



## Myasthenia Gravis Association of Queensland Inc

P.O. Box 16

MT. GRAVATT QLD 4122

NATIONAL FREECALL:

1800 802 568

ABN 92 055 613 137

Email: [info@mgaq.org.au](mailto:info@mgaq.org.au)

Internet: [www.mgaq.org.au](http://www.mgaq.org.au)

### COMMITTEE MEMBERS

#### President

CAROL BUCHANAN

#### Vice-President

SUSAN WHITE

#### Secretary

RON STEPHEN

E: [info@mgaq.org.au](mailto:info@mgaq.org.au)

#### Treasurer

DENISE HANNAY

E: [treasurer@mgaq.org.au](mailto:treasurer@mgaq.org.au)

#### Committee

ANITA JACKSON

DONNA FORMOSA

ROSALYN HOLLAND

IAN HOLLINGWORTH

KIRSTINE SHRUBSOLE

KAREN DOWNES

#### Newsletter Editor

GREG BREADEN

E: [MGAQ.editor@gmail.com](mailto:MGAQ.editor@gmail.com)

#### PATRON

DR CECILIE LANDER

Neurologist

Founder Member, of Brisbane

# Messages

Myasthenia Gravis Association Of Queensland Inc.

## APRIL 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

Welcome to another newsletter written in these uncertain times. Every news report seems to include information about the COVID-19 vaccine and many and varied information about who will receive it when. Then, on top of that, we have so many vials being wasted because of improper handling. So, please take the time to read the "Discussion Paper Regarding Covid Vaccinations" put together for the Myasthenia Alliance Australia. Dr Stephen Reddel, one of our top neurologists in whom many of us have great faith, worked with other specialists from many countries to develop this paper. The first section is for people with Myasthenia and their families and the second section is for the medical profession. Please endeavour to get this paper to your local GP and neurologist.

A new podcast which contains the information above is also available. In last month's newsletter, we advised that a new feature has been added to our podcast service whereby MGAQ Podcast subscribers will get an email when a new podcast becomes available. From this email, subscribers can just

click and play that episode in their browser. One can also access all previous podcasts.

As a result of the plea in last month's newsletter we have someone who has expressed an interest in possibly taking up the position of Secretary at our AGM in September. We appreciate all offers of help received.

We have received information that the MGBase (formerly called eNID) is in the final development phase and the aim is to hopefully be ready for a soft launch for the first handful of "Pilot" sites in Australia in early December. Some Australian neurologists are involved with the testing of the program, data entry and feedback re possible 'bugs' in the database. There is still some work to be done in relation to ethics documentation and having the site able to provide access to relevant personnel. The site still needs a logo, branding guidelines, a thorough content (CMS) review, etc. to ensure the program works smoothly.

Stay safe, keep well and hopefully your vaccination will soon happen.

*Thanks, Carol*

Supported by



Queensland  
Government

Ausenco

## MYASTHENIA ALLIANCE AUSTRALIA NEWS



### MAA UPDATE

The MAA Board keep very busy, as usual, engaging with Federal Government Departments, The Medical Advisory Board, Industry Stakeholders and Researchers. With this edition of the MGAQ newsletter there are two opportunities requiring membership engagement.

- As peak consumers of IVIG, the Myasthenia Community has been asked to participate in a survey regarding experiences when treated with IVIg. The goal of this research is to produce a flier for patients attending clinics which administer IVIg therapy. This is important work in making the experience less daunting. I do hope that our Community can respond strongly.
- As part of an on-going focus to make life with MG a little easier, we have been providing feedback for some months now, to a group who are keen to utilise technology and support people with neurological conditions. This group has developed an App, Careforia, to aid people in recording the details and tracking progress with their MG life experiences. It is ready for your use. Do check it out if you enjoy utilising technology.

More news next month. Keep well.

**Susan White, Chairperson**

### Consumer Research Survey - IVIg

If you would like to assist with the development of future resources for this valuable program, **we are looking for people to share their experience of immunoglobulin treatments.** Carers are also welcome to participate.

NPS MedicineWise is looking for people who have been prescribed immunoglobulins (antibodies) as part of their treatment to take part in a short survey online and/or an in-depth interview over the phone.

The aim is to help us understand what types of information, tools and resources are helpful for people along the patient journey.

The information will be used to develop resources for consumers as part of a national program about immunoglobulins.

The survey is to be completed online and will take about 10-15 minutes. You can access the survey here <https://surveys.nps.org.au/s3/2021-Consumer-Survey-on-Immunoglobulins> which will go live on 19 April and be available till the 14 May.

The in-depth interview would be completed over the phone / Zoom and take between 30-45 minutes. There is a \$50 gift card incentive for participation. Interviews will be available for the weeks of 19 April and 26 April. There are limited places available but to express your interest please email Angela Romero [aromero@nps.org.au](mailto:aromero@nps.org.au)

If you would like to take part in this project, or need further information, please contact Lia Mahony [lmahony@nps.org.au](mailto:lmahony@nps.org.au) or phone (02) 8202 7105.



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



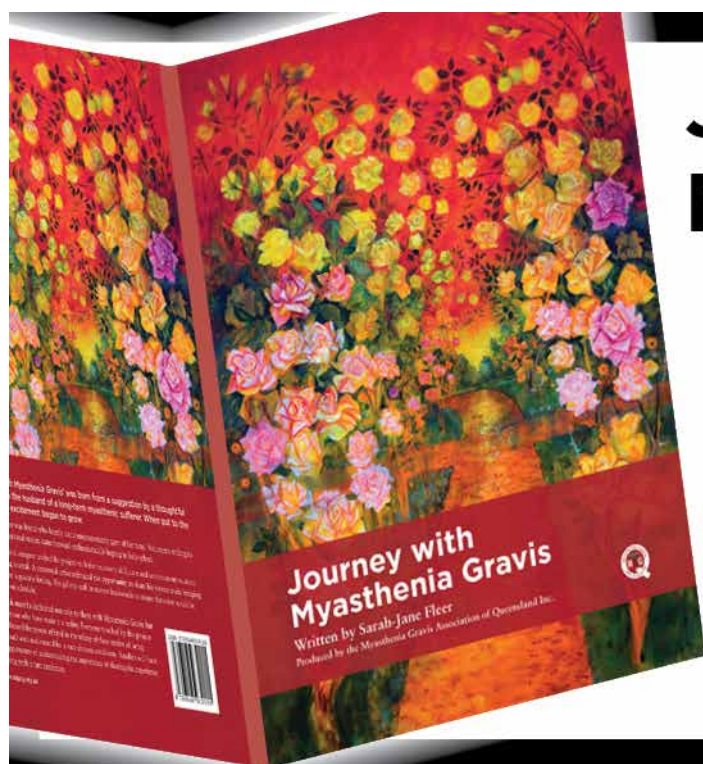
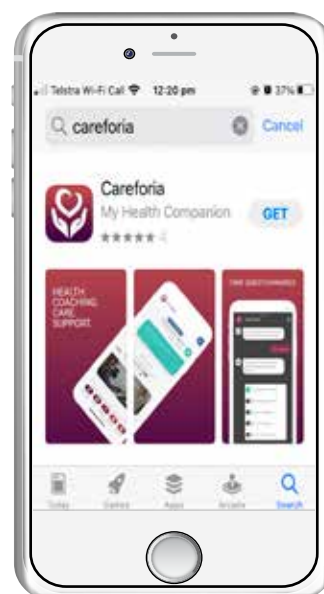
## Keeping track of your life when managing Myasthenia.

Management committee members as well as the regional co-ordinators, regularly suggest that people keep a diary of their symptoms, medications, lifestyle impacts etc. in preparation for their visits to the Doctor.

Giving a quick overview and having a clear summary of exactly what has occurred is very useful. Naturally, in the modern world people say "What is a diary?" Well, we are lucky enough to have attracted the keen interest of the **Careforia** team who have created a phone APP to help you. It has been targeted for people with Myasthenia and we hope it will be extremely useful.

If you are willing to try it out, go to the App store on your phone and search for **CAREFORIA**. Downloading the App is free of charge. There are some personal questions at the beginning but you can skip these by continuing through the process. The reminders and questions can be tailored to your needs and progress graphs can be created. We are assured that no data will be shared. As with all new technology you may need to persist a little to discover all the advantages.

We thank **Careforia** for bringing this opportunity to our community. They are happy to receive feedback.



## Journey with Myasthenia Gravis

A book by Sarah-Jane Fleer

Raising awareness of Myasthenia is as important as always. The book demonstrates the uniqueness of each journey with the condition.

It aims to support those affected as well as their families and friends.

If you would like to purchase a copy,

**Contact the Association**

**Freecall: 1800 802 568**

**Email: [info@mgaq.org.au](mailto:info@mgaq.org.au)**

**Website: [www.mgaq.org.au](http://www.mgaq.org.au)**





## MGAQ Inc. podcast series

# UPDATE

### Greetings All

In last month's newsletter, we advised that a new feature has been added to our podcast service whereby MGAQ Podcast subscribers would get an email when a new podcast was available. From this email, subscribers can just click and play that episode in their browser. One can also access all previous podcasts.

What we didn't say was the particular podcast was the first in a new series of audio stories. This particular podcast narrated the MGAQ's March Newsletter. As some of our memberships reading functionality has been impacted by their MG, we are now offering to provide an audio version of the monthly newsletter. We will test this service for the next six months and if it proves useful to members we shall keep it going.

In addition, a second Audio Book style podcast has been sent out to members covering the Covid 19 Vaccination Discussion Paper recently distributed in hard copy to members. In this podcast, Karen & Susan present an audio recording of the lay person section of the Covid 19 Vaccination Discussion Paper together with commentary. The podcast gives MGAQ Members an additional opportunity to listen to

and think about the presentation prepared by A/ Prof Stephen Reddel and colleagues.

We'd also like to mention that during March, we were fortunate to record a discussion with leading Podiatrist Nicholas Sprenger. Allied Health Services such as Physiotherapy, Speech Therapy, Dieticians and Podiatry can be very important supplemental services to MG sufferers. We all appreciate that maintaining mobility is critical to getting the most out of life and our feet, ankles and lower limbs are the foundation to this ability. Given Australia's medical system provides Medicare coverage for podiatry consultation costs for MG sufferers under one's Chronic Disease Management Plan, Podiatry is an opportunity worth considering. You will be able to tune in to listen to Nick Sprenger's podcast from 5am Wednesday, 21 April.

Remember, if you would like to be added to the MGAQ Podcast Subscriber List, simply email me, Dr Podcast, at the following address [podcast@mgaq.org.au](mailto:podcast@mgaq.org.au) and just say "Add me to the Subscriber List". That's all any member needs to do and when we publish each new podcast you'll get an email.

### Coffee and Chat at Calamvale - April 8

a great time was had with plenty of discussions and it was good to put faces to names.

(L-R) Chris, Donna, Margaret, James, Sue and Anita.



# The History of the MGAQ Continues...

Carol and I have been active members of the then Australian Myasthenic Association in Queensland Inc since we joined in about 1992. Aspects of the change of name to the Myasthenia Gravis Association of Queensland and unauthorised constitutional changes lead to the termination of membership of the then president. I was appointed as president in 1995 in the turbulent times which followed. Following the death of Marcia Millard on 11 April 1997, I took on the additional role of Secretary until the 1997 AGM when I became Secretary and Gordon Jiear became President. I continued as secretary until the AGM in 1999.



• Carol and Garry

Apart from the committee duties Carol and I edited, printed and posted the newsletter. In October 1997 the current format of MessaGes was adopted. Carol came up with the name "messages" highlighting who we are by capitalising the M and G. I started the presence of the Association on the internet by getting an email address and building the original website. Current and recent Committees have developed the web site and MessaGes into meaningful and modern means of communication.

Anita Jackson is the only surviving member of the Committees on which I served. In fact Anita was a committee person before we joined the association and has, I believe served on the Committee continuously ever since.

As most members know the road to a diagnosis is a rocky one. Carol's diagnosis was taken away in late 1996. We still remain members and supporters of all people who have a possibility of being Myasthenic. Carol is now accepted as having MG and as research continues, it is likely that she has had MG all of her life.



• Shirley, Gerald and Kath Ross



• Alan and Yvonne





## **Brisbane - Coffee & Chats**

**Toowoomba - Tuesday 11th May at 10.30am**  
**Picnic Point Cafe, 164 Tourist Drive,**  
**Toowoomba**

Please contact Anita on 0414 588 312.

## **GOLD COAST GROUP MEETING**

**Saturday, 27 March,**  
**Southport Sharks**  
**Club.**



## **LUNCHEON**

**Shepparton RSL Club,**  
**88 Wyndham Street, Shepparton,**  
**Sunday, June 27, 12 noon**

**RSVP necessary for Reservations by June 25.**  
**For further information, please call Pauline 0419 332 260.**



## **LUNCHEON - Sunday, March 21**



The first MGAQ MG Awareness Luncheon was held in Shepparton, Victoria, on Sunday, March 21<sup>st</sup> at 12pm.

It was well attended by those from around Country Victoria and Melbourne including Bendigo, Cobram, Echuca, Dookie and Shepparton.

It was uplifting to those diagnosed with MG to share their story for the first time and be a part of this greater MG community!

Thank you to everyone who attended and made this day special. We look forward to welcoming all to our next luncheon in June. For further information, please call Pauline on 0419 332 260.

**Left to Right: Mardi, Brad, Wilma, Robert, Dawn, Susan, Judith, Pauline and Sandra at the Shepparton RSL Club, Victoria.**

# Puzzlers

Puzzles by  
[www.thinkablepuzzles.com](http://www.thinkablepuzzles.com)  
[www.theteacherscorner.net](http://www.theteacherscorner.net)

## Word Search - Asian Countries (2)

S A N S T S T M S N N F G V A B  
E I A U R Y A Y A A E Q S A V D  
V S M I O I R U W N L P I X S Q  
I S O A S I L I D E T L A U L N  
D U T R A Y A A B I O E U L A Q  
L R A N S T A A N G A Z I T M A  
A F J D I P N L N K B R S V T T  
M F I C R O E O A E A I A Z H A  
R U K O N S M D K M N O U B A R  
P H I L I P P I N E S N H P I Q  
O V S N R H S G M N E M E Y L A  
N W T H A T F K P A K I S T A N  
S C A A A E R O P A G N I S N U  
K O N N I U R A M N A Y M Z D Y  
Q R A G T U R K E Y Q M V X O L  
X Z O L Y G T A M T X W K F J J

LAOS  
LEBANON  
MALAYSIA  
MALDIVES  
MONGOLIA  
MYANMAR  
NEPAL  
OMAN  
PAKISTAN  
PHILIPPINES  
QATAR  
RUSSIA  
SAUDI ARABIA  
SINGAPORE  
SRI LANKA  
SYRIA  
TAIWAN  
TAJIKISTAN  
THAILAND  
TURKEY  
TURKMENISTAN  
UZBEKISTAN  
VIETNAM  
YEMEN

## Answers

7	4	1	3	2	6	9	5
3	5	2	7	9	8	4	1
6	8	9	1	4	5	2	7
5	2	4	9	3	7	1	6
8	9	6	2	5	1	7	3
1	7	3	8	6	4	9	5
4	6	7	5	8	9	3	2
9	3	8	6	1	2	5	4
2	1	5	4	7	3	6	8

bamboozable 35  
Answers: 1. Too  
Good to Last; 2. Pat  
on the Back; 3. Life  
Behind Bars  
4. A Touchin;  
Moment; 5. Look  
Before You Leap;  
6. Three Wise Men.  
Word Change 23  
Answers:  
pole  
pose  
post  
past  
fast

## Sudoku

		5		7		6		9
	3	8	6	1				
4			5				2	1
	7				4	9		
	9	6		5		7	3	
	2		9		7			8
	8							3
3					8	4	1	
7		1	3	2	6	8		

## Word Change

pole
fast

## Bamboozable

GOOD LAST GOOD LAST	PAT THE	BARS BARS BARS BARS BARS BARS BARS BARS BARS
A MOMENT	LOOK ULEAP	YYY MEN

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

## News from around Queensland

### News from Cairns

Looking forward to catching up once again at **Cairns RSL Club, Boardroom on Saturday, 17 April at 11 am.**

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

### News from Townsville

Next lunch for Townsville MG group will be held on **Saturday, 17 April 2021 at The Avenue Hotel at 12 noon.**

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.**

### 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](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.**

### News from the Sunshine Coast

The next Sunshine Coast coffee and chat will be held on **Monday, 7 June at 10.30am, Kawana Club, 476 Nicklin Way.** For more information, please call **Vicki** on **0411 146 898** or email [avplummer@gmail.com](mailto:avplummer@gmail.com)

### News from the Gold Coast

Hi Everyone. MG Gold Coast group had their get together sharing experiences with other members on **Saturday 27 March** at **Southport Sharks Club.** Our next meeting will be at **10am on Saturday, 29 May at Kurrawa Broadbeach Surf Club.** I hope to see all there. Kind regards **Nader Amiri, Gold Coast Co-ordinator, 0415 834 401.**

### WHO is this?



**ANSWER NEXT EDITION**

**April: Donna Formosa**

# SAVE THE DATE

**30** years anniversary  
1991~2021

*Celebration*

**Sunday, 13th June 2021 - 10am**  
at **Hornets Football Club, Graham Road, Carseldine**