednesday, 29 May 2024

A submission is essentially about **sharing your story of living with MG** with national decision makers as they consider the benefits, costs, and delivery of new treatments. As we are quite a diverse bunch of people and each of our journeys is a bit different, an individual submission helps demonstrate the importance of having different treatment options to give us all the best care and quality of life.

Recent research and patient feedback show that there are still unmet needs and a burden for MG patients in Australia. The vision of the MAA is timely and equitable access to the best available treatment that most benefits each patient. We hope to achieve this by ensuring treatment options are available, accessible, and affordable.

☐ ☐ ☐

PARTICIPATE IN A FOCUS GROUP TO HELP DESIGN RESEARCH FOR MG PATIENTS

The MAA is working with Monash University researchers on the **VALUE-Ig** project. We are looking for **MG patients to participate in a focus group** to help design a study about patient preferences on treatments. This is an opportunity to provide input before the research is carried out and we invite you to take part.

This research project aims to recruit patients diagnosed with Myasthenia Gravis for participation in focus group sessions. These focus groups aim to explore the preferences of people who have Myasthenia Gravis towards different treatment options.

You are invited to take part in 2 focus group sessions with up to 4 other volunteers, plus Monash researchers. The focus group will be an online conversation that will last approximately one hour, so please make sure you can access the internet to participate.

As a small token of appreciation for your time and insights, you may choose to receive a digital gift voucher ($50) for taking part in the 2 sessions.

Please see the attached brochure on page 4 for more information.

If you are interested in participating in the study, have any questions or require more information, **please contact the Monash University researchers directly** via email: **value.ig@monash.edu or phone: 03 9903 4363**.

If you don't want to miss this opportunity, be quick to contact the team as there are limited places to keep the focus groups small. Thank you for helping the MAA to build the research and evidence for MG in Australia!

Kind regards
Natalie Windle, MAA Secretary

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

MONASH University

MONASH BUSINESS SCHOOL

Exploring Treatment Preferences of Patients with Myasthenia Gravis

The purpose of the project

This research project aims to recruit patients diagnosed with Myasthenia Gravis for participation in focus group sessions. These focus groups aim to assist with the development of our patient preference experiment survey, which will explore the treatment preferences of people who have Myasthenia Gravis towards different treatment options. Through focus group interviews, we want to understand what parts of treatment people value and those parts that people find difficult or worry about. This might include cost, treatment side effects, and treatment benefits. Additionally, we seek to ensure that the questions presented in the experiment are clear and understandable from a patient perspective like you.

The information we get from this study will be used to design Discrete Choice Experiments (DCE). DCEs are research methods used to understand people's preferences by presenting a series of choice tasks in hypothetical but real-life scenarios. Each choice task consists of two or three alternatives described by its characteristics. For example, people might be asked to choose between a treatment that works quickly but costs more, or another treatment that takes longer to work but is less expensive.

Your participation is very important

Your participation is really important because when more people join in, our research findings become more robust and dependable. This helps doctors and patients, ultimately improving outcomes for those with MG. It's essential to note that while the research itself may not directly benefit any individual patient, your involvement contributes to advancing overall understanding and care for everyone with MG.

What does participation involve?

If you decide to take part, we will ask you to sign a consent form or give your verbal consent before the focus group sessions. You are invited to take part in 2 focus group sessions with up to four (4) other volunteers, plus Monash researchers. The focus group will be an online conversation that will last approximately one hour.

What will happen to your information?

Your information will only be used for research related to this project. We will keep the data on secure servers at Monash University, and it will be deleted seven years after the final results are published to ensure enough time to validate the research findings.

How is the research project being conducted?

We will hold focus group sessions with patients and clinicians. Your data will be kept private and made anonymous.

Who is organising and funding the research?

Professor Dennis Petrie from Monash University leads this research, funded by the Medical Research Future Fund (MRFF) Grant.

Reimbursement

As a small token of appreciation for your time and insights, you may choose to receive a digital gift voucher ($50) for taking part in 2 focus group sessions. Vouchers will be provided by Prezzee (http://www.prezzee.com.au/). These vouchers can be converted to a retailer of your choice or donated to a charity of your choice.

If you are interested in participating in the study, have any questions or require more information, please contact us via email.

Email: value.ig@monash.edu

VALUE-Ig

CONVERSATION CONNECTION COMPANIONSHIP

MANGO HILL COFFEE & CHAT APRIL

SOUTH AUSTRALIA COFFEE & CHAT - MAY

Myasthenia Gravis Friends Western Australia Coffee & Chat -

Date: **Sunday, 2 June - 11.30 am**

Venue: **Flames Restaurant, 55 Central Avenue, Rossmoyne**

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

Have you seen the MGAQ Billboards on the Bruce Highway?

Site No: LS105A

Southbound Glenorchy

Located near Glenorchy, south of Maryborough on the Bruce Highway. It's on the left hand side as you travel south toward Tiaro & Gympie.

6.00m x 3.000m

-25.640846, 152.639038

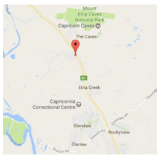
Site No: LS145A

Outbound Rockhampton

Located 15km north of the Rockhampton (Yeppoon turn-off) on the Bruce Hwy. It's on the left hand side as you travel north out off Rockhampton. (Approx. 1km south of the Caves)

6.00m x 3.000m

-23.189922, 150.467633



BECOME INVOLVED - MAKE A DIFFERENCE

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

BSB: 124032 A/C: 10263772

Creativity *for* Positivity

ART WITH HEART AUCTION

BIDDING NOW OPEN

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

Use your "Creativity for Positivity"

Please place your bids now at

airauctioneer.com/art-with-heart-auction-2024-myasthenia-gravis

Myasthenia Alliance Australia

MYASTHENIA GRAVIS ASSN. OF QLD INC.

mgnsw ... from weakness shall come strength

The Australian Myasthenic Association in NSW Inc
www.myasthenia.org.au

WELCOME TO OUR NEW MEMBERS

Tim & Diana, Burdell QLD
Doug, Forest Hill VIC
Pritika, Ocean Grove VIC
Philip, Rivervale WA
Madison, St Lucia QLD
John, Chatswood NSW
Lorraine, Mount Lofty SA
Christopher, Buddina QLD

QUEENSLAND LIGHTS UP FOR MYASTHENIA

June is International Myasthenia Gravis Awareness Month.

June Awareness month for Myasthenia Gravis is worldwide and MGAQ has organised through local Councils and private organisations to "Light Up" landmarks in recognition of Myasthenia.

Please go and view these landmarks. Take a moment to reflect on your myasthenia journey. Capture the image and share so myasthenia can gain more awareness in the community. This will help research. This will help you with your myasthenia journey.

Brisbane – 8th June

Story Bridge
Victoria Bridge
Reddacliff Place Sculptures
Tropical Dome
Wickham Terrace Car Park Architectural wall
Breakfast Creek Bridge at Newstead

Bundaberg – 3rd – 10th June

Fig Trees

Cairns – 4th – 28th June

Court House Gallery

City of Gold Coast - 7th – 13th June

Council Buildings

City of Logan – 4th June

Jacaranda Tower; Wine Glass Water Tower; Telfer St Tower

Emerald – 17th – 30th June

Council Chambers

Ingham – 4th June

Fountain

Ipswich – 1st – 7th June

Ipswich Civic Centre

Longreach – 8th – 22nd June

Longreach Water Tower

Mackay – 3rd – 9th June

Sir Albert Abbott Administration Building

Toowoomba – 20th – 30th June

Victoria Street Bridge

Townsville – 9th June

Qld Country Bank Stadium

Townsville – 8th-14th June

Townsville Sign
Victoria Bridge
Wharton Reef Lighthouse
George Roberts Bridge
Old Magistrates Court House
Central Park Boardwalk
Little Fletcher Bridge

 # Please note that the venues reserve the right to change the advertised dates.

PERTH LIGHTS UP FOR MG

Perth will light up again in TEAL on Thursday 6th June

in recognition of International Myasthenia Gravis Awareness Month.

We thank WA members and Rare Voices Australia (RVA) for making this possible.

NEWS FROM AROUND QUEENSLAND

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

COME ALONG - MEET IN PERSON

SUNDAY 9th JUNE – 10am for 10.15am START

ASPLEY HORNETS FOOTBALL CLUB, GRAHAM ROAD, CARSELDINE

Guest Speaker:

Associate Professor Jan Sansoni

Topic: *"Capturing Health Outcomes and Patient Perspectives"*

Explaining the great challenges of effective research.

RSVP IS ESSENTIAL AND OPEN UNTIL SATURDAY 8TH JUNE

Email info@mgaq.org.au or phone Susan 1800 802 568 to attend or ask questions

News from Cairns

The Cairns group will meet at **The Bluewater, 7 Harbour Drive Trinity Park on Saturday, 18 May at 11.45am.** I look forward to catching up with everyone. Visitors to Cairns are most welcome to join us. Table is booked under MGAQ. For more information, please contact **Donna on 0414 397 462.**

News from Townsville

Our next lunch is **Saturday, 15th June at 12 noon, Kirwan Sports Club, 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 the Sunshine Coast

For those on the Sunshine Coast and visitors to the area, please join us on **Monday, 3 June at 10.30am at Kawana Club, 476 Nicklin Way Kawana.** For more information please contact **Michael on 0447 887 652**.

News from the Gold Coast

We are meeting on **Saturday, 13 July at Southport Sharks Club, Corner Olsen and Musgrave Ave, Southport at 10.00am**. I look forward to seeing everyone there. For more information, please contact **Nader on** 0415 834 401.

ALL WELCOME

SPRINGWOOD - Saturday 18th May 2024 at 10.30am, More Cafe,
Shop 1/34 Fitzgerald Ave, Springwood Shopping Mall

RSVP Anita on 0414 588 312