



Myasthenia Gravis Association of Queensland Inc.

MessaGes

APRIL 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.



PRESIDENT'S REPORT APRIL 2022



It is difficult to realise that one-quarter of this year has already passed. This time last year we were talking and wondering what was going to happen with Covid and what are we still conversing about this year – what is going to happen with Covid? I hope that everyone who is immunosuppressed has taken the opportunity to show their doctor the ATAGI information statement and reiteration from Dr Stephen Reddel about the need for a fourth vaccination. It is interesting to read in the newspapers that some countries have already started more widespread fourth vaccinations.

I hope that those who have difficulty with reading the newsletter are finding the Newsletter Podcasts helpful. Many thanks to Mark for all his hard work and commitment to doing this for members who have difficulty with reading.

The MGAQ, in association with Myasthenia Alliance Australia (MAA), is still busy working with Rare Voices Australia and politicians in Canberra to ensure that our voice is represented in any decision-making which will benefit people with rare diseases. We must all remember that "Patient Voices Matter" and take every opportunity we can to have our voices heard.

It is wonderful to see the photos of groups meeting around the state. Myasthenia Gravis can be a lonely disease and having the opportunity to share stories, ask questions and gain general information from others is both important and invigorating. Also, do not forget to phone an acquaintance if they have not been to meetings for a while as they might just be going through a 'bad' patch in terms of coping with everything.

Our Light Up Project is growing bigger and more places around the state are becoming involved. More information will be in the next couple of newsletters and we hope that, if you get the opportunity, please take a photo and then send it to info@mgaq.org.au for possible inclusion in our newsletter. Also, please remember that not all photos might appear in the newsletter but they will be saved digitally for future use.

Happy Easter to all. Everyone please stay safe and well and enjoy the time you now have with friends, children, grandchildren and even great-grandchildren.



Warm regards, Carol

Myasthenia Gravis Association of Queensland Inc

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



WELCOME TO OUR NEW MEMBER

John, Cornubia QLD

SUNSHINE COAST GET-TOGETHER

MG Sunshine Coast enjoyed catching up at the Kawana Club recently.

Thank you Anita & Donna from MGAQ committee for joining us.



GOLD COAST MG GROUP GET-TOGETHER



Hi Everyone.

The MG Gold Coast Group had their get-together sharing experiences with other members on Saturday, 9 of April at Southport Sharks Club.

Our next meeting will be at 10am on Saturday, 18 of June at Kurrawa Surf Club in Broadbeach.

I hope to see all there!

Kind regards, Nader Amiri

Gold Coast Coordinator 0415 834 401

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.





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.

MY COVID STORY

Amanda Writes:

In 2020 I began my Home Stay, at my house.

My Rheumatologist suggested due to my medication regime this was the safest option. No one wore masks at this stage however the message delivered was clear "don't get close to anyone who does not generally live with you whilst you are on this medication". I'm taking Methotrexate and a new Biologic to stop the stampede of Arthritis marching through my body and taking over my joints. The advice extended to my grandchildren and if I had to see them I was to maintain a 1.5 meter distance. My husband's job was relatively safe but he's a junior social Basketball coach. For the past 16 years he's devoted his time to teaching 5 to 18 year olds, 3 nights and 1 day a week to them.

2021 was filled with appointments, but life is good no Covid here, we personally didn't know anyone who'd contracted it. I met people online who had been very unwell from catching Covid. We were afraid our children and family in the health industry might catch it.

We planned a holiday house swap for the Christmas new year break at the seaside town of Victor Harbor. I attended appointments in the week before we left and visited the Pharmacy to stock up. My Husband usually did the drug run but he was flat out at work. The Pharmacist was new and slow. I spent 15+ minutes waiting. A woman saw me as I sat and waited. I thought I recognised her as she waved eagerly to me. She approached me talking like she really knew me and proceeded to stand quite close over me. I was off guard as I hadn't spent much time out and had previously just popped in to a cheap shop to grab a storage tub. It was the 23rd December 2021.

My family and Grandchildren were coming for Christmas Eve, that is our tradition. 1 of the couples we were holidaying with and 1 of their son's family came along too. We sanitised and thoroughly cleaned. It was a wonderful night. All was well until 10pm. I hit a brick wall like no other.

My Husband helped me upstairs to bed at 11pm. I was very weak I thought my heart might stop whilst sleeping, I was thoroughly exhausted. Christmas morning, I just couldn't get going. We were due out for lunch. My Husband made all the preparations and we got going early. We were the first to arrive. I made myself comfy on the couch and fell asleep. I did my best to remain clear of touching anyone so they might not infect me! That day I mixed with a Private School principal, a Professor of Cancer research, a Sleep Scientist, some Grandparents 1 has Parkinsons and Leukemia, as well as a Major Projects CEO and 2 teens. 1 in school and 1 working in the Food Industry. All people who needed to be healthy just like me. I was so tired. We said our goodbyes at the end of the day and reached our destination by about 5pm.

Along the way I began to get a runny nose, at one point I thought I had a sore throat. The trip was 60 minutes. The next morning 26th of December I had a sore throat and a running nose. The friends we spent Christmas Eve with arrived just after lunch (the other couple would come tomorrow). All day I had a running nose but I wasn't quite as exhausted as I had been. My friend was unwell we put it down to travel sickness, not uncommon for her. I felt that sore throat again but it didn't last so I figured

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



CONTINUED FROM
PREVIOUS PAGE

MEMBERS' FORUM

'maybe I'm run down it will be better tomorrow'. Tomorrow came and went, the other couple arrived settled in and we were busy enjoying each other's company. The 28th I woke to a stuffy nose and tiredness. My friend was also unwell. We had a few activities planned an outing and dinner so off we went. I was a bit nervous about this nose issue and the pathetic sore throat that came and went. The running and stuffy nose made absolutely no sense to me. I had been told not to use the CPAP machine if I had a cold. This later turned out to be the wrong advice!

On the 29th our friends left prematurely. In the afternoon I organised my 3rd PCR, the testing station is only 3 minutes' drive. I was gone 16 minutes. The Station in Victor Harbor was running very efficiently. The tester advised my results may take up to 48 hours due to on site processing. My very patient husband realised we needed to return home, so he packed the car and drove home. Dad got a real surprise when we opened the front door! I went straight to bed I was flat. That was the 29th and I was certain my test would return positive.

By the 31st of December I was checking my phone regularly hoping for the result to be negative. I had several texts with my friend to find out if she had managed to secure an appointment for testing, she was very unwell and had all the classic reported symptoms of Covid. There were no appointments for days! I hunted, reached out to friends, and found a Pharmacy that sold Rat kits and dispatched my husband to pick up 4. I told my friend the location. Both our men had no signs of being unwell. Hubby had been home 10 minutes when my friend rang and told me her Rat kit result was positive, her husband negative. It had been a very warm afternoon, we had to wait 30 minutes for the test box to return to room temperature before I could use it. I was so nervous setting it up. 48 hours had come and gone and still no result notification. As soon as I put the 1st drop on the test cassette it bled quickly up the strip and was turning bright pink. Both lines appeared straight away, the bottom one was faint. I had it. My heart was pounding it was just after 9pm and I was wide awake. I tried to relax but all I could think of was the people I had been near over the festive period. I had begun to get anxious and at 11.03 pm a text from SAPathology came in I missed it. I heard the notification from SAHealth at 11.45pm it read in brief your COVID-19 test on 29-Dec-2021 is POSITIVE. You have to remain isolated until released.

I sent this message to my close contacts:

"Hello this is a text for my close contacts. I've just received a positive result from a covid test I had taken on the 29th December at a covid testing station. I became unwell on the 26th. I saw you on the 24th. Contact tracing have advised me to let you know my positive status. Please know I'm extremely sorry I have exposed you unknowingly. Amanda"

I varied the date for each of the 24 people I had contact with and sent them out between 12.27am and 1am.

I couldn't sleep until 3am.

It took me 3 days to get over that. Some of the recipients didn't respond or acknowledge they'd received my message. I wasn't as sick as my friend who had spent 3 days flat on her back hardly eating or drinking. I had my taste and smell and no headache or muscle aches. My only symptoms were a running and stuffy nose, occasional sore throat and extremely fatigued. Toward the 4th day my tongue felt like I had burned, like a burn from the 1st slurp of a hot cuppa. These symptoms continued for 15 days. I filled in a daily symptom checker, sent by SAHealth. The final message from them was received on the 8th of January 2022 at 9.31pm telling me I was cleared as an active case of COVID-19. I had to remain in isolation until 11:59 pm that day. They further advised if I still had symptoms that I was to remain in isolation until they had resolved.

My husband and I did not isolate from each other, neither did my friends. No one else became sick or unwell from the contact with me over December or January.

I was triple vaccinated having my 3rd shot just 16 days prior to testing positive

Amanda



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.



QUEENSLAND LIGHTS UP

June is International Myasthenia Gravis Awareness Month.



The following buildings and landmarks will be illuminated in Blue/Teal in the month of June.

BRISBANE - Friday 10 June

- Story Bridge
- Victoria Bridge
- Reddacliff Place Sculptures

BUNDABERG - Month of June

- Fig Trees

CAIRNS - 8 to 30 June

- The Court House Gallery

EMERALD - Month of June

- Emerald Council Chambers

GOLD COAST - Friday 3 June

- SkyPoint Observation Deck

IPSWICH - JUNE

- Ipswich Civic Centre

LONGREACH - 10 to 20 June

- Longreach Water Tower

MACKAY - Monday 6 to 12 June

- Sir Albert Abbott
Administration Building

TOOWOOMBA - JUNE

- Victoria Street Bridge

TOWNSVILLE - 7 to 13 June

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

TOWNSVILLE - 12 June

- Queensland Country Bank Stadium

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

The MGAQ wish to thank the following for their support of International Myasthenia Gravis Awareness Month

- Brisbane City Council
- Bundaberg Regional Council
- Cairns Regional Council
- Central Highlands Regional Council
- Skypoint Gold Coast
- Longreach Regional Council
- Mackay Regional Council
- Stadiums Queensland
Queensland Country Bank Stadium
- Townsville City Council
- Logan City Council

LISTEN to audio Newsletter via **MEMBER ACCESS**



Oh MG I NEED YOUR BOTTLES

Hey everyone, let me introduce myself. My name is Chloe Wigg and I am a visual artist and person with MG. I have done a number of exhibitions focusing on resilience and I am an advocate for those with invisible disabilities.

I am going to be working on a project over the next few years and am looking for 2000 empty mestinon bottles (bottles, lids, the whole kit and kaboodle). They can be the timespan bottles, instant release 60mg, 10mg bottles or any other strength bottles.

This will represent the roughly 2000 MG sufferers in Australia and will be turned into hanging snowflake sculptures.

If you have some bottles please send to:

PO BOX 628, Rochedale South 4123

MGAQ is also happy to accept empty Mestinon bottles at all of their gatherings



COFFEE & CHAT MORNINGS

myasthenia gravis

**south
australia** friends

mgsouthaustralia@gmail.com

**Saturday 7th May 2022 10.30am.
All Welcome.**

Coffee & Chat mornings are held at the Hope Inn, 348 Port Rd, Hindmarsh, SA 5007 in the Apple Room, Ph: 8471 3093 (hotel).

We begin at 10.30am and conclude at 12 noon.

Wheelchair entrance via South Rd sliding door.

Ample parking with 3 entrances.

Drinks are available from the front bar.

Meals available from 12pm. (Rhineland Bakery next door)

COFFEE & CHAT IN WA



Contact Annette on 0413 855 077 if you are in WA.

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



NEWS FROM AROUND QUEENSLAND

News from Cairns

Your local contact in the Cairns region is Donna who can be contacted on 0414 397 462 or email donnaformosa64@gmail.com

News from Townsville

The next luncheon get together is booked for **Saturday, 30 April at 12 noon** at the **Kirwan Sports Club, 159 Bamford Lane** (*please note the change of venue*)

Family members are welcome. Please RSVP to **Daphne** on 0400 778 637 or email daphclay@gmail.com. I look forward to your company.

News from Mackay

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

Thank you to everyone who came to our last get together on April 11. For more information on the Sunshine Coast group, please contact Vicki on 0411 146 898 or email avlplummer@gmail.com

News from the Gold Coast

Our next meeting will be at **10am on Saturday, 18 June at Kurrawa Surf Club in Broadbeach.**

Your local contact for the Gold Coast group is Nader. His contact number is 0415 834 401.

DATE CLAIMER!

JUNE AWARENESS FUNCTION SUNDAY, 12 JUNE, AT 10.30AM

Sunnybank Community & Sports Club, 470 McCullough St, Sunnybank
Guest Speaker: **Louise Healy** from **Rare Voices Australia**



COFFEE & CHATS

RSVP Anita on 0414 588 312

SPRINGWOOD

– Cafe 63

Thursday 28th April at 10.30am 99 Cinderella Drive, Springwood

SUPPORT your Association by taking **MEMBERSHIP.**