



Myasthenia Gravis Association of Queensland Inc.

December 2023

Messages



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 2023

It is hard to believe that this is our final newsletter for 2023. The next one will be printed and distributed in February next year.

It is amazing to think what this association has achieved this year. Our focus is still on Member Welfare, Awareness, Research and Advocacy and I think that we have met many goals in each of these areas. The large amount of materials available to members as well as some for non-members is certainly appreciated by those who receive it. Our updated website, the new information book as well as the Drug Alert Card have all proven to be very popular. We receive many comments about the two billboards along the Bruce Highway and people talk about the surprise and adulation they get from seeing them. The same can be said about the Light Up Project which has grown to include many parts of Queensland as well as other states starting to join this activity during MG month in June.

Our partnership with the Myasthenia Alliance Australia continues to grow as the alliance is being recognised more and more as a peak body advocating for people with all types of Myasthenia Gravis. Research has become a big focus with a range of researchers willing to be involved in same. "Patient Voices Matter" certainly has become a catchcry as your voices through filling in surveys and adding opinions has given us the capacity to work with the MAA to advocate for access to medication, better support services etc. One example is the PBAC (Pharma-

ceutical Benefits Advisory Committee) considering the need for Ultomiris (Ravulizumab) to receive PBS funding. We need to be telling the government that people with Myasthenia need to have access to a range of viable treatments. I must also mention our strong relationship with Rare Voices Australia who are very supportive of the research and resultant trends to be followed up.

Do not forget our awareness activity for early 2024 with the **Art with Heart Auction being commenced in February**. We are still seeking donations for this event.

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.

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.

I hope that all members and their families have a wonderful Christmas filled with joy, love and happiness.

Thanks, Carol

Myasthenia Gravis Association of Queensland Inc

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



MYASTHENIA ALLIANCE AUSTRALIA

NEWS UPDATE

This is the final update for 2023 with much still to report to our readers. There has been a flurry of activity in the weeks since the Conference with research projects and potential connections being progressed.

Our key priority through the Christmas period is to ensure that submissions to the PBAC are submitted prior to January 31st. A **new treatment, Ultomiris (Ravulizumab), has been presented for consideration at the March 2024 PBAC meeting seeking PBS funding.** Ultomiris is a long-acting complement C-5 inhibitor treatment with demonstrated statistically significant improvements in myasthenia. It is the first time that such a treatment pathway is being offered in Australia. The Australian MG Community needs to tell the government that we want this choice and that we want it available equally and equitably. The PBAC (Pharmaceutical Benefits Advisory Committee) need to understand the challenges of our condition and that more treatment options are wanted. Both the MAA and MGAQ will make a submission on behalf of everyone. However, individuals can make an additional submission highlighting their individual lived experience with myasthenia and why they feel that there are un-met needs. Please watch out via the websites, Facebook and newsfeeds for further information about making a personal submission. The information will include hints on making your response as effective as possible.

The Conference **Feedback forms** have been collated and key points noted. It was very pleasing to see that the conference opportunity was very well received and that attendees learnt so much. The feedback tells us that people want access to new medications, they want to see more research undertaken and they want to raise greater awareness of Myasthenia.

People also asked for more information about the patient experience, they wanted details of how to exercise safely and sero-negative patients want to understand more about this variant. The MAA can report that they are already exploring **research opportunities which will focus on the lived experience.** The recently published Journal article gives insight around the Quality of Life impacts from both the condition itself and from the side-effects of treatments.

At the previous Conference there was a keen focus on the world leading research conducted by **University of Qld Physiotherapists in regards to activity and MG.** Included in this newsletter is an article which confirms that it is safe and necessary for people with myasthenia to encourage muscle activity. Best advice requires patients to manage fatigue levels and seek guidance. More information is available on the MGAQ website and within the "member only" area.

Data from **MGBase** is emerging as a key research resource with more information about this to be shared in 2024. It is wonderful to know that many more patients are now participating in this data collection and patient care tool.

Should a next conference occur it has been noted that Q & A time should be longer as it was extremely interesting and only a limited number of the many questions were able to be answered. People want to understand more about what constitutes a Myasthenia Crisis with what steps should be taken and when. Hopefully more information can be provided in the months ahead.

The **Art With Heart Project** was launched at the Conference and will kick off in February by requesting donations of goods/artwork/crafts. If we truly want to increase awareness of myasthenia then everyone (patients/family/carers/community) must clearly demonstrate that this is important. We must have a good selection of products and then we must talk about it!

The MAA team is currently presented an ever increasing array of opportunities for supporting people with Myasthenia. If you are an MGAQ or MGNSW Association member please do consider getting involved. The work is rewarding and the team is awesome to work with.

Wishing everyone a joyful Christmas season, with good care and best health outcomes in the year to come. Thanks to everyone for their support and contributions in 2023. It has been an amazing year at so many levels. The Annual MAA report will follow in February.

Most kind regards, Susan White (MAA Chairperson)

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

2023 MAA National MG Conference - Sydney



• Xavier and Jewel from Terumo meet with researcher Steve Vucic.



• Kirstine and Anna with their presenter gifts.



• The volunteers are ready to share information



• Susan welcomes a full house.

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

I had the pleasure of attending and volunteering at the 2023 Myasthenia National Conference. It was a privilege to be involved with such a professionally organised and run conference.

I appreciate the sheer amount of volunteer hours, months and months of work, thought and resources that went into producing an educational, informative and memorable occasion for the myasthenia community.

To be able to speak with so many professionals, ask questions from interested people, meet and hear people's stories and offer a little help and guidance where possible, was so very worthwhile.

I was extremely touched listening to people's MG journeys, humbled to hear how they are learning to live and cope with this often debilitating condition, one that alters the path we were originally on. To let them know that they are not alone, that there are others who understand. Meeting and talking and offering a friendly ear to those with MG and their carers and family was the highlight of my day.

Huge congratulations to the MAA for facilitating a very successful 4th National Myasthenia Conference.

Denise

The Conversation, Connection and Companionship was evident among the Myasthenia community that was gathered at the MAA Conference. As a volunteer representing MGAQ, I listened to stories particularly from the carers and helped them connect with our website and resources. The stand out message for me was how important it was to be an advocate for yourself or your family member.

Donna



What a wonderful and satisfying experience the recent Myasthenia Alliance Australia Conference was.

The introduction of each of the guest speakers showed what a very knowledgeable and professional group they were. The diverse range of topics they covered offered a wide array of interesting and relevant information.

Another important aspect of a conference such as this one is the opportunity for people with Myasthenia Gravis to mingle and talk with new and old friends. It was wonderful to see people from different towns and states chatting away and obviously enjoying the company and conversation.

I personally found the whole experience very stimulating and gained a great deal of satisfaction from listening to the speakers and having time to talk with a wide variety of people. Hopefully these new acquaintances will continue to flourish.

Carol

Scan to apply for
Membership or to
renew your existing
Membership



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



TOWNSVILLE



GOLD COAST



MANGO HILL



WESTERN AUSTRALIA



Myasthenia Gravis Friends *Western Australia* Coffee & Chat -

Venue: **Flames Restaurant, 7/55 Central Road, Rossmoyne**

Date: **Sunday, 4 February - 11.30am**

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

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

FEBRUARY 2024 - JUNE 2024

GET YOUR DONATIONS READY NOW!



www.myastheniaalliance.org.au



29 RARE
FEB DISEASE
2024 DAY



SHARE YOUR COLOURS

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

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



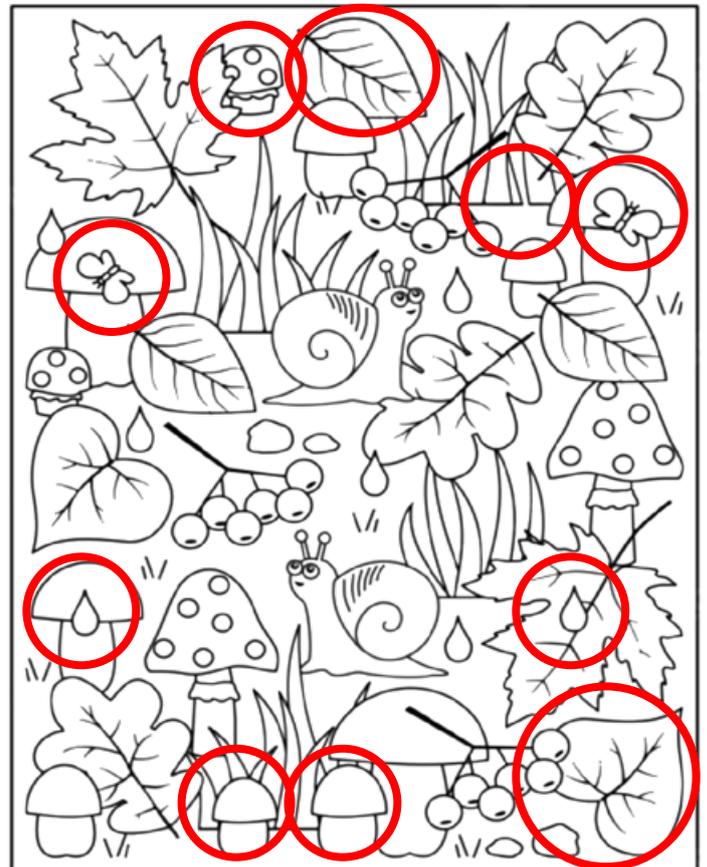
Merry
Christmas and a safe
and happy
New Year!

MessaGes will take a break over January and looks forward to resuming
in February 2024. Thank you to all contributors during 2023.

Puzzlers

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

THE 10 DIFFERENCES from the November Newsletter.



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

Inaugural Queensland Parliamentary Event

Rare Voices Australia (RVA) thanks everyone who attended our inaugural Queensland Parliamentary Event dedicated to people living with a rare disease.

This drop-in event provided RVA Partner group/organisation leaders with the chance to interact directly with parliamentarians who stopped by to meet RVA and others who represent people living with a rare disease.

As the national peak body for Australians living with a rare disease, the Parliamentary Event provided RVA with the opportunity to advocate for the following strategic aims:

- Advocate for a stronger presence in Queensland's Parliament
- Work with parliamentarians to develop an implementation plan for progressing relevant aspects of the Australian Government's National Strategic Action Plan for Rare Diseases
- Identify the relevant division within Queensland's Department of Health responsible for progressing a strategic approach to rare diseases.



- Melissa Camilleri (RVA Partner, Australian Pompe Association) and Anita Jackson (RVA Partner, Myasthenia Gravis Association of Queensland)
- Joe Kelly, Member for Greenslopes and Deputy Speaker, and Louise Healy (RVA)



Anita, represented the MGAQ recently at the Rare Voices Australia inaugural Queensland Parliamentary event for people living with a rare disease.

<https://rarevoices.org.au/recap-inaugural-queensland-parliamentary-event/>

USING EXERCISE TO IMPROVE STRENGTH, MOBILITY AND DAILY FUNCTION

A vast majority of people with Myasthenia Gravis are not aware that exercise can help to physically and emotionally manage their condition and improve their quality of life. Many people with MG often worry about how their specific condition will respond to exercise. This is a common concern and if you worry about this, you are not alone! In fact, only 11% of people with MG perform exercise as a part of their treatment plan.

However, research shows that for people with MG, exercise can improve strength, balance and flexibility, which makes it easier to perform daily tasks such as showering, walking and climbing stairs. Exercise can also decrease depression and make you feel more positive while enhancing your mood. It can also improve the effectiveness of medication and help the immune system to function at its best, decreasing the severity of your symptoms.

When looking to start an exercise program, many people worry that exercise may cause them to become more fatigued or that it may worsen their condition. Others may worry about their safety while exercising (especially if vision and balance are affected). Others may feel disheartened or overwhelmed by their diagnosis or may not know how to begin a safe exercise program.

Regardless of how long you have had MG or how severe your symptoms, a specialised exercise program can make a significant difference in your life. So how can you get started with exercise and who should you see to get a tailored exercise program? While there are so many options for exercise, it is recommended to see an allied health professional who has knowledge of this condition and experience in prescribing exercise for people with MG.

Physiotherapists

When thinking about seeing a physiotherapist, most people think about manual hands-on treatment. However, physiotherapists also prescribe exercise and can create specialised exercise programs for you.

Seeing a physiotherapist is the safest option when embarking on a new exercise program as all physiotherapists have knowledge of MG as well as extensive knowledge of the body.

Regardless of the severity of your symptoms, a physio will be able to create a tailored program for you based on what you need to work on, focusing on:-

- ▶ Improving your strength and balance
- ▶ Improving functional abilities
- ▶ Breathing control
- ▶ Increasing stamina and reducing fatigue

In seeing a physiotherapist, you may be shown a range of exercises that you can perform at home. Or alternatively, you may be able to attend specific exercise classes at the physiotherapy clinic.

While any physiotherapist will be able to help you, not all physiotherapy clinics will have the facilities for you to exercise on site. As such, it is a good idea to look for private clinics, hospitals or universities which specialise in neurological conditions and rehabilitation and have access to gym equipment, Pilates machines or hydrotherapy to aid your exercise programs.

Exercise Physiologists

Similar to physiotherapists, most exercise physiologists will be able to create a specialised exercise program which is tailored to your specific needs. Exercise physiologists have an in depth knowledge of the body and their entire university degree is focused on creating exercise programs for specific conditions.

As a part of seeing an exercise physiologist, you would usually be taken through a tailored exercise program at the gym or clinic. Depending on your level of function, you may also be prescribed simple exercises that you can perform at home.

Most exercise physiologists have access to a wide range of exercise equipment to assist your exercise program.

When seeing a physiotherapist or exercise physiologist, you don't need a GP referral and most people with private health insurance are able to claim a rebate. If you do choose to obtain a GP referral, you may be able to also claim some sessions back through Medicare.

Whichever exercise specialist you choose, your exercise program should focus on developing strength but not pushing you too hard (you should not feel overly fatigued after exercising). Ultimately, exercise should improve your condition, not worsen it, so it is best to go with someone who is experienced and is able to help manage your condition with exercise and improve your quality of life.

NEWS FROM AROUND QUEENSLAND

News from Cairns

Please join us for a **Coffee & Chat at Artview Gallery, 220 Toogood Road, Bayview Heights, 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 2024, Sports Club, 159 Bamford Lane, Kirwan, Townsville.**

Our Christmas lunch was a lovely event and thanks to everyone for coming. We all looked so beautiful.

Have a Happy Christmas and all the best for 2024.

Please RSVP to **Daphne on 0400 778 637 or email daphclay@gmail.com**

News from Mackay

For local support, please contact **Mary on 07 4959 5251**

News from Bundaberg

For more information, please contact **Denise on 0431 571 399.**

News from Hervey Bay

For local support, please contact **Jan on 0429 622 438.**

News from the Sunshine Coast

Sunshine Coast group will meet on **Monday, 5 February at Kawana Club, 476 Nicklin Way Wurtulla at 10.30am for Coffee and Chat.** All are welcome.

Please bring empty Mestimon bottles for Chloe's art project.

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

News from the Gold Coast

Hi Everyone. The MG Gold Coast group had their get together sharing experiences with other members on Saturday 18th of November at Kurrawa Surf Club. Our next meeting will be at **10am Saturday, 13 January at Southport Sharks Club.** I take this opportunity to wish everyone a merry Christmas and a happy new year. I look forward to seeing you next year! Kind regards **Nader on 0415 834 401.**



COFFEE & CHATS

Wellington Point - Saturday 17th February at 10.30am

**Wellington Point Farm House Restaurant and Cafe,
2/623 Main Road, Wellington Point.**

Please bring empty mestimon bottles for Chloe's art project.

ALL WELCOME!

RSVP Anita on 0414 588 312