



Myasthenia Gravis Association of Queensland Inc.

MessaGes

October
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 OCTOBER 2024

Many thanks to the people who attended the Annual General Meeting last month. Our theme of Conversation, Connection and Companionship was certainly well received and members, both new and familiar, had time to talk and share information and stories from the past year. As we did not have a guest speaker everyone was relaxed and welcomed the opportunity to just catch up with others and welcome new members.

It is great that we have a full executive for the management committee but, unfortunately, we did not fill all general positions. The call for nominations for two committee members was not successful and thus the workload of our nine members will certainly continue to increase. Remember that, if you have a bit of spare time to give, it would be appreciated as every little bit helps. We are also looking for project managers for some smaller activities which will have a start and end date attached so people know the level of commitment required.

Congratulations to members past and present who have contributed to the workings of the Myasthenia Alliance Australia (MAA) which is celebrating ten years of work and service for people living with Myasthenia in Australia. The political and social landscape has certainly changed over that time and the MAA has been instrumental in raising awareness of

living with MG as well as advocating for access to the most up-to-date services and resources for the MG community.

On page 3 of this newsletter you will see information about a **survey being facilitated by the MAA**. Please take the time to look at it and, if possible, complete it.

This survey is available to everyone with it being available both online and hardcopy.

Things are looking good for our **Christmas Get-together on Sunday 10th November 2024, 11.30am at Southport Sharks Club, Gold Coast. Please remember to RSVP on 1800 802 568 so the venue can cater for our numbers.** We now have our Christmas function early so that it does not clash with activities with family and friends.

Wishing everyone a safe lead up to the festive season and hope that all loved ones are organising to have a joyful time together.

National Carers Week is celebrated in October. MGAQ is happy to introduce a virtual coffee and chat via zoom in the comfort of your home for our carers. See page 7 for details.

Thanks Carol

Myasthenia Gravis Association of Queensland Inc

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



10 Years celebrating Advocacy, Research, and Unity

For the past 10 years, the Myasthenia Alliance has been a driving force in uniting the community, advocating for optimal medical treatments, and amplifying a collective voice on key issues impacting those with Myasthenia. By harnessing resources cooperatively, the Alliance has supported vital research and championed the well-being of individuals across all forms of the condition. Together, we have made significant strides and remain committed to continuing this important work for years to come.

The three founding members who have been integral to our wonderful first 10 Years share their insights...

“ Carol says- After a very detailed and concise planning process the Myasthenia Alliance Australia (MAA) was founded in 2014. This group, which had a clear focus on the national agenda, was made up of the incorporated state associations.

As a foundation member of the MAA I have seen it grow from very humble beginnings to a highly strategic group with strong affiliations with government, pharmaceutical companies and other not-for-profit advocacy organizations. The work of this alliance cannot be underestimated. The work with the state associations to raise needed funds for the 'build' of MGBase, the ongoing advocacy with members of parliament in relation to the provision of services and products for people living with MG, the ever-increasing recognition by pharmaceutical companies, the strong affiliation with both internationally and nationally recognised lead neurologists and the involvement in a wide breadth of research are just a broad indication of what the MAA has, and continues to, achieve.

I am very proud to have been a part of such a widely-recognised and proactive small group of individuals constantly working to improve the lives of people living with MG and their families. I know that the MAA will continue to gain further recognition into the future. ”

“ Susan says- “Who would have thought” is my catchcry! It has been an amazing ten years of new, interesting and purposeful experiences where we are confident that we have made a difference for the Australian Myasthenia community. It has also been a joy to work with such wonderful team members. A small but mighty group. Each volunteer offers so much to this organisation and they offer so much of themselves and their time. There is great potential for the future endeavours of the MAA. ”

“ Glenda says- As a founding member, starting out I did not know what to expect, but very pleased we are still going strong and are supporting the MG community. ”

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



Myasthenia
Alliance Australia

Market Research on Generalized Myasthenia Gravis (gMG)



The MAA respectfully requests patient support in further telling the story of their experiences with all forms of Myasthenia. Please note, we are very pleased that this survey can be completed via a hardcopy option. Please call Libby on 0407 110 204 to arrange this.

Late last year Alexion asked several people living with MG to participate in an online insight gathering project that aimed to better understand the current patient and doctor dynamics so that they can help support people living with gMG by addressing unmet needs at different points in time along the patient journey.

Several members of our community put up their hands and shared their experience which was incredibly important in shaping a real world understanding of life with MG and has assisted Alexion's efforts to bring access to new treatment options.

The main takeaways identified gaps in what patients may need or expect and their clinical experience:

- ◇ The disconnect between HCPs and people living with MG is very real. All people living with MG interviewed recall difficulties and challenges with HCPs at some point in their journey – especially early on. Some doctors can downplay the impact of MG which may cause them to appear ignorant or dismissive.
- ◇ People living with MG can feel underwhelmed with their healthcare experiences, under-prepared and forced to advocate for themselves. People living with MG who are not managed by MG specialists can face a more challenging journey. The physical and emotional rollercoaster of MG can leave many people living with MG feeling isolated and socially outcast. Managing side effects can prevent people living with MG from reaching their own personal goal of wanting to just feel “normal”.
- ◇ It can take years to get to a point where people living with MG feel some level of satisfaction with treatment.
- ◇ Doctors are focused on clinical markers to judge success more often than what a person living with MG might consider their own treatment or health goal.

JOIN OUR MARKET RESEARCH ON
Generalized myasthenia gravis (gMG)

The research aims to better understand the current patient and doctor dynamics to help support people living with gMG by addressing unmet needs along the patient journey.

DETAILS OF THE SURVEY:

15-MINUTE ONLINE SURVEY
Please note the link below needs to be completed in one sitting.

ACCESS ON
<https://rebrand.ly/1816Pearl2>

If you are unable to do the survey online, could you please text 0407 110 204 or email libby.noble@alexion.com and a hard copy will be arranged for you to complete.

This survey is sponsored by Alexion Pharmaceuticals (UK) Ltd, 1 Talavera Road, Marquarie Park, NSW 2113.

Whilst much of what was shared and learned from the exercise will not be new to many of you, the findings have helped Alexion to develop a **more robust survey** that will help more people living with MG validate the gaps raised in the initial phase of the project.

The purpose of this survey is to get to an even deeper understanding of the impact of gMG on the lives people living with MG and validate the gaps needs.

The self-completed online survey will take participants about **15 minutes**. We have partnered with Elbow Insights and Strategy, a market research agency that specialises in this area, to help us develop and distribute the survey.

We are hoping we can have your help in sharing this research with community members so that those interested can participate in the survey.

If you are interested in helping us, you can use the link below to preview the survey or contact us to get your personalised link. Please note participants who use the link below needs to be completed in one sitting.

<https://rebrand.ly/1816Pearl2>

If you are unable to do the survey online, then please reach out to Libby at Alexion email libby.noble@alexion.com or text her on 0407 110 204, and she will organise to send you a hard copy.

VALE SHIRLEY JOHNSTON

Shirley Johnston was at the very first meeting of MG in Brisbane in May 1991. This was the first time that people who had MG were able to meet and talk about their journey with MG and their medications. Shirley was in remission at that time but she was eager to meet others who had MG and to get the Association going.

We still have some of the founding members in the Association today.

Shirley had many different positions on the Management Committee and was

awarded a Life Membership as the association appreciated her many years of service. Her last role was looking after the 1800 phone number. There are many members who have a very soft spot in their hearts for the wonderful association they had with Shirley as she was always happy to help.

As the MGAQ grew more and more people from all over Queensland started phoning the 1800 number and the charming and friendly Shirley could answer questions and send out information gathered from usually overseas but with the changing of the internet we could then send out our own information.

Shirley's family was also there to help whether it was getting the Newsletter ready for mailing or other mailouts. Also, we cannot forget Shirley's yummy recipes in the Newsletter.

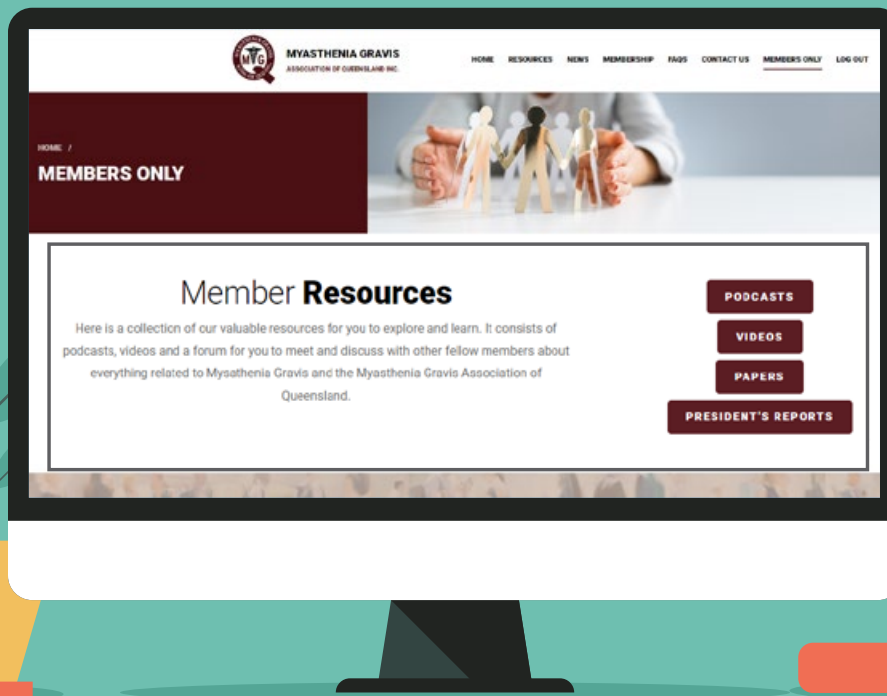
Shirley will still be in our hearts and we will remember the fun times we had with her.



Shirley Olive Johnston
17th August 1934 — 28th August 2024

Rest in Peace

MGAQ MEMBERS' ONLY LOG IN DETAILS UPDATE



All financial members of the MGAQ
can access the 'for members only' section of the website
which provides convenient access to a wide variety of useful
information in the form of:

- Videos of presentations made by experts in a variety of fields along with the 2023 MAA National Conference Videos

- Podcasts

- and Library Resources

Member Log in details are updated annually, with the new login details taking effect November 1, 2024.

You will receive an email from the Treasurer, Denise, at denisehannay21@gmail.com during the last week of **October**.

Please use the new supplied log in details from November 1, 2024 to access the '**for members only**' section of the MGAQ website.

If you haven't renewed your membership you will not be **sent an email with the new login in and thus you will not be able to access this important section of the MGAQ website.**

UPDATED MGAQ RULES

Our association was very lucky to have McCullough Robertson Lawyers do the update to our Rules so that we meet legislative requirements as outlined by the Office of Fair Trading.

It was quite an involved process and the pro bono offer from these lawyers was gratefully accepted.



- The photo shows Aaron Dahl, Emma Perberton and Will Harris with the Certificate of Appreciation sent to them in acknowledgement of the vital work they completed for the MGAQ.

“

SUPPORT *your Association* by
VOLUNTEERING.

”

NEWS FROM AROUND QUEENSLAND

News from Cairns

Please join us in Cairns on **Saturday, 26 October**, at **Vines Cafe (Limberlost Nursery) 113 Old Smithfield Road, Freshwater at 10.30am** for an informal Coffee & Chat. Visitors to Cairns are most welcome. For more information, please contact **Donna on 0414 397 462**.

News from Townsville

Townsville MG lunch will be our **Christmas Lunch** and is on **Saturday, 16 November 2024**, at **12 noon at Kirwan Sports Club, 159 Bamford Lane, Kirwan**.

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

News from the Sunshine Coast

The Sunshine Coast group will meet on **Monday, 4 November at 10.30am at Kawana Club, 476 Nicklin Way, Wurtulla**. All visitors to the area are also welcome.

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

News from the Gold Coast

Hi everyone. Our next meeting will be **for lunch at 11.30am on Sunday 10th November at Southport Sharks Club, Corner Olsen and Musgrave Ave. Southport**. I hope to see you all there. Visitors are welcome.

For more information, please contact **Nader on 0415 834 401**.



COFFEE & CHATS

RSVP Anita on 0414 588 312

Mango Hill/Northlakes – **Saturday 30th November at 10.30am**,
Mango Hill Coffee Club,
Cnr Anzac Ave & Halpine Drive, Mango Hill
– *All Welcome!*

WHAT'S COMING UP

What's On?	When Is It?	Where Is It?
MGAQ Christmas Function	Sunday 10th November 2024 at 11.30am	Southport Sharks Club, Corner Olsen & Musgrave Avenue, Southport

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

Coffee & Chat
Support



Conquer MG Anywhere!

www.mgaq.org.au

1800 802 568



‘Caring for yourself whilst caring for a loved one’

**Wednesday, 30 October
at 10.30am**

In this session we will be talking about Carer Gateway and the FREE supports that are available to all carers in Australia.

*Don't miss out!
We'll see you there!"*

MGAQ is happy to introduce a virtual coffee and chat via zoom in the comfort of your home.

"...Before I attended a Carers Wellway's course I was struggling as a carer for my wife with MG, especially after her 16 day stay in hospital (including 6 days in ICU). The course was non-judgmental and full of practical tips on how to handle the situation with my wife. I strongly recommend it to any carer who want to improve their expertise..."

Bill (former MGAQ committee member and MG carer).