



# Messages

MYASTHENIA GRAVIS ASSOCIATION OF QUEENSLAND INC.

**DECEMBER 2020**

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.

## Myasthenia Gravis Association of Queensland Inc

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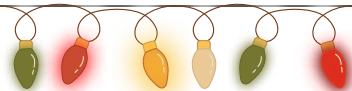
#### PATRON

Dr Cecillie LANDER

Neurologist

Founder Member, of Brisbane

## PRESIDENT'S REPORT



Another year nearly over! The Christmas Function held at Redcliffe RSL was a happy day of meeting old and new friends. The committee enjoyed the opportunity to simply socialise after yet another outstandingly productive year.

Members will receive a full copy of the MGAQ President's Report and the Myasthenia Alliance Australia President's Report as an attachment with this newsletter if you receive it by email. If you receive your newsletter by mail, the Reports will come in a separate envelope. Please take the time to read these as they provide a very detailed snapshot of the worthwhile work done this year.

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 nearly 30 years, a milestone that we will certainly celebrate next year. 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.

Queensland Health funding will continue for the next two years with the possibility of a two year

extension beyond that is very encouraging and is recognition of the work we all do. I do wish to acknowledge the continued support from Queensland Health. It is always a pleasure to have an extended meeting with them each year to show all that has been achieved during the previous twelve months.

Thanks must go to all the medical professionals who we consider to be active supporters of the MGAQ. They always provide time and expertise very freely and are always there should the association need advice. Some of these neurologists have had a vested interest and involvement with the production of our eNID database, news about which we should receive in the first half of 2021.

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 lifting of some of restrictions people have had to adhere to for many months.

Thanks, Carol

### Supported by



Queensland  
Government

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## MYASTHENIA ALLIANCE AUSTRALIA NEWS



## MAA UPDATE

Your MAA Board have kept busy despite the pre-Christmas distractions. It has been an unusual and challenging year in so many ways and embracing the joy and connection of the Christmas period feels more important than ever.

I would like to sincerely thank your committed MAA Board team for all their work this year and for the support they have provided to me as we have explored and embraced the opportunities to improve the lives of those across Australia affected by MG in all its forms.

The Annual report is now available and will be distributed to MGAQ members with this newsletter.

For others, it is available at [www.myastheniaalliance.org.au](http://www.myastheniaalliance.org.au)

There is much work looming for 2021 and many opportunities to be developed. I hope that readers will continue to keenly follow our efforts and offer support as they are able.

With very best wishes to all.

**Susan White - Chairperson.**

Follow the work of the Alliance by registering at the website [www.myastheniaalliance.org.au](http://www.myastheniaalliance.org.au)

## CLOSED slack COMMUNITY OPEN TO MG SUFFERERS AGED 18-35 ONLY



- Specially created to meet the needs of this younger group who are thinking about careers, relationships, making a family, travelling etc.
- Discussion to be guided by the participants and supported by the Doctors.
- Find this group via the [mgaq.org.au](http://mgaq.org.au) home page and look for the link under **SOCIAL INTERACTION**

Find this group by emailing [info@mgaq.org.au](mailto:info@mgaq.org.au) for access.

# ARE YOU UNDER 18?

**In 2021, the MGAQ will celebrate 30 years supporting people with Myasthenia Gravis in Queensland as a volunteer Association.**

**As part of our celebrations, we are offering our YOUNGER PEOPLE a competition to help raise awareness by telling a story about their journey with MG.**



## **THE COMPETITION IS OPEN TO THREE AGE CATEGORIES**

Junior (5 to 8 years); Primary (9-13 years); Young Adult (14-18 years).  
There is a prize of \$500 for the best entry in each age category plus consolation prizes.

**Entries open 1 December, 2020 and close 10 March, 2021.**

For more information download flyer from

<https://tinyurl.com/y4xavcfx>

Email: [info@mgaq.org.au](mailto:info@mgaq.org.au) or Freecall 1800 802 568.





## MGAQ Inc. podcast series

# UPDATE

**"Greetings"** and welcome again to another update on the MGAQ's podcast service. 31 December 2020 brings to an end, the first year of the MGAQ's podcast service. During 2020, despite the Covid-19 outbreak, we produced and published 13 podcasts related to Myasthenia Gravis. The last of these podcasts for 2020 was Dr Johan Kuyler's, a neurologist based in Bundaberg with 75 MG patients, wonderful discussion which included a host of useful suggestions for all MG sufferers to think about.

We start our 2021 series with a discussion with Sharon. Sharon suffers from a very rare condition called Lambert Eaton Myasthenic syndrome (LEMS). Her story reflects the energy and passion of many of our members who use the challenge their condition presents as a stepping stone to significantly helping the broader myasthenia community. Sharon's story will be available from January 6th 2021.

*All the best for Xmas. We trust you enjoy the time with family and friends and the team looks forward to bringing you more interesting discussions through 2021.*

## MGAQ Videos and Podcasts AVAILABLE NOW via the MGAQ Website

A wide range of informative Videos, Podcasts and Journals items can now accessed by visiting the **'members only'** section of the MGAQ website at [www.mgaq.org.au/members-only](http://www.mgaq.org.au/members-only) Once you have access to the members-only area, you'll be able to view, listen or read on your smart phone, iPad, tablet or PC.

All members will need a username and password to login and access the members only pages. Financial members can request a password by visiting [www.mgaq.org.au/user/register](http://www.mgaq.org.au/user/register) and completing the online form.

**IMPORTANT:** Please be sure to use an email address that is known to the MGAQ. This will allow us to verify that it is indeed you that is making the password request!

As the MGAQ website is administered by volunteers, please understand that it may take a little while to receive your login credentials via email.

Follow up with [info@mgaq.org.au](mailto:info@mgaq.org.au) if you don't receive your password within a week or so.



## MURIEL'S DID YOU KNOWs?

- The record jump recorded by a kangaroo is a whopping 9 metres (30 feet) in a single leap!
- Two native Australian animals, Platypus and Echidnas, are the only two mammals in the world that lay eggs to give birth
- Koalas sleep for about 20 hours per day
- Tasmanian Devils have the strongest bite per body size of any mammal
- There are 4 different species of kangaroo in Australia, with the Red Kangaroo being the largest. The largest Big Red ever seen was 2.1m tall (6ft 9in) and weighed 91kgs (200lbs)!



# MGAQ Inc. Christmas Function

## Sunday, 13 December at Redcliffe RSL

Our Christmas function on Sunday was enjoyed by all who braved the weather to attend. The occasion produced much merriment and camaraderie.

The Redcliffe RSL was a great venue with wonderful ocean views and beautiful food.







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](mailto: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.**

## More handy tips for living with MG.

1. Helen says that having a walker readily available reduces risk of falls and gives you somewhere to sit down when needed. Helen also says that she has a gopher/mobility scooter ready for outings. This allows her to use her energies wisely and to attend her regular activities.
2. Susan says to drop your head forward for some or all of the hair-drying process so that the arms are not held high for so long.
3. Susan also says to invest in a personal shopping trolley. The ones with four wheels are great to push like a pram and take much less energy. There are also versions that come with a handy seat.

If you have any tips to help others living with MG, send them to [info@mgaq.org.au](mailto:info@mgaq.org.au) or Freecall **1800 802 568** or Post to **PO Box 16 Mt Gravatt 4122**.



## LUNCHEON

Join us for our first Regional Victoria MG Awareness Luncheon to be held in Shepparton, Victoria.

**All are welcome for lunch at the Shepparton RSL Club, 88 Wyndham Street, Shepparton on Sunday, March 21, 2021 at 12 noon.**

There is plenty of parking available with meals and drinks at Bistro prices! Meet others with MG and their carers for a casual get-together!

Everyone is welcome, we hope to see you there!

**RSVP necessary for Reservations by March 19. For further information, please call Pauline 0419 332 260.**



# MGAQ Group Get-togethers

*Everyone is very welcome to attend.*



## MG GOLD COAST

Nader says "sharing experiences with other members on **Saturday 28 November at Southport Sharks Club.**"



## TOWNSVILLE

We enjoyed our Christmas lunch on **Saturday, 28 November.**

Pictured: Serafina, Shirley and Daphne.

## SUNSHINE COAST

Vicki says "we had a really enjoyable catch up at the Coffee & Chat get-together on **7 December at Kawana Bowls Club.**"



## SOUTH AUSTRALIA

Amanda says "it was lovely to meet other local snowflakes over a hot drink, sharing information and views on medication."



**Brisbane -  
Coffee & Chats**

## CLEVELAND

*Fiction Bar*

*Friday, 29 January  
at 10.00am*

## NUNDAH

*Royal Hotel*

*Thursday, 4 February  
at 10.00am*



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

## news from around Queensland

### News from Cairns

Our final gathering for 2020 was held at **Gallos Dairyland on the beautiful Atherton Tablelands on Saturday 5 December**. We all agreed it was a wonderful venue to end a very challenging year. We look forward to catching up with everyone at our next gathering on 6 March 2021.

**Rare Disease Day - February 28 2021** - Once a year on the last Sunday of February, come and join Rare Friends in Cairns as they walk, ride and run to support locals affected by Rare Disease and commemorate International Rare Disease Day.

For more information or to RSVP please contact **Donna on 0414 397 462** or [donnaformosa64@gmail.com](mailto:donnaformosa64@gmail.com)

### News from Townsville

The Townsville MG group enjoyed our Christmas lunch on Saturday, 28 November. We would like to wish the committee and all members a very happy Christmas and all the best for 2021. We appreciated the newsletters and all the support that this wonderful committee has provided for all members.

Our next lunch is on **Saturday, 20 February 2021**. Details in 2021.

For more details contact **Daphne on 0400 778 637** or [daphclay@gmail.com](mailto:daphclay@gmail.com)

### News from Mackay

For more information, please contact **Muriel on (07) 4954 1221**.

### Hervey Bay – Wide Bay Burnett Region

For more information, please contact **Jan on 0429 622 438** or [janpowell3@bigpond.com](mailto:janpowell3@bigpond.com)

### News from Gladstone – Wide Bay Region

For local support in the Gladstone – Wide Bay region, call **Garth on 0408 155 954** or **(07) 4973 7983**.

### News from the Sunshine Coast

The Sunshine Coast Coffee and Chat get-together on 7 December at Kawana Bowls Club was well attended. We had a really enjoyable catch up.

The next Coffee and Chat for the group will be the **1 February 2021 at 10.30am at the Kawana Bowls Club**.

Wishing everyone a wonderful Christmas and New Year. Regards Vicki.

Call **Vicki on 0411 146 898** or email [avlplummer@gmail.com](mailto:avlplummer@gmail.com)

### News from the Gold Coast

Hi Everyone, the MG Gold Coast group had their get together sharing experiences with other members on Saturday, 28 November at Southport Sharks Club.

Our next meeting will be at **10am on Saturday, 23 January at Kurrawa Surf Club in Broadbeach**.

I hope to see all there. P.S. I take this opportunity to wish everyone a Merry Christmas and a Happy 2021

Kind regards **Nader Amiri, Gold coast Co-ordinator, 0415 834 401**.



### WHERE IN QUEENSLAND?

**Last month:**

**Normanton**

Let us know where you think it is:

Send to: [info@mgaq.org.au](mailto:info@mgaq.org.au)  
or post to **MGAQ, PO Box 16, Mt Gravatt, Qld, 4122**

*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 2021. Thank you to all contributors during 2020.