



Myasthenia Gravis Association of Queensland Inc.

MessaGes

MAY
2023



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 MAY 2023

It seems that nearly every newsletter now I seem to be writing about members being vigilant about their health. Now Covid is still with us but to a lesser degree but an early start to the influenza season is another concern. People who have not contracted Covid should have had their fifth booster and also had their 'flu vaccination. Just keeping on top of things is a real chore sometimes but it is something we all must do.

On May 22 there will be a new podcast released. This will be a very interesting one with all of Helen T's newsletter stories from 2022 being collated into one podcast. Dr Podcast and the management committee urge you to find the time to listen to this as it contains much interesting and informative information in story form about living with Myasthenia. Also, the podcasts already listed on the website with links in the newsletters have been produced for members. These take a great deal of time and effort to produce so please have another look at the topics.

June is a special month in the Myasthenia Gravis 'world' and it continues to be especially significant for Queensland. The MGAQ theme of "**Queensland 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 when you go out so that someone might ask you the meaning behind it.

By now everyone should be aware of the fourth **Myasthenia National Conference to be held in Sydney on Saturday 21, October**. This association is very lucky to have such great support from very well-respected neurologists who support us in this way by giving so freely of their time. Registrations will open in June with early registrations being offered from that date. More information is on page two of this newsletter.

If you live close enough to Brisbane I urge you to attend the **Get-together on Sunday 11 June with our guest speaker Dr Reuben Beer BPharm MBBS FRACP, Neurologist** providing us with information about "**Current treatments for Myasthenia Gravis**". The venue for the **June Function is Hornet's Football Club, Graham Road, Carseldine**.

Further details are in this newsletter.

Thanks, Carol

Myasthenia Gravis Association of Queensland Inc

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



MYASTHENIA ALLIANCE AUSTRALIA

NEWS UPDATE

There is awesome news to be shared with you this month!

An article has now been submitted by the “Patient Reported Outcomes Project” Research team to the **Journal of Clinical Neurosciences**. This is an important Journal for our condition and it is hoped that the lengthy and particular process of preparing the Journal Article will be well rewarded. The stages to acceptance takes many weeks. Updates will be provided as they become available. The MAA thank the partnering Researchers for their diligence in consolidating, correlating and analysing so much information. For more information about this significant project please see the info-graph on page 3 of this newsletter.

Planning for a fourth **MYASTHENIA PATIENT CONFERENCE** is well underway. The date is set as **Saturday October 21st, 2023**. The hosting venue is the **Education Centre at the Concord Hospital in Sydney**. The time is **9-4.30pm**. Catering has been secured, a varied and comprehensive programme is being fine tuned and registration documents will soon be available. As usual, it is a major event for the small MAA team but they are excited to make this opportunity available to the Myasthenia community in Australia. Whilst this is the fourth time such a day has happened, it can only be offered with the generous support of a few highly skilled Specialist Doctors and with the efforts of the volunteers involved. Therefore, please do take this opportunity to attend, very seriously. The venue has strict limits on the number of attendees so less places will be available than at the 2019 event.

Why consider attending a targeted Conference? What should be expected from the day? Will I manage physically? These are questions that people might be asking.

The venue is small and compact and car-parking is close by and easy to access being a Saturday. All lectures will be in the main auditorium so minimal moving around. There is space for wheelchair access and somewhere to park walkers. A cup of tea or coffee will be available for you on arrival and then a satisfying morning tea with late lunch to follow will be offered. The venue is intimate so there'll be plenty of opportunities to talk with others. The Specialists who speak all have a particular interest in this condition with lots of clinical experience. They are keen researchers and well informed. Their lectures will be adapted to suit a patient group. New treatments are coming and information about them will be provided. You are welcome to attend as a family or with your Health professionals if they are interested.

Your volunteers have chosen to stay at Olympic Park which is a short taxi ride away. Think about pacing this outing by combining it with a holiday plan - what a great excuse!

Hopefully registration will be opened in June as part of the June Awareness events. Another season of the “Art With Heart” campaign will be launched in conjunction with the Conference. This time will be about us, the rare group of people with Myasthenia! Please don't miss out.

Best regards

Susan White - MAA Chairperson

If you are not already registered with the Alliance please go to

www.myastheniaalliance.org.au

THANK YOU!

Myasthenia Gravis (MG) Australian Survey 2022

A Summary for Participants

Study objective: What did we hope to achieve?

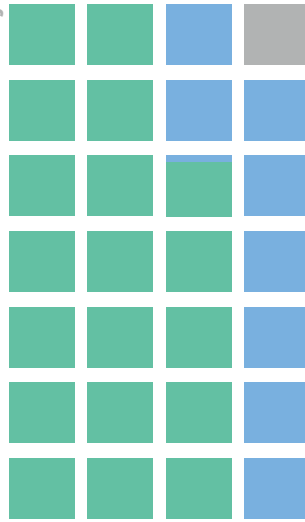
Generate evidence required to advocate for people living with MG to have timely and equitable access to better health service, better funding, and more reimbursement pathways.

Study design: How did we collect the data?

Surveyed MG patients electronically about quality of life, personal histories with MG, and the financial and clinical aspects of living with MG.

280 Respondents **Average Age 60.5**

67.5% Female **32.1%** Male **0.4%** Nonbinary



Average **2.9 years** from first symptoms to diagnosis

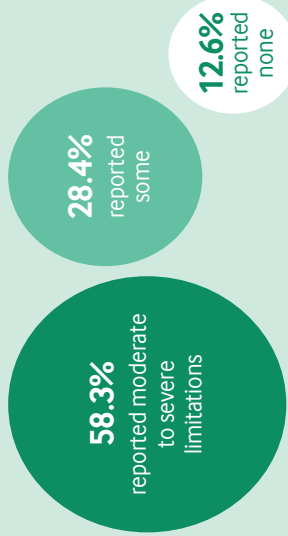
1.5 Years Male

3.6 Years Female

50% from capital cities | **50%** from regional areas

Participant Experience With MG

Most were limited in daily tasks and activities

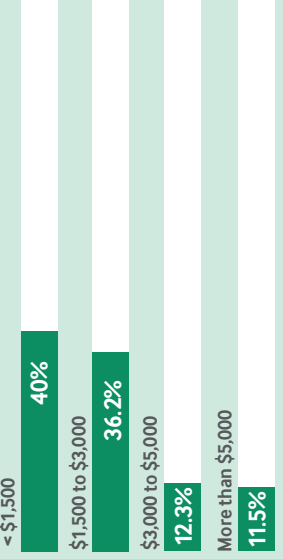


During the past 12 months:



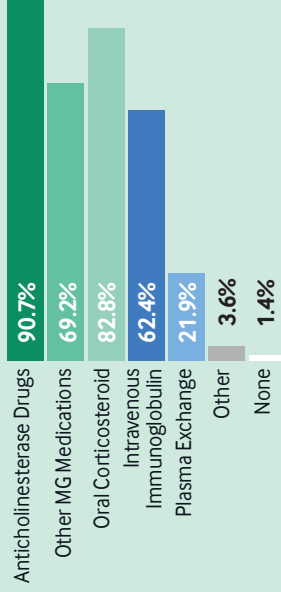
During the past 12 months:

48% required additional medical intervention
Those who required additional intervention reported out-of-pocket spending:

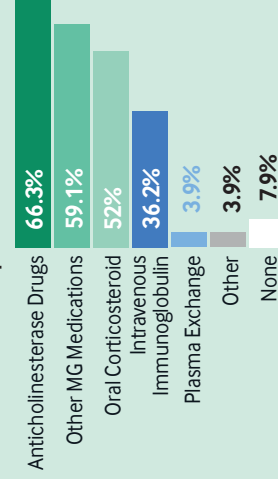


Participants reported their treatments used, currently or in the past

All current and previous medications and procedures*



Current medications and procedures*



33.7% reported that their thymus had been removed

Next steps: What will we do with this data?

- Share it with neurologists in clinical conference
- Publish it later in 2022
- Use it in dialogue with the Minister of Health as part of a larger effort to improve treatment options

*These categories are not mutually exclusive.

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.

We are not always visible

A real life story of living with an invisible disability

After a couple of heavy weeks my husband came to me recently and asked if I would like to go out for dinner. Romantic - yes. An easy task - nope. My initial response was 'no, it's too hard to navigate around all the issues. Ah, he had done his research, decided on a restaurant not too far from us, on ground level, with easy comfortable chairs and access, with air conditioning etc, so I agreed - albeit a little hesitantly.



We got all dressed up for the evening, because this is probably the first time we went out for an evening meal in a couple of years. We parked in the designated disability parking bay and walked in. The receptionist immediately rushed to us and asked us to move the car. We assured her that we have a Disability Badge and that it is displayed, but she insisted that we move the car. Afterwards she explained that she didn't believe I was disabled (probably as I didn't use a wheelchair). But by then I was already quite upset and embarrassed that this was causing a scene and my night was getting ruined. We left the restaurant, with me in tears. My husband was disappointed as he had called the restaurant in advance to make sure I will be comfortable.

I am diagnosed with 2 rare conditions. Stiff Person Syndrome and MuSK positive Myasthenia Gravis. Two years ago I was in palliative care, unable to move my muscles. I still have many issues but on a good day I can now walk a few steps unaided.

Until I fell ill I myself never understood much about disabilities, let alone having to live with invisible disabilities and how they impact our lives.

An invisible disability is a condition that affects an individual's functioning, yet is not immediately apparent to others. This type of disability can impact a person's ability to participate in daily activities, work, and social interactions. Unfortunately, invisible disabilities are often misunderstood, overlooked, and stigmatised. It is essential to raise awareness and understanding of these disabilities to promote inclusion and support for individuals living with them.



**NOT ALL
DISABILITIES
ARE VISIBLE**
#ThinkOutsideTheChair

Examples of invisible disabilities include chronic pain, mental health conditions, neurological conditions, and autoimmune disorders. These conditions can affect an individual's physical, emotional, and cognitive functioning, leading to difficulty with memory,

concentration, mobility, and communication.

People with invisible disabilities face challenges in being understood and getting support because of the lack of visible signs of their condition. In some cases, they may be met with skepticism or disbelief, leading to feelings of isolation and frustration.

One of the biggest challenges for people with invisible disabilities like us is the lack of awareness and understanding amongst others. It is not uncommon for people to dismiss someone's condition because they cannot see physical evidence of it. This can make it difficult for individuals with invisible disabilities to explain their limitations and needs to others, leading to feelings of shame or embarrassment.

To support individuals with invisible disabilities, it is essential to create a more inclusive environment.

Organisations and individuals can raise awareness of invisible disabilities by sharing stories of people with these conditions, promoting inclusive policies, and challenging ableist attitudes and behaviours.

Invisible disabilities are a significant issue that affects a large number of people. It is essential to become aware and understand the needs of people who are not visibly disabled.

Vino

**Message
from
Tony**

Tony here - a recent member.

I wanted to express my appreciation for the many aspects of care I have received from MGAQ already. I want to thank you for the attention to detail, resources and thoughtfulness. even after years this illness is still confusing and relentless at times. For many of us it and can leave us feeling "alone" but your service has gone a long way to supporting the MG Community.

THANK YOU ALL, TONY

VALE KRIS KLITGAARD

A True Gentleman



It is with sadness that we inform members of the passing of Kris Klitgaard on 14 April.

Kris and his lovely wife, Barbara, joined the Myasthenia Gravis Association of Qld in 2000. Kris joined the management committee and was Treasurer for a number of years – a role he really enjoyed. Kris was a management committee member until 2010.

Kris offered optimism, encouragement and support to others with Myasthenia Gravis and was well loved by those who knew him as well as by all the members of the Management Committee.

**KRIS WAS ONE OF LIFE'S
TRUE GENTLEMEN.**



VICTORIAN REGIONAL MG LUNCHEON

to be held on

Sunday, 25th June at 12 noon

Shepparton RSL Club, 88 Wyndham Street Shepparton

RSVP by Friday 23rd June.

For all bookings please call/text Pauline on 0419 332 260

Oh MG I NEED YOUR BOTTLES

My name is Chloe Wigg and I am a visual artist and person with MG. I am going to be working on a project over the next few years and am looking for 2000 empty Mestionon bottles. This will represent the roughly 2000 MG sufferers in Australia and will be turned into hanging snowflake sculptures.

MGAQ is happy to accept empty Mestionon bottles at all of their gatherings.

SUPPORT your Association by **VOLUNTEERING.**

JUNE IS MYASTHENIA AWARENESS MONTH

COME ALONG - MEET IN PERSON

SUNDAY 11th JUNE – 10am for 10.15am START
HORNET'S FOOTBALL CLUB, GRAHAM ROAD, CARSELDINE

Guest Speaker:

Dr Reuben Beer BPharm MBBS FRACP, Neurologist

Topic: *“Current Treatments for Myasthenia Gravis”*

RSVP IS ESSENTIAL AND OPEN UNTIL SATURDAY 10TH JUNE

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

MGAQ INC. PODCAST SERIES - UPDATE

Helen T is a regular contributor to the MGAQ monthly newsletter. Helen's stories are reflective and uplifting. Six of her stories from 2022 have been collated into a podcast for members and will be published on 22 May 2023.

All financial members of MGAQ have access to all the podcasts at www.mgaq.org.au

For more information, please email info@mgaq.org.au or call 1800 802 568.

MYASTHENIA AWARENESS

The MGAQ Banner will be displayed on the **Story Bridge** in **Brisbane** (*inbound*) from 29 May to 11 June.



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 – Friday 2nd June

Story Bridge
Victoria Bridge
Reddacliff Place Sculptures Donna Marcus:
Steam 2006
Tropical Dome
Wickham Terrace Car Park Architectural wall
Breakfast Creek Bridge at Newstead

Bundaberg – Wed. 7th June- Wed. 21st June

Fig Trees

Cairns – Thursday 8th June to Friday 30th June

Court House Gallery

Emerald – Tuesday 13th June to Monday 19th June

Emerald Council Office

Gold Coast - Sunday 4th June to Monday 5th June

Sky Point

Gold Coast – Tuesday 27th June to Friday 30th June

Gold Coast City

Ipswich – Monday 12th June to Sunday 18th June

Ipswich Civic Centre

City of Logan – Sunday 4th June

Jacaranda Tower, City of Logan
Telfer St Water Tower, City of Logan
Wineglass Water Tower, City of Logan

Longreach – Thursday 8th June to Thursday 22nd June

Longreach Water Tower

Mackay – Thursday 1st June to Wednesday 7th June

Sir Albert Abbott Administration Building
Library Kiosks

Toowoomba – Thursday 1st June to Friday 9th June

Victoria Street Bridge (Russell St to Ruthven St)

Townsville – Thursday 8th June to Wed. 14th June

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

Townsville – Thursday 8th June

Queensland Country Bank Stadium

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

***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
City of Gold Coast
Ipswich City Council
Logan City Council
Longreach Regional Council
Mackay Regional Council
Queensland Country Bank Stadium
SkyPoint Gold Coast
Toowoomba Regional Council
Townsville City Council

MG

Exhibition Inspiration



Top right: Snow drift made from cotton stuffing and the spriggy tube from the medication lid

Top left: All equipment used, box, bottles, lids rings ect.

Middle: Mestinon bottles arranged in a snow flake pattern

Bottom left: Crochet snowflake inspiration

Bottom right: Lid rings with different teal wools crochet over the top.

Please send bottles to
Chloe Wigg
PO Box 628,
Rosedale South,
Queensland 4123

NEWS FROM AROUND QUEENSLAND

News from Cairns

You are invited to join us for informal Coffee & Chat on **Saturday, 27 May at 11am at the Cairns RSL Club Boardroom, Cairns Esplanade**. Visitors to Cairns are most welcome! For more information, please contact **Donna on 0414 397 462**.

News from Townsville

Townsville MG lunch **Saturday, 22 July 2023, 12noon at Sports Club, Bamford Lane. Kirwan**. For more information, please contact Daphne on **0400 778 637**.

News from Mackay

Sir Albert Abbott Administration Building and Library kiosks will illuminate in teal from **Thursday, 1 June to Wednesday, 7 June for Myasthenia Awareness Month**. I encourage you to use this opportunity to share the awareness with your family and friends. For local support, please contact **Mary on 07 4959 5251**

News from Bundaberg

We would love to see you at an informal Coffee & Chat on **Saturday, 1 July at 10am, The Spotted Dog, Railway Hotel North Bundaberg**. Susan who is the MAA Chair, MGAQ Communication Officer and also the voice behind the MGAQ freecall 1800 number will be in attendance. This will be a great opportunity to have general questions answered. 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

The Sunshine Group will next meet on **Monday, 5 June at Kawana Club, 476 Nicklin Way Kawana**. For more information please contact **Vicki on 0411 146 898**.

News from the Gold Coast

MG Gold Coast group will have their next meeting on **Saturday, 27 May, 10am at Southport Sharks Club, Corner Olsen & Musgrave, Avenue Southport**. Hope to see you there and don't forget to bring your empty Mestimon bottles for Chloe's art project. For more information, please contact **Nader on 0415 834 401**.



COFFEE & CHATS

RSVP Anita on 0414 588 312

WELLINGTON POINT – Thursday 18th May at 10.30am, Wellington Point Farmhouse Restaurant, 625 Main Road, Wellington Point – All Welcome!

WELCOME TO OUR NEW MEMBERS

Gary F,
Beachmere, Qld

Colin P,
Hillcrest, Qld

Rebecca S,
Table Top, NSW

Frances J, Preston
VIC

Beverley P,
Hillcrest, Qld

Anthony E,
Hawthorn, SA

Kathleen J,
Ringwood East VIC

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

MEMBERSHIP SUBSCRIPTION RENEWAL

It's that time of the year again, when Membership Subscriptions for the financial year 2023/2024 are due.

The envelope in which your newsletter is enclosed will advise you when your membership expires. If you look along the top line you should see "YOUR NAME" followed by some figures in smaller print than your address.

If you receive the newsletter by email and are unsure whether or not you are currently financial, **please phone our 1800 802 568 freecall number or email treasurer@mgaq.org.au to enquire.**

The majority of members will have 7/23 which tells you (and us) that you are financial to 30 June 2023. Others may show 6/24 or even 6/25 to indicate they have saved time and postage by paying in advance.

If you are unfinancial, **please take a minute to phone on the FREE call number, 1800 802 568 and advise whether or not you wish to retain your membership and receive all resources.**

We are also giving you the option of paying your subscription directly into our bank account.

New payment option for members of "Perpetual membership"

Cat A (Myasthenia Member) & Cat E (Associate Member) \$250 and Cat D (Carer Member) \$125. This one-off payment would mean that you never have to worry about renewing your membership again. Please note that a Cat D membership must be attached to a Cat A Myasthenia Membership, it is not a stand-alone membership.

MEMBERS CAN NOW ALSO PAY THEIR ANNUAL FEES VIA THE MGAQ WEBSITE www.mgaq.org.au/membership-application-form and select **Membership Renewal**

Our bank details are:

BANK: Bank of Queensland BSB: 124 032 ACCOUNT NUMBER: 10263772

ACCOUNT NAME: Myasthenia Gravis Association of Qld Inc.

REFERENCE: Your Name and Initials

If you use the direct deposit method, it would help if you could email us at treasurer@mgaq.org.au to advise that you have paid directly into our bank account and the date of the transaction. This will assist the Treasurer in reconciling with the Bank Statement.

Your receipt will be emailed or forwarded to you by mail.



If you wish to pay by Cheque or Money Order, please use the following form and forward to:

The Myasthenia Gravis Association of Queensland Inc.

PO Box 16 MT GRAVATT Qld 4122 or email treasurer@mgaq.org.au

Herewith please find my cheque / money order / cash for the sum of \$ _____ being annual

subscription \$ _____ and/or Donation \$ _____ MGAQ/MAA (Please circle)

NAME _____ **Category A Myasthenia \$20**
(or) Category E – Supporter \$20 Perpetual Membership Category A or E \$250

ADDRESS _____

And for _____ **Category D – Carer \$10**
Perpetual membership \$125 (Cat D Carer membership must be attached to a Cat A Membership.)

ADDRESS _____

Mobile _____ Email _____