



Myasthenia Gravis Association of Queensland Inc

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Messages

Myasthenia Gravis Association Of Queensland Inc.

DECEMBER 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 this is our final newsletter for 2021. The next one will be printed and distributed in February next year.

Our Christmas Get Together at the Caloundra Power Boat Club on Sunday, 12 December was very successful. It was great that those who could make it had time to catch up with friends, meet new acquaintances and generally mix and mingle. The management committee members enjoyed putting faces to names and getting to know people they had not met before.

This year has been another very busy but productive one for the association. We should all feel proud that this association has been in continuous operation for 30 years, a milestone that we celebrated in June. Our "30 Years Celebration" book certainly brought many smiles when people looked at the photos from over the years.

You will note that the newsletter contains information about the need for people to be involved with completing surveys. The catchcry that "Patient Voices Matter" is starting to be heard by all levels of government. If you have not completed the survey advertised in this newsletter we urge you to do so because, as a group with a rare disease, it is important that we get

as many people as possible urging government agencies to take note of what we are attempting to achieve. An example of this advocacy is the inclusion of Rituximab on the PBS from February for people with Myasthenia Gravis.

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.

The MGAQ funding from Queensland Health will continue into next year and we thank them most sincerely for their ongoing support.

The committee will now take a break and resume activities in February. Their work throughout this amazing year is much appreciated by me. I wish them a well-deserved rest and a happy Christmas. The management committee also wishes everyone a Christmas filled with family, love, laughter and, most importantly, good health. It is our hope that families can be together, particularly with the easing of some of most restrictions people have had to adhere to for many months.

Thanks, Carol

Supported by



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Government

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

MYASTHENIA ALLIANCE AUSTRALIA NEWS



MAA UPDATE

Wow! *How awesome is the Australian MG community!* There have been 264 respondents to the **Patient Reported Side Effects Outcomes Survey** as at December 6th! Of these, 34 have not fully completed the survey and it is hoped that they will return to the survey to complete their data entry. (Please call if you are having problems - we have a good history around sorting issues.) Thank you everyone! We are on track to reach the targeted numbers!

At the recent Project Team Meeting, a sneak preview of the data from a selection of questions showed that the grouped responses are very consistent with the member information which feeds through to the MAA. This indicates that a wide range of people have responded and that the data is very credible. This sneak preview showed significant use of treatments and also some surprising treatment trends which Dr. Vucic will be keen to discuss in his report. This preview was very much a teaser but the team was keenly engaged and began planning key foci for the analysis. There will certainly be an assessment comparing metropolitan care versus regional care.

The survey cut off date was originally set for December 20th but it was decided at this meeting, to extend this date until January 28th 2022. With all that has been happening in the Nation, this will allow people to take a breath over the Christmas period, to find the time to reflect on their MG life and to undertake the survey which takes around 45 minutes. **There will be no further extensions** as everyone is keen to begin the analysis and reporting. **January 28th will be the final date!** Do not miss out! <https://redcap-bdsi.anu.edu.au/surveys/?s=PWPFW73R73>

The **Myasthenia Alliance Australia Annual Report - October 31st 2021**, is now available. In summarising the past 12 months, it was strongly demonstrated how wonderfully successful the year proved and that it was an extremely active time for the Board. View the report here https://myastheniaalliance.org.au/wp-content/uploads/2021/12/MAA_Presidents-Annual-Report_2021.pdf

To all who follow and support the work of Myasthenia Alliance Australia, the Board says thank you and wishes everyone much joy this Christmas Season and best possible health in 2022.



Susan White, MAA Chairperson.

SURVEY TARGET

230

350

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

SUPPORT your Association by taking **MEMBERSHIP.**

MGAQ Inc. Christmas Function

A very successful Christmas Get together was held at the Caloundra Power Boat Club with 22 people attendance. Old friends and new mixed and mingled and shared stories about this past year as well as their Myasthenia journeys. Some people travelled quite a distance to join us and everyone enjoyed a lovely meal. A surprise was a secret santa gift for everyone from Carol's niece.



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



MGAQ Inc. podcast series

UPDATE

Greetings All

And welcome to the Podcast Team's report for the December MGAQ MessaGes newsletter.

During November, we published three podcasts. The first of these involved a discussion with respiratory specialist, Dr Alex Ritchie. In this podcast, Dr Ritchie talked 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. The second recording was 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. Finally, the third of our podcasts was our Monthly MessaGes newsletter.

This month we will have only a single podcast, that being the audio version of our MessaGes Newsletter.

On behalf of all the team members and contributors to the MGAQ Podcast Series, we wish all our listeners a very happy Christmas and may the new year of 2022 provide you each with many wonderful and enjoyable times. Please note that if you are having any challenges in getting access to the MGAQ podcast service, 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

MGAQ.org.au Member Log-in

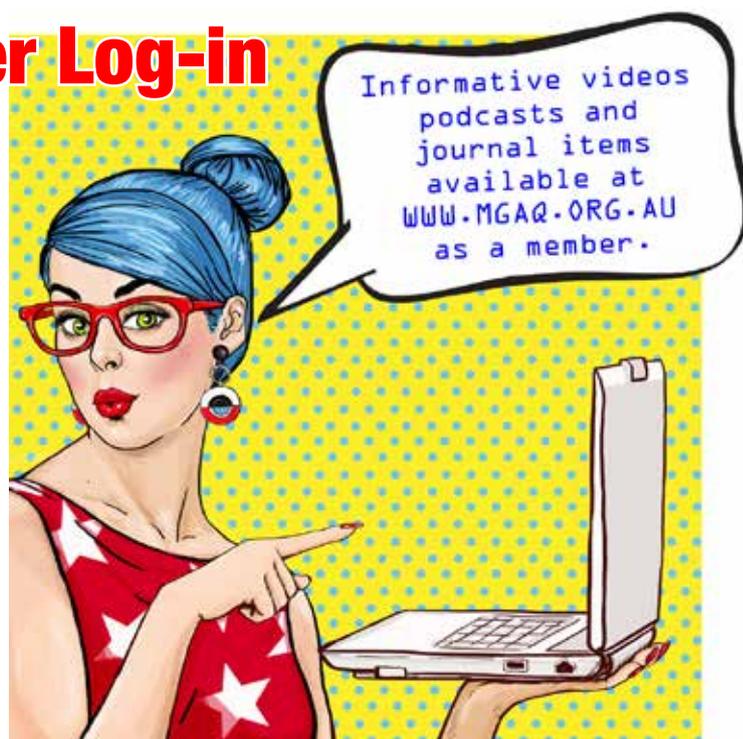
The MGAQ website has many additional features available only to financial members. These include videos of presentations from past speakers inclusive of leading specialists. All general meetings of the Association are recorded and posted.

In addition, the complete list of Podcast recordings are available too.

The contents of library materials available to members is listed and a hint towards the range of research papers the Association can help members access is given. A detailed list of the papers will soon be posted.

An email was sent to all paid up financial members with instructions to sign in.

If you do not have this email, please contact **1800 802 568** or email info@mgaq.org.au





Australian National University



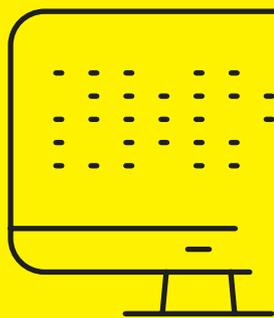
THE UNIVERSITY OF SYDNEY



Myasthenia Alliance Australia

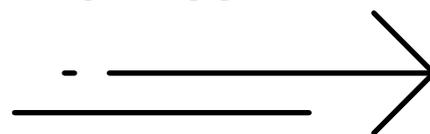
A collaborative project

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.

The 'Bundy Bunch' Get-together



A very enjoyable morning was spent with fellow Myasthenia members in Bundaberg, when we all got together at the Spotted Dog on 20 November for a great catchup.

It was lovely to welcome and introduce Susan White (the voice behind the freecall number) to our local members. Susan and her husband Mark visited us from Brisbane and everyone appreciated the time Susan took in answering all of our questions. It is always lovely to hear how everyone is travelling, and what has been happening in their lives.

Carol told us how she has been going sailing with a group that caters for people with particular needs and she thoroughly recommends it to everyone.

The 'Goldie Group' Get-together



Hi Everyone - MG Gold Coast group had their get together sharing experiences with other members on Saturday 20th of November at Southport Sharks Club. **Our next meeting will be at 10am, Saturday, 5 February at Broadbeach Kurrawa Surf Club.** I hope to see all there.

Kind regards, Nader Amiri, Goldcoast Co-ordinator 0415834401



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.

Colour it!



I am a creator; an artist, a crafter, and now I've taken to writing. I love to create. People ask me how or where I get my inspiration? I create all manner of things from what I feel or from what I see, and the form the creation takes depends on what I want to work with at the time. I am inspired by the joy of colour, shape and form, or by events around me.

Whilst slow with the symptoms of Myasthenia Gravis (MG) I found I didn't have the energy to paint, and I definitely did not have the dexterity to manipulate with my fingers to crochet or knit or type; so, I would dress in colour instead. I would use colour to cheer myself and it became one of my comforts. My wardrobe is full of colourful clothing. I scout for colour in shops and op shops. Colour always improves my mood and brings happiness into my day.



Now that my MG symptoms are more controlled, I have returned to creating in paint on large or small canvases, and crocheting or knitting with yarn. I also sew and potter in our garden. Recently I have taken to creating with words. Creating is not limited to this

though. To my husband's consternation, I am continuously changing our living environment to reflect how I feel, for instance, I rearrange cushions in the house to bring more colour to a room or I knit or crochet coloured throw rugs (a greater need for us who live in the cooler climates) to create the effect I want. Even outside in the garden, I take cuttings from my favourite plants and plant them in new places to produce a repeat of the pattern of colour and shape all over our garden. Our garden is full of colour.

We each have a unique interpretation of the world. No one quite sees things how we do. How we express ourselves is an important way of sharing our world view. Our creations (whatever they might be) are the expression of our experience and others deserve to see and share in them. I share a lot of myself through my creations and the use of colour. What do you share of yourself with the world?



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.

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

News from around Queensland

News from Cairns

For more information, contact Donna on 0414 397 462 or donnaformosa64@gmail.com

News from Townsville

The Townsville group will be meeting on **Saturday, 19 February 2022, at The Avenues Hotel, 70 Kern Bros Drive, Kirwan commencing at 12 noon.** All are welcome. If you can come, please RSVP to Daphne on 0400 778637 or 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 – 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

Please join us on **Monday, 7 February at 10.30am, Kawana Bowls, 476 Nicklin Way, Wurtulla.** All are very welcome. For more information please contact Vicki on 0411 146 898 or email avplummer@gmail.com

News from the Gold Coast

For more information contact Nader Amiri, Gold Coast Co-ordinator, 0415 834 401.



Brisbane - Coffee & Chats

CLEVELAND – Thursday, 3 February, 10.30am

Crusoe Cafe, 12/152 Shaw Street West

Please contact Anita on 0414 588 312.

Welcome to our new member

Arman, Southport, Qld

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 2022. Thank you to all contributors during 2021.

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