



# MessaGes

Myasthenia Gravis Association of Queensland Inc

**MARCH 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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MGAQ Facebook page:  
<https://www.facebook.com/mgqld/?fref=ts>  
MGAQ Discussion Forum:  
<https://www.facebook.com/groups/mgqld/>

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Founder Member, of Brisbane

## PRESIDENT'S REPORT

G'day all,

Things continue to progress for the MGAQ.

We are pleased to announce that two eminent people have kindly accepted an invitation to be Guest Speaker at MGAQ events in 2016. Neuro-ophthalmologist, Dr Anthony Pane from the Queensland Eye Institute, will give a presentation to the mid-year function on Sunday 12 June 2016. And Ms Megan Fookes OAM, Advisor Policy and Stakeholder Relations for Rare Voices Australia (the not-for-profit organisation which advocates for people who have a rare disease, - MG is classified as a rare disease) will present at the AGM to be held on Sunday 11 September 2016. Full details of both events will be published in future issues of MessaGes.

February has been a very successful month in spreading awareness of MG to the general community via radio interviews and newspaper articles. Details of these and links to audio or copy of each are on page 5 of this issue.

We have been successful in obtaining a volunteer to perform the bookkeeping aspects of the Treasurer's position. However, a volunteer to take on the overall Treasurer's responsibility is still required to enable the MGAQ to continue functioning. If interested, please, pretty please, contact Acting Treasurer, Susan White, or myself. Once again I remind our members - **No Treasurer means No MGAQ.**

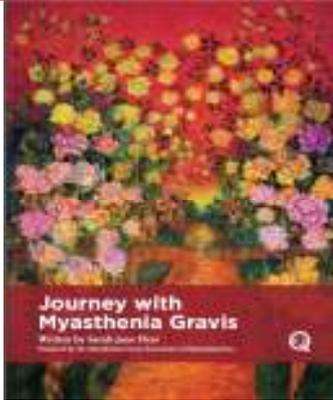
Finally it has become apparent that the MGAQ Chat Lists published regularly in MessaGes have become inaccurate over time due to members not renewing their membership, changing address or phone number without advising the Secretary of the change, and for various other reasons. We intend to bring these Chat Lists up-to-date and publish all three (3) lists together quarterly. Please refer to the item concerning this matter on page 3 of this issue.

Cheers

*Graeme*

Supported by



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

Due to the recent and significant price increases from Australia Post it is highly likely that the fees charged to post out the "Journey" book will have to rise. If you are thinking about purchasing a copy, now could be an advantageous time to do it. 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.

Contact Susan on 0419 912 652 , email at [info@mgaq.org.au](mailto:info@mgaq.org.au) or go to the website [www.mgaq.org.au](http://www.mgaq.org.au) to order your copy.

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**MYASTHENIA ALLIANCE AUSTRALIA**

The Alliance Committee have begun the year with enthusiasm.

A 2018 Conference is on the agenda. Conversation with internationally located Associations will commence with a view towards collaborative ideas being explored.

Dr. Stephen Reddel and Dr. Katherine Buzzard spoke at the 2015 Conference about a data base for Neuro-immunological Patients (eNID). This project is progressing well and the MAA has agreed to assist in this work where possible when the time is ready.

The MAA has declared June to be "Australian MG Awareness Month". Do think about how you can spread the word to raise awareness of this rare disease. This is a month to acknowledge yourself and the challenges you face. Perhaps just meeting up for coffee with friends and family would be a treat.

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

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**CORPORATE SPONSORSHIP**

The Myasthenia Gravis Association of Queensland Inc. sincerely thanks Ausenco Limited for its generous sponsorship of our association. Ausenco Limited is a multinational engineering, procurement, construction management, and operations service provider to the energy and resources sectors. Its head office is in Brisbane.

It is through the wonderful support of companies such as Ausenco that our association is able to support its members and have others come to know and understand a little, or more, about this chronic and rare illness. While our association's Vision is to improve the quality of life for people with Myasthenia Gravis and their families by providing support, advocacy, research and developing public awareness, we must also ensure that we remain a dynamic, progressive association in synergy with our members.

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Our characters are the result of our conduct -- Aristotle

### REVIEW OF MGAQ CHAT LISTS

The Chat Lists which are published in the monthly newsletter have been in existence for a considerable number of years. As is the case with lists which are subject to consistent amendment over time, it is apparent that the Lists currently in use are not accurate for various reasons, such as members changing location or phone number and forgetting to notify of their new information, members passing away, or, indeed, oversight on the part of the MGAQ, etc.

Consequently, the Management Committee has decided to discontinue using the existing Chat Lists and construct a new Consolidated Chat List which will be published quarterly. This new list will continue to show Given Name, Contact Phone Number and Location and will be ordered alphabetically by Location within State.

To enable the List to be constructed would members who are willing to be on the Chat List please advise via email to [info@mgaq.org.au](mailto:info@mgaq.org.au), or telephone Freecall 1800 802 568 or by letter, of their Full Name (Surname will not be listed), contact phone number and location, i.e. Suburb or town name. It would be appreciated if this information could be forwarded by **30 April 2016**. Only those members who respond to this request will be placed on the new Chat List.

New members since **1 July 2015** need not respond to this request unless their information has changed since they completed the Application for Membership form.

Thank you for your assistance in this matter.

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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@mgaq.org.au](mailto:info@mgaq.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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### Future Planned Activities

- Sunday 12 June 2016                      Mid-year function – Southern Cross Sports Club, Mt Gravatt  
Guest Speaker Dr Anthony Pane, Neuro-ophthalmologist
- Sunday 11 September 2016            Annual General Meeting – Southern Cross Sports Club, Mt  
Gravatt. Guest Speaker Ms Megan Fookes AOM
- Sunday 11 December 2016            Christmas function – Gold Coast – venue TBA

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## Around Queensland

### News from Cairns

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 first lunch for 2016 was held at the Duke of Edinburgh Hotel Walkerston. It was well attended by 12 members and our two guest speakers, Dr Jessica and Dr Eileen from the local Chiropractice. The lunch was enjoyed by all .The presentation given by our guest speakers was appreciated by all and they also answered questions from the members .

The next lunch get together will be held at the Boomerang Hotel /motel on Sunday 24/4/2016 .

Bill Harris – PH: 49541221

### News from Townsville

Our next lunch is at The Avenues Hotel Kirwan Townsville

12 noon on 30th April 2016

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

### News from the Sunshine Coast

We will hold our next meeting at Buderim Tavern on Saturday 2nd 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:-

Colin & Sandra – Macleay Island QLD

Kerri – Hyde Park QLD

Thomas – Centenary Heights QLD

Maree – Pimlico QLD

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## VICTORIAN SUPPORT GROUP

An Incorporated Association has now been formed in Victoria. This is very exciting news and we hope that Victorians will get behind the group and help it to be strong. It is early days and the spokesperson has indicated that it is 'low key' at present. Small gatherings have been organised and a website is available for contact. Please go to [www.mygravis.org.au](http://www.mygravis.org.au) for more information.

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I hear and I forget. I see and I remember. I do and I understand – *Confucius*

Little things affect little minds – *Benjamin Disraeli*



## 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 owls?
2. What is the name of Hobart's daily newspaper?
3. What is a female ferret called?
4. What is the capital of the USA state of California?
5. How many Noble gases are there?
6. Which novel was the sequel to '*Little Women*'?
7. Sb is the chemical symbol for which element?
8. Which old time film star's horse was called 'Topper'?
9. Who was the second Premier of Queensland?
10. In which Australian state or territory is Mallacoota?
11. In which year did Sir Robert Menzies become Prime Minister of Australia?
12. Which Strait separates Kangaroo Island from Yorke Peninsula in South Aust?
13. Which male first name stems from the Greek word meaning 'crown'?
14. Which popular article of clothing originated in the French city Nimes?
15. What did Oscar Wilde describe as "The unspeakable in pursuit of the uneatable"?
16. The movie '*Rocky*' took place in which city?
17. In which year was the Republic of China established?
18. Which Royal Navy Captain wrote in 1804 "I call the whole island Australia, or Terra Australis"?
19. What colour is vermilion?
20. Which horse won the 100th Melbourne Cup in 1960?

**Answers:** 1) Parliament; 2) The Mercury; 3) Hob; 4) sacramento; 5) Seven; 6) Good Wives; 7) Antimony;  
8) William Boyd (Hopalong Cassidy); 9) A. Macalister; 10) Victoria; 11) 1939; 12) Investigator Strait; 13) Steven, Steve or Stephan;  
14) Denim; 15) Fox Hunting; 16) Green, Philadelphia; 17) 1912; 18) Matthew Flinders; 19) Orange-Red pigment; 20) Hi Jinx.

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The weak can never forgive, Forgiveness is the attribute of the strong – *Mahatma Ghandi*



## “Closed Facebook Group” vs “Open Facebook Page”

Many people ask what the difference is between the two MGAQ Facebook Pages.

**MGAQ Discussion Forum** is a “Closed Facebook Group” which allows like-minded people to communicate between each other in a safe forum. New members need to JOIN and then be approved by Admin before they can join the conversation. Only members who also belong to the group can see the posts or chats within it. This is a wonderful forum to share your MG Journey and chat to others on their MG Journey. To join:- <https://www.facebook.com/groups/mgqld/>

**The MGAQ Facebook Page** is an “Open Facebook Page.” The difference is that this page is Public and can generally be seen by anyone on Facebook. The Facebook page allows the MGAQ to communicate broadly with people who “Like” the page. When the MGAQ publish a post or an announcement it appears in the newsfeed of people who “like” the page. To spread the awareness of MG we need as many people as possible to “Like” the page. Help us to achieve this by visiting the MGAQ Facebook Page and click “Like” at <https://www.facebook.com/mgqld/>

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## ORPHANET JOURNAL OF RARE DISEASES

The MGAQ was delighted to participate in a research paper entitled “The Involvement of Patient Organisations in Rare Disease Research: a mixed methods study in Australia”. It was published by Deirdre Pinto, Dominique Martin and Richard Chenhall through the University of Melbourne. It is an interesting paper which highlights the importance of organisations such as ours in initiating and supporting research into rare diseases. It discusses how ‘patient communities influence the directions, practices and cultures of biomedical science’. It supported the importance of data registries such as is occurring with the MG Survey run in conjunction with the RBWH and University of Queensland. It confirmed that the majority of organisations are indeed small volunteer-run groups such as MGAQ and that these groups do have a significant influence, although there are significant challenges for these organisations. The paper reiterated the importance of policy support at a government level and the need for patient registries and bio-banks. Unification amongst the Support Organisations was suggested as an advantageous progression. For the full article go to [www.ojrd.com/content/11/1/2](http://www.ojrd.com/content/11/1/2)

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**Before any surgery inform  
your doctor, anaesthetist or  
dentist that you have MG**

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If I had a dollar for every girl that found me unattractive, they would eventually find me attractive.

I want to die peacefully in my sleep, like my grandfather. Not screaming and yelling like the passengers in his car.

## Teenager's Life Transformed by Ground-Breaking Charity Research

*A teenager who has been reliant on a wheelchair for seven years is able to walk again, thanks to ground-breaking research funded by the charity.*

Jimmy Webster, aged 17 (pictured below), who with his family has been an active member of the **myware** Kids Group, has a severe form of congenital myasthenia. This meant that Jimmy was unable to stand and sometimes needed help to breathe. But now Jimmy, from Cardiff – grandson of Heywood and Middleton MP Jim Dobbin – has seen his life transformed after taking a 'miracle drug' developed by scientists during research funded by **myaware**.

Scientists at the Weatherall Institute of Molecular Medicine, University of Oxford, suggested that Jimmy could trial Salbutamol, alongside another drug called pyridostigmine. Within three days Jimmy could stand and, two days later, he took a few steps. Jimmy said: "I was suddenly able to stand - it was weird. I was under the impression that I would always have this trouble but I can take 150 steps now. I am quite proud, amazed and very grateful to the research team."

For years Jimmy struggled with day-to-day tasks most of us take for granted, such as getting out of bed, washing and getting dressed. He sometimes needed ventilation to open his airways because the muscles would collapse. His eyelids would droop involuntarily and he would be unable to hold out his arms. Jimmy said: "It was frustrating growing up. My friends would go off and I'd be left on my own – they'd forget about me. I got really tired of watching other people play football."

Before taking the new drug, Jimmy would not have been able to go away to university but he has been offered a place at the University of Oxford and is now able to accept it. His mother, Kerry, said: "Jimmy's at an age where his friends are going away and, before he started taking the medication, there was no way he would have been able to function on his own. He was reliant upon care for everything, even getting dressed. "Now he is able to do more and more by himself and he is really challenging himself. As a mum, this is what you want. I can see his life really developing and flourishing now – it's so nice to think that he will get to have the independent experiences that people expect to have at his age. It's all about hope – you never expect change to happen but you hope. It's a little miracle."

Despite the challenges Jimmy has faced, he has competed in wheelchair karate for several years. Since taking Salbutamol he has won a number of tournaments, including second place in the Welsh league and third place in the Welsh national wheelchair karate championships.

In people with myasthenia, the brain tells the muscles to work but the message fails to get through. Salbutamol appears to stabilise the connection between the nerve and the muscle. Scientists who discovered it could have such a significant impact on myasthenia symptoms are now looking into how it may benefit other related disabling genetic conditions. Research involves testing how the drug alters the nerve to muscle connection. Professor David Beeson, who leads the Oxford team and has been studying the causes of myasthenia for 30 years, said: "In Jimmy's case we got the combination of drugs just right and we were very pleased. Results like these make the work rewarding. "Myasthenia is one of the few genetic muscle diseases where there are effective treatments and the work we do can be transformational in terms of the quality of daily living."



*Published in the Summer 2014 Edition of MyawareNews, the newsletter of the MG Support organisation, MYAWARE, in the UK*