



Myasthenia Gravis Association of Queensland Inc

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Messages

Myasthenia Gravis Association Of Queensland Inc. NOVEMBER NEWSLETTER

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

It is hard to believe that our next newsletter will be the last for 2021. They say that time flies the older you get and that certainly seems to be the case for me.

Denise, our treasurer, is still trying to find out if people who are not up to date with their membership still want to remain as financial members of the MGAQ. If you receive any inquiries from her about this, please take the time to either reply to her email or phone 1800 802 568 so that she can make the appropriate changes.

At the face-to-face meeting with Queensland Health, they were amazed at the work of the association and the outreach we have achieved across the state. They were also particularly impressed with the support materials we have developed for our members. Positive comments were also received about the quality and range of guest speakers we have and the addition of podcasts. I am sure our new management committee will continue to support members again in 2022.

You will note that the newsletter contains information about the need for people to be involved with completing surveys if they apply to them and their condition. The catchcry that **"Patient Voices Matter"** is starting to be heard by all levels of government and pharmaceutical companies.

Things are still looking good for our Christmas Get-together at the Caloundra Power Boat Club, on Sunday 12 December, 11.30am lunch sitting. Please remember to RSVP on the 1800 820 568 so the venue can cater for any restrictions that may be in place at that time.

Congratulations to everyone living with Myasthenia who have stayed safe and well. The restrictions have certainly been very prolonged and often frustrating but seem to be working for Queensland. Let's hope that all our members get to spend Christmas with loved ones, many of whom they have not seen for a long time.

Thanks, Carol

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

MYASTHENIA ALLIANCE AUSTRALIA NEWS



MAA UPDATE

RITUXIMAB - A Story to SUCCESS!

In March 2019, more than two and a half years ago, an MGAQ member, who lives in Regional Qld, contacted the Association to share a story. The member's family had made contact with the local Federal Member hoping to receive some support in accessing a particular medication at a reasonable price. The medication was Rituximab (a B cell suppressing medication) and it was not PBS supported for myasthenia patients. Local Federal Member, Keith Pitt, joined with the Association and also Dr Kuyler, to write to Minister Hunt. A thoughtful reply was provided explaining the obstacles to the request and indicating the possible limited pathways a patient may consider. The Federal Government could not assist. The Pharmaceutical Company did not have a suitable process and the Q'ld State Health Department option involved gaining access through the RBWH in Brisbane. This was not likely and would be a minimum two year process. The final option was to fund it privately. The anticipated cost (at this time) was \$16,000 every six months.

The MGAQ joined with the federally focused Myasthenia Alliance Australia (MAA) to pursue this disparity. Why was it that a drug which was in use and proving to be effective for patients with Myasthenia, be available in such a limited way. Patients with Rheumatoid Arthritis could receive the medication via the PBS. What were the stumbling blocks for our condition? The MAA Medical Advisory Board representative, Dr Stefan Blum, agreed to assist the MAA in writing to Minister Hunt about the situation. A recently published Journal Article showing the benefits was included. It seemed like such a convincing case. The reply once again highlighted the obstacles and suggested the usual alternative approaches. Again, the MAA explored these recommendations and dug deep to gain insight and information. This next process took a year of dedicated persistence. It resulted in a second letter to Minister Hunt indicating and explaining in detail that the suggested pathways were unachievable.

The MAA engaged the support of Rare Voices Australia (RVA) in approaching the Minister directly and also his Office. Thanks to Nicole Millis (RVA CEO) the MAA were able to fully explain the limitations of the process. Concurrently, A National Strategic Action plan for Rare Diseases was being developed. It was launched by



A/Prof Stefan Blum and Susan White acknowledge and celebrate this achievement.



Meeting virtually with The Hon. Keith Pitt MP, Federal Member for Hinkler in Bundaberg, MGAQ member Vic Andressen, and committee member Denise Hannay. Vic with the help of his daughter-in-law Lyn Toft, first brought the issue of Rituximab to our attention and set things in motion.



Nicole Millis RVA CEO, Trevor Evans MP and Susan White are in Canberra asking Health Minister Greg Hunt for assistance.

Follow the work of the Alliance by registering at the website www.myastheniaalliance.org.au

SUPPORT your Association by taking **MEMBERSHIP**.

MYASTHENIA ALLIANCE AUSTRALIA NEWS

Minister Hunt February 2020. This plan calls for the repurposing of medications - a process to allow alternate pathways.

Finally in October 2021 the PBAC was able to make the recommendation for Rituximab to be made available via the PBS to conditions such as Myasthenia Gravis. The process is now in place and it is hoped that Specialists will soon be able to offer this medication to ALL myasthenia patients who may benefit and that the patient will incur no more than the maximum \$41.30 PBS charge.

The MGAQ reached out broadly across Queensland and the MAA more broadly across Australia. Great support and understanding was received from many of our politicians as they began to understand the need. The included photos show the the joy of this important win for A/Prof Stefan Blum, Keith Pitts MP, Trevor Evans mP, Nicole Millis RVA CEO, MGAQ member Vic Andressen and his daughter-in-law Lyn Toft, MGAQ Committee member Denise Hannay and Susan White representing the MAA Board. We know however, that many more people who gave this quest their full support are also celebrating. For the patients this will benefit, there is a sense of relief and hope.

Patient Reported Outcome Survey Progress

Thank you, thank you, thank you to ALL the people who have ensured that we are half way to the minimum target numbers already! This support is very gratifying and much appreciated. Some respondents are not technology users but have asked for help and made it happen. What stars you are!!!

Meeting the completion target by Christmas - how can this objective become a reality?

- The research team are aware that some people are slow to return to the survey when choosing the 'save and return' option. There has been a couple of calls for support due to difficulties. These people have received prompt support and managed to complete the task soon after. If there are indeed consistent areas of difficulty with this new technology survey tool it is important that the technology team learn about issues so please reach out and let us know by emailing nidhi.menon@anu.edu.au or call **1800 802 568. Help is at hand!**
- MGNSW and MGAQ have actively approached their Myasthenia families and also the Specialists who regularly support these members. As a result, the participation rates are very high in these States. Making further contact in the States without established Associations is important. Everyone needs to be have an equal opportunity to be supported via this data. Individuals in these States can help by offering to share the link directly with affected others and by appealing to their Specialists to support this project. If people are not comfortable with this latter step, the MAA is there to make contact. Please notified us of the Specialist's contact details including the clinic receptionist details. **Send the information to info@mgaq.org.au.**
- As this project is here to help all MG Australians, please help the MAA Board in making this project a success. Share your ideas with us! - What else can be done? - What are the obstacles?
- Didn't choose to proceed but now want to - email nidhi.menon@anu.edu.au or call **1800 802 568** for assistance.
- Remember - as soon as the target is reached, the data analysis can begin and information can be made accessible.
- Use this link - <https://redcap-bdsi.anu.edu.au/surveys/?s=PWPFW73R73>

Another progress update will be given in mid December.

Susan White, MAA Chairperson.

SURVEY TARGET

180

350

Follow the work of the Alliance by registering at the website www.myastheniaalliance.org.au

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



MGAQ Inc. podcast series

UPDATE

Greetings All

Greetings All and welcome to the Podcast Team's report for the November MGAQ MessaGes newsletter. Since October our subscriber list has grown from 215 to 227, which reflects the increasing annual membership, and regular contacts on the podcast service from 110 to 121.

During October, we published two podcasts. The first, on the morning of Wednesday, 6 October, included a discussion with Prof. Andrew Kornberg from the Royal Childrens Hospital in Melbourne on the subject of Congenital and Juvenile Myasthenia. The second was an audio version of the MGAQ's Monthly MessaGes newsletter.

This month, the podcast team will publish three recordings.

The first of these, which will be published on Wednesday, 17 November, involves a discussion with Dr Alex Ritchie. In this podcast, Dr Ritchie talks to us about respiratory considerations for people with MG including the role of a respiratory specialist for sufferers of myasthenia gravis, what happens in a myasthenia crisis, what one can do to sense and minimise the impacts of a crisis as well as the role of sleep with MG.

Our second recording, to be published on Wed 24th November, is a talk with Prof Steve Vucic with a discussion on the extremely important *"Myasthenia Gravis Patient Reported Outcome Survey Research"* Project into the encompassing impacts of the range of treatment options provided to people with MG in Australia. This podcast has been previously sent out to members but given the importance of this survey and how close we are to making our target goal, we are again asking members to have a listen to Prof Vucic's comments regarding the nature and importance of this survey to all myasthenia sufferers.

Finally, as has been our practice for the past six months or so, we continue to generate an audio version of the Monthly MessaGes newsletter.

We wish all our listeners stay safe in these somewhat different and challenging times and trust you are all enjoying the run-up to Christmas 2021. Please note that if you are having any challenges in getting access to the podcast service, please note that you can contact Dr Podcast either via email at podcast@mgaq.org.au or you can make contact via the **MGAQ Freecall No. 1800 802 568**.

MGAQ Podcast



Myasthenia Gravis Friends *Western Australia*

Coffee & Chat - Sunday, 21 Nov.

Venue: **Dome Café, 2160 Albany Hwy (cnr Main Street), Gosnells**

Date: **Sunday, 21 November from 10.30am to 1pm**

For more information, please contact Annette on 0413855077.



Australian National University



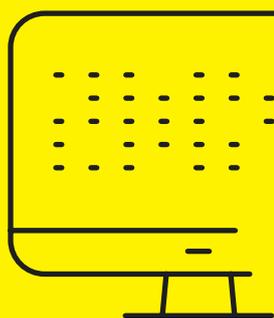
THE UNIVERSITY OF SYDNEY



Myasthenia Alliance Australia

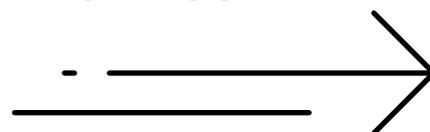
A collaborative project

Myasthenia Gravis Patients



Report Side-effects Experienced from MG treatments

ONLINE SURVEY



<https://redcap-bdsi.anu.edu.au/surveys/?s=PWPFW73R73>

Dr. Steve Vucic and the Biological Data Sciences Institute are gathering information via an online survey on the side effects of treatments used in managing Myasthenia Gravis.

Gathering this information strengthens conversation with Government, assists treating Physicians and also Researchers, and helps to understand the quality of life impacts for patients.

FOR MORE INFORMATION CONTACT:

Susan White

Freecall 1800 802 568

Email

info@mgaq.org.au

Study Investigator (Dr Nidhi Menon) nidhi.menon@anu.edu.au



Scan QR Code using your QR reader on your smartphone or tablet to complete the survey.

"The ethical aspects of this study have been approved by Australian National University Human Research Ethics Committee (Protocol 2021/269)."

"This work is supported by Terumo Blood and Cell Technologies Australia"

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

You're invited to the
MGAQ Christmas Function

to be held at
Caloundra Power Boat Club
2 Lamerough Parade, Golden Beach

on
Sunday, 12 December

11.30 am lunch sitting

For more information / RSVP - Contact Susan
Email: info@mgaq.org.au • Freecall 1800 802 568



south australia friends

COFFEE & CHAT

**Come and join us for Coffee & Chat on Saturday 20th November
10.30am-12 noon, The Hope Inn, South Road cnr of Port Road, Hindmarsh.**

There is ample parking at the venue. For more information, please contact Amanda on 0419816661.



Pictured L-R: Lynne, Jo-Ann, Tony and Maureen. Picture by Amanda and Meff had to leave early.



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.

Music soothes my soul

I am finding a new zest for my life because I have finally taken care of something that was too long ignored. It had been forgotten amidst the immediate demands of Myasthenia Gravis (MG), and we all know MG can be demanding of time, energy and resources. Being so focused on finding wellness with MG meant that I paid less attention to other areas of my health.

The realisation came last week when I was listening to a cello playing modern classical music and I appreciated how happy it made me. I had just updated my hearing aids and was able to hear the nuances of the music once again. It was in this moment that I understood how much I had missed being able to hear clearly. I am not a musician. I cannot play an instrument. I couldn't even tell you the first thing about musical notes; but I have always loved music. There is something about it that soothes my soul.

It is quite ironic then, that I began to lose my hearing in my late 20s and it then deteriorated further to be a substantial loss in the ensuing years. The cause was never determined, but I recently learnt that it may be connected to my lifelong autoimmune issues. Initially, I regularly updated my hearing devices to assist me to hear more clearly but unfortunately when my MG journey began, I neglected to do this and substantial time passed. I suppose it is akin to not getting new glasses when you know you can't read as well with your current prescription.

MG symptoms demand attention because they are often the 'loudest' (pardon the pun). However, this experience has been a big learning for me with regards to taking greater care of all aspects of my wellbeing. The relatively simple task of updating to new hearing aids has improved more than just my hearing. I now have a greater sense of overall wellness and the benefits of this I am noticing every day. I am happier when able to listen to music and I am glad I have been reminded. Once again, music soothes my soul.

Helen T

About the Author: I was diagnosed with Myasthenia Gravis in 2012. I live on the Far South Coast of NSW with my Husband and our big black Labrador. I enjoy creative endeavours like painting, crochet and knitting, reading and watching old movies, and writing.



Welcome to our new members

Ronald, Toowoomba, QLD
Barbara, Jandakot WA

RSVP ARE NOW REQUIRED FOR ALL FUNCTIONS DUE TO COVID-19 RESTRICTIONS

News from around Queensland

News from Cairns

Please note in your diary our final get together for 2021 is on **Saturday, 27 November at 11.00am at the Cairns RSL Club Boardroom, Cairns Esplanade.**

If you are visiting Cairns at this time, you are most welcome to join us. **Please contact Donna on 0414 397 462 or donnaformosa64@gmail.com**

News from Townsville

We will be meeting on **Saturday 4th December at The Avenues Hotel, 70 Kern Brothers Drive, Kirwan, commencing at 12 noon.** All welcome. If you would like to be part of Secret Santa gift exchange, please bring a gift to the value of up to \$20. Looking forward to your company. Family members also welcome. If you can come, please RSVP to Daphne on 0400 778637 or daphclay@gmail.com

News from Mackay

The Mackay group met at Souths Suburban Bowls Club on Sunday, 14 November.

It was wonderful to catch up with those who attended. This was our last get together for 2021 and I look forward to our gatherings in 2022. For local support please contact **Mary on 07 4959 5251.**

News from Bundaberg

Please join us for *Coffee and Chat* get together on **Saturday, 20 November, 10.00am at the "Spotted Dog at the Railway Hotel", 78 Perry Street, North Bundaberg.** We will be in the Canecutters room from 10.00am to 11.30am. Table has also been booked in the bistro should anyone wish to stay for lunch. 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

For more information please contact **Vicki on 0411 146 898** or email avplummer@gmail.com

News from the Gold Coast

Our next meeting will be on **Saturday, 20 November at 10.00am at Southport Sharks Club.**

I hope to see all there. Kind regards. For more information contact Nader Amiri, Gold Coast Co-ordinator, **0415 834 401.**



Brisbane - Coffee & Chats

**CALAMVALE – Degani Coffee, 662 Compton Road
Wednesday, 24 November at 10.30am**

Please contact Anita on 0414 588 312.

what's coming up

What's On	When Is It	Where Is It?
MGAQ CHRISTMAS FUNCTION	SUNDAY, 12 DECEMBER	CALOUNDRA POWER BOAT CLUB 2 Lamerough Parade, Golden Beach 11.30 am lunch sitting

Please note that due to COVID-19 Government Guidelines and Restrictions, the advertised event may change.

LEARNING more about helping out is as easy as **PHONING 1800 802 568.**