



# MessaGes

Myasthenia Gravis Association of Queensland Inc

**FEBRUARY 2016**



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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Internet: [www.mgaq.org.au](http://www.mgaq.org.au)  
MGAQ Facebook page:  
<https://www.facebook.com/mgqld/?fref=ts>  
MGAQ Discussion Forum:  
<https://www.facebook.com/groups/mgqld/>

### COMMITTEE MEMBERS

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**PATRON**  
Dr Cecilie LANDER  
Neurologist  
Founder Member, of Brisbane

## PRESIDENT'S REPORT

G'day all,

One year gone and another one beginning. I hope our members enjoyed a great Christmas with families and friends and stayed safe and healthy over the Festive period.

The 2015 Christmas function held at the Caloundra Power Boat Club on the Sunshine Coast was a great day with about 30 members and families attending. The food was good, the chatter plentiful and the company excellent.

The necessary approvals and paperwork regarding the resumption of funding from Queensland Health have been completed and we look forward to receiving the first instalment.

2016 celebrates the 25<sup>th</sup> anniversary of the MGAQ – a remarkable achievement considering its humble beginnings and the fact that it has always been a purely volunteer-run organisation. I congratulate all the past and current members of the Management Committee for their untiring efforts on behalf of the MGAQ members and look forward to many more years of operation

The committee is currently in discussions with someone regarding the performance, voluntarily, of the book-keeping aspects of the Treasurer's role (i.e. receiving monies, issuing receipts, paying accounts, entering all transactions in the ledger, etc). If the discussions come to fruition, it will mean that the position of Treasurer will not include carrying out those book-keeping aspects of the job, but the MGAQ will still need someone to become Treasurer and take overall responsibility of managing the finances of the Association

So as a final plea to members please give some thought to whether you or someone in your family or circle of friends is prepared to step forward and give consideration to taking on the Treasurer's position. As stated previously, full support will be provided to whoever takes on the job.

I look forward to catching up with all those who are able to come to the Picnic in the Park at Robell Domain, Springfield Central, on Sunday 13 March. It is a great family-friendly location with lots of shade and amenities. Full details are on page 8 of this issue.

I am pleased to inform our members that we have received our first corporate donation, details of which will be in the March issue of MessaGes.

Cheers

*Graeme*

Supported by

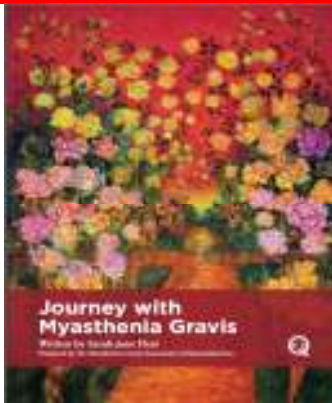


**Queensland  
Government**

**PROJECTS - UPDATED****SURVEY STATUS**

The survey remains an important aspect of the work of the Association. It had been hoped that information pertaining to further work that will result from the data collected to date, could be shared with our members in time for Christmas but alas nothing has eventuated! We can tell you though, additional surveys are indeed going out each and every month and a new round of data entry is soon to take place. This painstaking work is again to be completed by a volunteer. Our sincere appreciation is extended to the young man who will so generously give of his time to complete this task.

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**"JOURNEY WITH MYASTHENIA GRAVIS" - A BOOK BY SARAH-JANE FLEER**

Due to the recent and significant price increases from Australia Post the fees charged to post out the "Journey" book will rise from \$5.00 to \$6.50 from 1 April 2016. If you are thinking about purchasing a copy, now would be an advantageous time to do it and save yourself from paying the increase in postage. Head to our website [www.mgaq.org.au](http://www.mgaq.org.au) for the Order Form.

Raising awareness of Myasthenia is as important as always and every opportunity to do so should be snatched. The book is such a great tool for demonstrating the uniqueness of each journey with the condition.

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**Shirley's Recipe****MANGO JAM****Ingredients:**

3 or 4 ripe mangoes  
Zest and juice of 1 lemon (approx. 1 tablespoon of juice is needed)

1 cup raw sugar

**Method:**

Place all ingredients into a pot. Stir and leave for ½ hour so sugar is partly dissolved. Simmer for 45 minutes stirring regularly, but not constantly (to avoid it sticking to the bottom of the pot. Once congealed, scoop into jars, seal and allow to cool.

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**GOOD NEIGHBOUR**

A young farm boy accidentally overturned his wagon load of corn. The farmer who lived nearby heard the noise. "Hey Willis!!" the farmer yelled. "Forget your troubles. Come in and eat dinner with us. Then I'll help you get the wagon back up." "That's mighty nice of you," Willis answered, "but I don't think Pa would like me to."

"Nonsense, come on!" the farmer insisted. "Well, okay," the boy finally agreed, "but Pa won't like it."

After a hearty dinner, Willis thanked his host. "I feel a lot better now, but I know Pa is going to be real upset."

"Don't be foolish!" the neighbour said with a smile. "By the way, where is your Pa?"

"Under the wagon!"

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**CHAT LIST**

Each member of our Management Committee is happy to speak with you, while the following members, who include MG sufferers or their carers have offered to join our Chat List. If you have a need to have a yarn, particularly about how MG affects you, please ask if it is convenient to talk, and respect the privacy of those whom you call.

In the interests of one's privacy, we have not listed surnames. Do not be embarrassed by ringing a stranger and asking to speak to say, "Fred or Mary". If you wish to disclose your surname, that is your prerogative. Simply explain that you are a MYASTHENIC or a CARER.

**The opinions expressed by the person you call are entirely those of that person. 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 there is also the FREECALL telephone number for Australia manned by Shirley and is 1800 802 568. Please do not hesitate to call if you feel the need. If the 1800 802 568 is not answering, please leave a message and Shirley will get back to you as soon as practicable. Your call is valuable to us, so please do not hang up without leaving a message.

**MGAQ SUPPORT LINE 1800 802 568****CHAT LIST – QUEENSLAND REGIONAL COORDINATORS**

DONNA	0414 397 462	CAIRNS
DEBBIE (Taroom)	4628 6103	DARLING DOWNS
NADER	0415 834 401	GOLD COAST
BILL	4954 1221	MACKAY
JEANNE	0437 048 361	ROCKHAMPTON
COLLEEN	5493 6391	SUNSHINE COAST
DAPHNE	4773 3695	TOWNSVILLE
GARTH (Gladstone)	4973 7983	WIDE BAY/BURNETT
JANET (Hervey Bay)	0429 622 438	WIDE BAY/BURNETT

**CHAT LIST – INTERSTATE MEMBERS**

BARRY / JO	02 6285 2661	CANBERRA ACT
MARILYN	02 6291 3436	GOWRIE ACT
JULIUS	02 9365 5828	BELLEVUE HILL NSW
PROSPER	045 9966 153	CABARITA NSW
BARBARA	02 9524 9224	CARRINGBAH SOUTH NSW
ROBERT	02 6652 6745	COFFS HARBOUR NSW
MAX	02 6621 6386	LISMORE NSW
PENNY	02 4868 2213	MOSS VALE NSW
FRANK	02 6767 1031	TAMWORTH NSW
KERRIE	0435 389 883	TWEED HEADS SOUTH NSW
MAUREEN	02 4476 3734	NAROOMA NSW
CANDY	02 6847 3732	WARREN NSW
ELLEN	07 5599 9511	WEST TWEED HEADS NSW
DIANNE	02 4589 3306	WINDSOR NSW
ROLAND	03 9796 6592	NARRE WARREN VIC
TAMARA	0409 186 809	HOPPERS CROSSING VIC
CORAL	03 5865 1378	KATAMATITE VIC

DENNIS	0402 285 520	PATERSONS LAKES VIC
BARBARA	03 9776 4985	SEAFORD VIC
DORA	03 5821 4191	SHEPPARTON VIC
EDMUND	03 9509 8920	CAULFIELD NORTH VIC
MELITA	0412 124 017	ELTHAM VIC
ROBERT	08 9578 3113	GIDGEGANNUP WA
DIANE	0421 387 904	CARINE WA
DIANE	03 6327 2563	RIVERSIDE TAS
DAPHNE	03 6428 6733	SQUEAKING POINT TAS
CRYSTAL	0459 472 165	ALICE SPRINGS NT
TERRI	0419 681 044	BERRIMAH NT

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## **EMAIL ADDRESSES OF CURRENT FINANCIAL MEMBERS**

As the age of technology embraces us more and more each day, we ask that members notify us of their email address so that we might get information to them in a more timely fashion.

An example of the use of email notification to members is where the Association becomes aware of a problem with supply of medications (as has occurred in the past) and can alert members to check with their pharmacist.

The request is entirely voluntary, and your email address will only be used for contact between the Association and yourself. It will not be disclosed to any other person or organisation. The newsletter will not be emailed to you unless you have requested it.

If you are willing to provide your email address, please email the Secretary at [info@mgag.org.au](mailto:info@mgag.org.au) and include your Full Name and Address in the email, and if you now wish your newsletter to be delivered via email, indicate accordingly.

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## **Obituary**

It is with sadness we advise of the passing of Mrs. Rona Okely of Maddington, W.A.

Rona was one of the driving forces of the now-defunct Myasthenia Gravis WA Friends and Support Group and will be sorely missed by all who knew her.

The MGAQ has written a letter of condolence to Rona's husband, Ron.

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## **Future Planned Activities**

Sunday 13 March 2016	Picnic Brisbane – Robell Domain, Springfield Central
Sunday 12 June 2016	Mid-year function – venue and Guest Speaker TBA
Sunday 11 September 2016	Annual General Meeting – venue and Guest Speaker TBA
Sunday 11 December 2016	Christmas function – Gold Coast – venue TBA

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Cheers to a new year and another chance for us to get it right.

*Oprah Winfrey*



## Around Queensland

### News from Cairns

Cairns MGAQ met on Saturday 19<sup>th</sup> February for a social get together and lunch at the Cairns RSL Club. It was great to catch up with everyone after the Christmas break. Future dates for your diary:- Saturday 16<sup>th</sup> April; Saturday 18<sup>th</sup> June Cairns RSL Club, Esplanade commencing at 11.00am.

Donna Formosa  
0414397462 or 40392148

### News from Mackay

Our last get together was held on 29 November at the Boomerang Hotel/Motel for lunch. Muriel (the unpaid secretary) decorated the tables for a Christmas theme.

Ten people attended including Ron & Pam for the first time. Two others were away for medical treatment. All attending received a small gift and had an enjoyable time.

It was decided our next get together will be held at **Duke of Edinburgh Hotel, Walkerston for lunch at 12.00 noon on Sunday 28<sup>th</sup> February**. The April get together will be held on Sunday 24<sup>th</sup> April at the Boomerang Hotel/Motel at 12.00 noon.

Hope all the MGAQ Members are enjoying their start to 2016.

Bill Harris – PH: 49541221

### News from Townsville

The Townsville group met for lunch on Saturday 6<sup>th</sup> February 2016. We had 13 people at the lunch and we enjoyed our catch up.

Our next lunch is at The Avenues Hotel Kirwan Townsville

12 noon on 30<sup>th</sup> April 2016

Daphne – 0400 778 637  
Email: [daphclay@gmail.com](mailto:daphclay@gmail.com)

### News from the Sunshine Coast

We had a pleasant lunch time gathering at Buderim Tavern last Saturday with a new member, Barry. As with all of us when we are first diagnosed with this condition, I am sure he was reassured to speak with other sufferers and realise he is not alone. That is the main aim of our get – togethers; in one word.....support.

We will hold our next meeting at Buderim Tavern on Saturday 2<sup>nd</sup> April at 12 noon. You may come for lunch, just a coffee or maybe a drink of water and a chat. All welcome.

Colleen McLean  
0409 491 789  
[colleen4551@gmail.com](mailto:colleen4551@gmail.com)

## NEW MEMBERS

We welcome the following new members:-

Trevor — Yeppoon QLD  
Mark — Eatons Hill QLD  
Judith (Jude) — Caloundra QLD  
Diane — The Gap QLD  
Ronald & Pamela — Mackay QLD

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Go to Heaven for the climate, Hell for the company – *Mark Twain*

**MEMBERS' FORUM**

There are no contributions this month.

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 make 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.



**RARE DISEASES DAY - FEB 29TH**

The MGAQ are keen supporters of the work undertaken by Megan Fookes and her staff at "Rare Voices Australia" [www.rarevoices.org.au](http://www.rarevoices.org.au). This Not-For-Profit organisation aims to advocate for people who are affected by a rare disease. Myasthenia Gravis falls into this group. Each year a day is set aside to highlight this sector of our population. It falls on the final day of February each year. The following has been taken from the website to explain a little more about it.

*"Rare Disease Day takes place on **the last day of February each year.***

*The main objective of Rare Disease Day is to **raise awareness** amongst the general public and decision-makers about **rare diseases and their impact on patients' lives.***

*The campaign targets primarily the general public and also seeks to raise awareness amongst policy makers, public authorities, industry representatives, researchers, health professionals and anyone who has a genuine interest in rare diseases.*

*Since Rare Disease Day was first launched by EURORDIS and its Council of National Alliances in 2008, thousands of events have taken place throughout the world reaching hundreds of thousands of people and resulting in a great deal of media coverage.*

*The political momentum resulting from Rare Disease Day also serves **advocacy purposes.** It has notably contributed to the advancement of **national plans and policies for rare diseases** in a number of countries.*

*The campaign started as a European event and has progressively become a world phenomenon, with the USA joining in 2009 and participation in over 80 countries throughout the world in 2015. Hundreds of cities continue to take part in Rare Disease Day and we hope even more will join in 2016. Some countries have decided to raise rare disease awareness further, for example, Spain declared 2013 as the National Year for Rare diseases." [www.rarediseaseday.org/article/what-is-rare-disease-day](http://www.rarediseaseday.org/article/what-is-rare-disease-day)*

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**THE JOYS OF FLYING**

*The world's first fully computerized airliner was ready for its maiden flight without pilots or crew. The plane taxied to the loading area automatically, its doors opened automatically, the steps came out automatically. The passengers boarded the plane and took their seats.*

*The steps retreated automatically, the doors closed, and the airplane taxied toward the runway.*

*"Good afternoon, ladies and gentlemen," a voice intoned. "Welcome to the debut of the world's first fully computerized airliner. Everything on this aircraft is run electronically. Just sit back and relax. Nothing can go wrong ... Nothing can go wrong...nothing can go wrong..."*

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## KEEP YOUR BRAIN ACTIVE WITH THE TRIVIA QUIZ

Here are some questions for you to try. (Answers are at bottom of this page)

1. What is the collective noun for a group of ravens?
2. Who wrote 'The adventures of Pinnochio'?
3. What is green horseradish known as in Japan?
4. What is the capital of the USA state of Nebraska?
5. What is the chemical symbol for Manganese?
6. Who wrote the Inspector Rebus series of novels?
7. What is the capital of the Falkland Islands?
8. Which old time film star's horse was called 'Champion'?
9. Who was the first Premier of Queensland?
10. In which Australian state or territory is Taroona?
11. Who did Novak Djokovic beat in the 2016 Australian Tennis Open Men's singles final?
12. Hellespont was the ancient name for which narrow sea strait?
13. In which film is there a computer called Mother?
14. Ailurophobia is the fear of which animals?
15. Which magical creature played "along the cherry lane"?
16. What are the colours of the Benin flag?
17. A South African Rand consists of 100 what?
18. Which river flows through Warsaw, the capital of Poland?
19. Who was the youngest of the Marx brothers?
20. Which horse played Mr Ed in the TV series of the same name?

**Answers:** 1) Unkindness; 2) Carlo Collodi; 3) Wasabi; 4) Lincoln; 5) Mn; 6) Ian Rankin; 7) Port Stanley; 8) Gene Autry; 9) Robert George Wyndham Herbert; 10) Tasmania; 11) Andy Murray; 12) Dardanelles; 13) Alien; 14) Cats; 15) Puff the Magic Dragon; 16) Green, yellow & red; 17) Cents; 18) Vistula; 19) Zeppo; 20) Bamboo Harvester

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A journey of a thousand miles must begin with a single step – *Chinese Proverb*

## **PICNIC IN THE PARK**

**WHEN:** Sunday 13 March 2016 from 10:00am

**WHERE:** Robell Domain Springfield Lakes (off Sinnathamby Blvd) UBD Map  
NN Refce An

**WHAT DO I NEED TO BRING?** Yourself and whomever else you wish to bring along – the more the merrier. Don't forget your picnic lunch. Children very welcome.

**RSVP:** Ring our FREECALL 1800 802 568 and tell Shirley if you are coming, but please let her know by **Friday 4 March 2016**

### **HOW DO I GET THERE?**

#### From Brisbane , Sunshine Coast and Gold Coast

Proceed on the Centenary Highway towards Warwick (Yamanto). Take the Springfield Central (Greenbank Arterial Road) exit. At the roundabout at the foot of the exit ramp, turn left onto Greenbank Arterial Road. At the traffic lights, turn right into Sinnathamby Blvd. At the second set of lights turn right into Education City Drive. Proceed straight at the roundabout and turn left at 'The Circle'. This will lead to a parking area. From the car park walk towards the Robell Domain Café and follow the MGAQ signs. If you get lost call Graeme on 0407173771.

#### From west of Springfield

Same as above except for:

Connect with Sinnathamby Blvd from either Augusta Parkway or Centenary Highway. From Sinnathamby Blvd, turn left into Education City Drive.

#### Public Transport

If you would like to come to the picnic but are unable to drive to the venue, there is a regular train service to Springfield Central station. If you will be coming via train, please let us know and we can arrange to pick you up from the station.

**NOTE:** Facilities at the Robell Domain include play areas for children, a cafe which sells snacks, ice creams and hot and cold drinks, and lots of paved walking paths if you wish to wander around and take in the full extent of the Domain. It is also a short walk across to the Orion Shopping Centre which has heaps of places for eat-in or take-away. If the weather is warmish, it is only a short walk to the free entry swimming 'Lagoons' so you may wish to bring your bathers. (The Lagoons are attended by life guards).

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People who know everything are a great annoyance to those of us who do – *Isaac Asimov*

I can resist everything except temptation – *Oscar Wilde*

When you are courting a nice girl, an hour seems like a second. When you sit on a red hot cinder, a second seems like an hour. That's relativity – *Albert Einstein*