



# Messages

MYASTHENIA GRAVIS ASSOCIATION OF QUEENSLAND INC.

**FEBRUARY 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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## PRESIDENT'S REPORT

Welcome to 2020 and I hope that this newsletter finds you all safe and well. As I perused the 2019 newsletter I then wrote about the terrible bushfires and floods pre and post Christmas and, sadly, Australia is suffering the same catastrophic weather events. I know that we all feel for those who have suffered tragic losses and also those very brave men and women who put their own lives on the line to save others.

While we had a break over Christmas and New Year, work behind the scenes has continued. The new Rules (Constitution) that was accepted at the AGM has now been approved by the ACNC and Office of Fair Trading so that document will guide our operations henceforth. I am pleased to report that all reports to Queensland Health re our grant have been completed and that we have a slight increase in our funding for this year. Also, the groundwork for the production of our podcasts is near completion and work will commence in the first half of this year.

Another coup is the realisation of the MAA eNID project with the launch date forecast for early

April. Please go to the MAA website to read more about this huge project.

We ask that people pay their annual membership and that is one of the few sources of income outside of the grant mentioned above that we get to keep the association running. Even the cost of postage for the newsletters and information packs is a big item for the association. Remember that, if your membership has lapsed, you do **NOT** have to backpay for those years. We only expect people to pay the 2019-2020 membership. If in doubt please feel free to contact [info@mgaq.org.au](mailto:info@mgaq.org.au) or **1800 802 568**. It is amazing the diverse range of services we can offer to our members with very little funding. Also remember that some services and information are only provided to paid-up members.

The full complement of volunteers on the management committee are looking forward to what we hope will be a very successful year for the association and its members.

*Thanks, Carol*

*Supported by*



Queensland  
Government

Ausenco

**MYASTHENIA ALLIANCE AUSTRALIA NEWS**

# UPDATE

The MAA meet for the first time this year in late February to focus on what is sure to be another very productive year.

Minister for Health, the Hon. Greg Hunt will be present at a Parliamentary Event in honour of Rare Diseases Day, scheduled for February 26th and hosted by Rare Voices in conjunction with Dr Mike Freeland MP and Trent Zimmerman MP. At this event Minister Hunt will launch the National Strategic Action Plan for Rare Disease. The MAA has been invited to attend and I am delighted with the opportunity to represent the MAA at this Canberra event. Planning for this opportunity is under way.

We have received exciting news from the MS-Base Foundation to advise that the final user acceptance testing phase is about to commence with a planned launch of the eNID MG project

set for April. The MAA, thanks to generous support from several significant donors and from the State Associations of NSW and Queensland, has been able to make a significant financial contribution to this project to ensure its success. Subsequent hosting, maintenance, minor updates and the user help desk facilities will be supported by MSBase. We are hopeful that this project will be a huge success.

As the year gets under way, please help us as we endeavour to help you. If you have not already done so, go to [www.myastheniaallianceaustralia.com.au](http://www.myastheniaallianceaustralia.com.au) and subscribe to the newsletter. Your registration builds the advocacy profile required to influence policy.

More news next month.

**Susan White,**  
**MAA Chairperson.**

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

**JUNE**  
Myasthenia Gravis  
Awareness Month

The Story lights up for MG

MGAQ.ORG.AU

#RareDiseaseDay  
rarediseaseday.org

## 2020 RARE DISEASE DAY AUSTRALIA EVENTS

WE ARE THE  
300 MILLION



RARE DISEASE DAY®

Twitter @rarediseaseday Facebook @rarediseaseday Instagram @rarediseasedayofficial

SHOW YOUR SUPPORT THIS RARE DISEASE DAY

**29 FEBRUARY 2020**

There are over 300 million people  
living with a rare disease worldwide

Rare Disease Day is organised by EURORDIS-Rare Diseases Europe  
and 60 National alliances of patient organisations for rare diseases.

Rare Disease Day takes place on the last day of February each year, this year being 29 February, with the main objective to raise awareness among the general public and decision-makers about rare diseases and their impact on people's lives.

### CAIRNS

Sunday, 23 February

Rare Disease Day Fun Run & Walk 2020, Cairns Esplanade @ 8.30am  
Organised by Rare Friends FNQ [www.rarefriends.org](http://www.rarefriends.org)

### BRISBANE

Thursday, 27 February

The Story Bridge, Kangaroo Point will be lit Blue, Purple and Green

Thursday, 27 February

The Victoria Bridge, South Brisbane will be lit Blue, Purple and Pink

Saturday, 29 February

Brisbane City Hall, Adelaide St, Brisbane will be lit Blue, Pink and Green

*The light up is organised by Rare Voices Australia [www.rarevoices.org.au](http://www.rarevoices.org.au)*

### MELBOURNE

Friday, 28 February

The Genetic Support Network of Victoria (GSNV) will be holding an event to mark Rare Disease Day in 2020 on **28 February from 9:30am – 4.30pm at the Royal Children's Hospital in Parkville**. All are welcome to attend.

*Hosted by Genetic support Network of Victoria.*

### PERTH

Friday, 28 February  
to 1 March

Perth's Parliament House will light up in green from 28 February to 1 March to mark Rare Disease Day.

Saturday, 29 February

Perth's Council House will light up pink, blue and green on 29 February to mark Rare Disease Day.

*Organised by Rare Voices Australia.*

### SYDNEY

Sunday, 1 March

Sydney's Town Hall will be lit up pink on 1 March to mark Rare Disease Day.

*Organised by Rare Voices Australia.*

For more information go to <https://www.rarediseaseday.org/event/australia/222>





# WHAT'S NEW FOR THE MGAQ

## From Karen Downes - Committee Member.

I am very excited to be a part of the team to bring in the new MGAQ resource of Podcasts and Vodcasts for our members.

My hope is they will be a venue to provide a MG based Education resource merged with an Introspective element as we have MG experiencers relate their personal stories, all tinged with a sense of humour and positivity.

I am on my own learning curve as I facilitate the

content for the pod and vodcasts, revisiting my skills in open dialogue and taking my own first baby steps into this for me a new technology.

I am sure with Mark White and Ian Hollingworth, this new MGAQ resource will be up and running in the near future. I would like to thank Mark for all the time he has put into the immense research and effort to get this project off the ground.

The **Drugs to be Used With Caution** information has been formatted into a wallet card containing members personal details as requested. This item will replace the previous *Medi-Alert Card*.

The online application can be found at:  
<https://mgaq.org.au/medi-alert-card>

An application form will be included with this newsletter or can be downloaded from at anytime from the website:

[https://www.mgaq.org.au/sites/default/files/2019-12/MGAQ\\_Medi\\_Alert\\_Wallet\\_Card\\_Application.doc](https://www.mgaq.org.au/sites/default/files/2019-12/MGAQ_Medi_Alert_Wallet_Card_Application.doc)

and sent through to the committee via [info@mgaq.org.au](mailto:info@mgaq.org.au)

or posted to

**MGAQ, P.O. Box 16, Mt. Gravatt, QLD 4122**

All personal details will not be kept once your card has been prepared. As there may be an initial rush to access the new cards, your patience will be requested. There is no additional charge to have this credit card sized, laminated document sent to you.

The Committee trusts that you find this resource invaluable and thank member Sandi, for the suggestion and skills to make this card happen.

## REQUEST FOR MEDI-ALERT WALLET CARD

Family Name .....

Given Names .....

Home Address .....

..... Postcode: .....

Phone ..... Date of Birth: .....

GP ..... Ph: .....

Specialist ..... Ph: .....

Hospital. ....

..... Ph: .....

ICE Contact .....

Phone .....

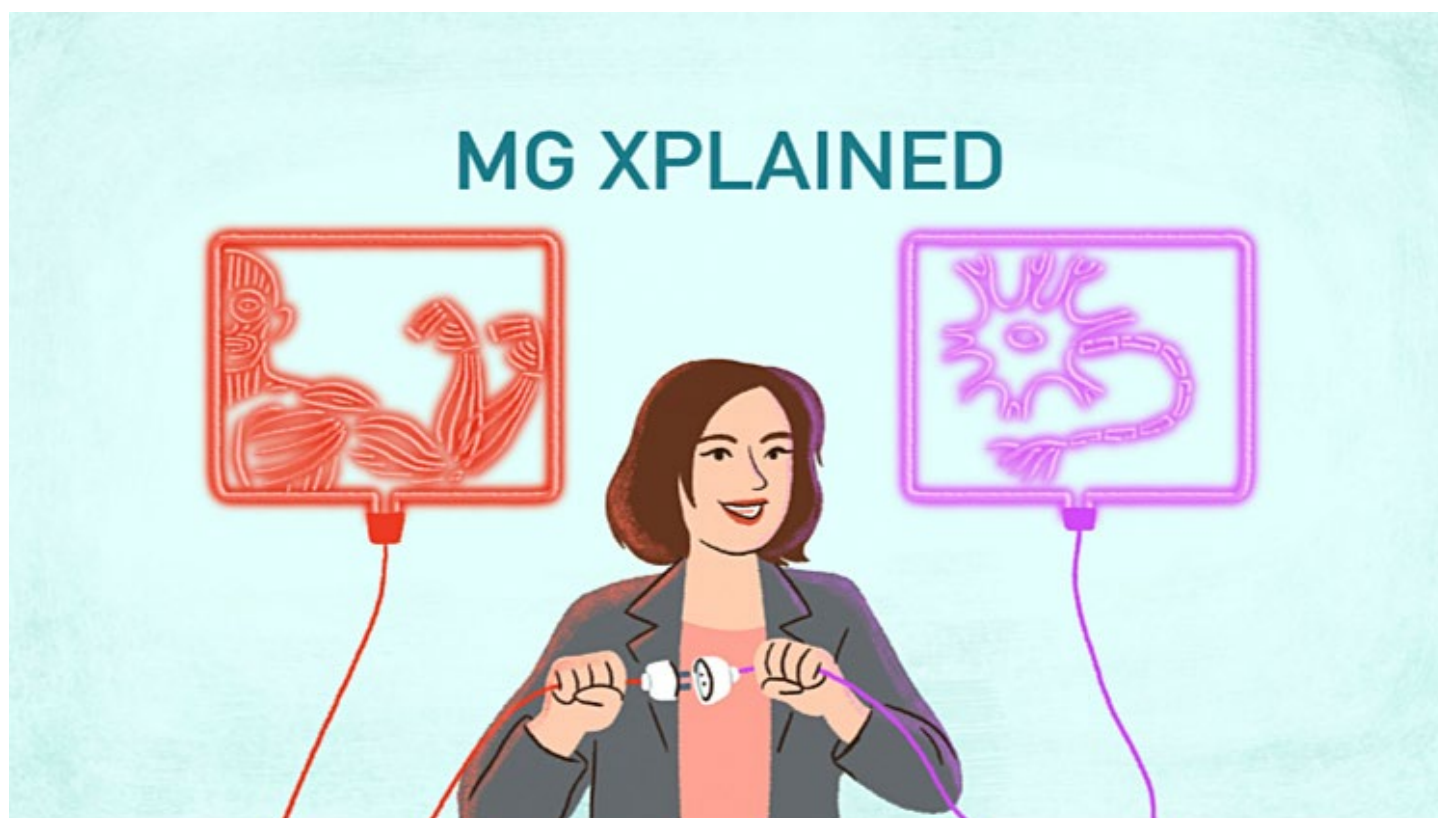
*ICE = In Case of Emergency*

Signature: .....

Please forward request to:

**MYASTHENIA GRAVIS ASSOCIATION OF  
QUEENSLAND INC  
PO BOX 16, MOUNT GRAVATT QLD 4122**

**NOTE: Medi-alert cards are only available to members of the association**



MG Xplained by  
**MedicineX**

Supported/Sponsored by  
**CSL Behring**  
Biotherapies for Life™

## MG Xplained – A WONDERFUL NEW RESOURCE

The booklet “MG Xplained” is a wonderful resource that has been uploaded to the MGAQ website. This resource was not produced by the MGAQ but we were very lucky that CSL Behring sponsored the production of this very user-friendly, easily understood explanation of Myasthenia Gravis. We wish to thank CSL for this wonderful support of such a worthwhile project. The association also acknowledges the work of Dr Stefan Blum who advised throughout the writing and production to ensure that all the informa-

tion contained within was accurate and relevant.

This booklet should prove very useful for family, friends and others who do not understand the condition to find out more about Myasthenia and how it affects people both medically and in daily living.

The Medicine X booklet also has a Q scanner for phones. We hope that people will take advantage of this download so they have ready access to it when explaining Myasthenia and its ongoing effects.



Scan the code or visit  
<https://mgxplained.com.au/>  
to learn more about mgxplained



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.**

## Assistant Dogs and Myasthenia Gravis Can they help us?

### *Jan writes:*

This is a question most of us have not even thought to ask - until now!

I will step back a bit and hope I don't bore you. In 2014 I was pushed into the Nurses Counter, accidentally ending up with a fractured hip and smashed wrist.. I needed a total hip replacement and a wrist that works but have lost some dexterity in small actions. My stay in Hospital was horrific and after 6 weeks I was diagnosed with Osteoporosis and a fall risk!

Later I was diagnosed with PTSD. During my treatment for this it was suggested I needed an Assistance dog because I wouldn't go into a shopping centre or anywhere with crowds, I was too frightened that I would get knocked over again breaking a bone and the pain was still too raw to contemplate going out. I had a wheelie walker, but at 69 it helped but made the depression worse as I didn't want to get that old so quickly!!!

We did research and bought a Kelpie puppy who had been specially chosen from her litter to be quiet, calm and loving.

We picked her up at 8 weeks old, and started getting her used to going out in public by taking her everywhere with us, to outside coffee places etc.

When we started her training the trainer said the course was a 'body language' course as



she already knew my needs. This was because after having her from 8 weeks old she knows my good times, and my bad times and those in between. It was all so true!

We finished our training, passed and Nancy, my lovely dog, is with me always.

Now to get to the point, is she helping me with MG or just PTSD?

I really can't answer that BUT early on I noticed that when I was getting tired she would

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slow down her pace, would look at me and has been known to stand in front of me! I told the trainer this and he said that she was telling me I was either too stressed or too tired and needed to sit down or go home!



I have also noticed that when I am tired and get the MG walk, I often walk into her, she stands still and firm and looks at me!

After 18 months trained I am so much better that it is hard to know which job I need her most for, I am much more relaxed, not afraid to go out in Public, and, know that Nancy will let me know before I realise it that I am getting tired and need to rest!

So..... does an Assistance dog help with MG? Yes I believe they can, we all, I think, carry an element of stress when we are out, will I get too tired? Will I have a crisis? Who will know and help? so I find it very comforting to have Nancy with me knowing she will let me know to rest. An added bonus is I find people stop and talk to me about her, sometimes want a pat, and when I am ok and let them pat her, they always thank me and often say they feel better after patting her. This makes me feel useful again and happy! To get the most benefit from this partnership, the dog must really relate very well to you, know your needs and know how to tell you using the body language method, and you must trust her to help you!

I hope this article has given you food for thought, if you need anymore details, training etc., I am very happy to talk and answer any questions. Thank you for taking the time to read this article.

**You can get Jan's details by phoning Freecall 1800 802 568.**

## NEWS FROM AROUND QUEENSLAND

### News from Cairns

Rare Disease Day is celebrated in Cairns on Sunday, 23 February with a Fun Run/Walk on the beautiful Cairns Esplanade at 8.30am. This event is hosted by Rare Friends Far North Queensland and Dynamic Running. The MGAQ supports Rare Disease Day and look forward to as many of our members participating again this year to bring awareness of Rare Disease. Please register at <https://www.rarefriends.org/>

Our Cairns group will hold its first meeting of the year on **Saturday, 21 March at the Cairns RSL Club Boardroom at 11.00am.** Dates for the diary for 2020 are Saturday, 20 June, Saturday, 19 September and Saturday, 21 November.

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

### News from Townsville

The next lunch will be held on **Saturday, 29 February at 12 noon at The Avenues Hotel, Kirwan.** All Welcome.

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

### News from Mackay

We were fortunate to have a new member join us for the December lunch at the Rice Buffet. Her husband and daughter also came along and enjoyed meeting others with MG.

The next lunch will be held on **Sunday, 23 February at 12 noon at Souths Suburban Bowls Club, 39 Wardrop Street, West Mackay.**

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

### Hervey Bay – Wide Bay Burnett Region

If you are in the Hervey Bay area, please join us for a catch up on the **first Tuesday of the month at Bunnings Café, Boat Harbour Rd & Main St, Pialba at 10.30am.** The next one is on **3 March.**

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

For more information about the Sunshine Coast group, call Colleen on 0409 491 789 or email [colleen4551@gmail.com](mailto:colleen4551@gmail.com)

### News from the Gold Coast

Our next get together will be on **Saturday, 15 February at the Kurrawa Surf Club, Broadbeach at 10.00am.**

For more information on the Gold Coast group, please contact Nader on 0415 834 401.

### News From Brisbane

Coffee & Chats are a good opportunity to connect with people in your area. All are welcome.



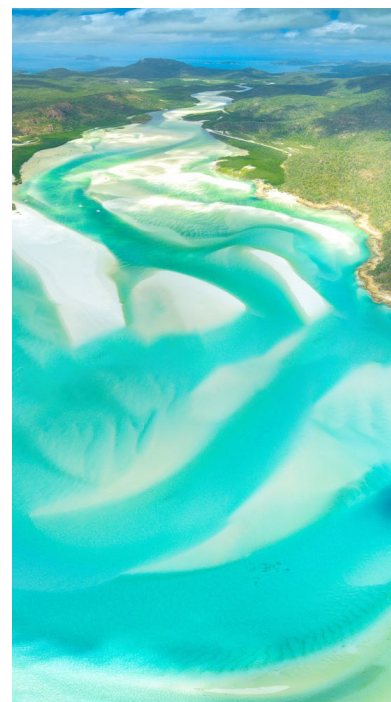
Burpengary

Cleveland

Nundah

Ipswich

For more information, Contact Anita on 0414 588 312



### WHERE IN QUEENSLAND?

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 first American case of myasthenia gravis

Reported here is an account of the illness of Indian Chief Opechankanough (died 1644), which may represent the first recognized case of myasthenia gravis. Historical publications based on colonial correspondence with England are the sources for this article.

To my knowledge, this is the first article in the medical historical literature to mention this famous and influential Indian. Historical accounts state that Opechankanough was so weak as to be unable to walk, making it

necessary that he be carried about on a litter. Moreover, his eyelids were so weak they had to be raised by his attendants. Additionally, a hint of improvement in this weakness after rest is suggested by one historical account.

The differential diagnosis of Chief Opechankanough's weakness is discussed. The historical setting of this famous chief in Colonial America and Colonial Virginia is described, as well.

*Author information: Department of Neurology,  
University of Virginia Medical Center, Charlottesville.*

# *What I enjoy on a good day.*



**"Hitting the  
slopes!"**  
*Ian H*

Send your message or photo to

**Myasthenia Gravis Association of Qld Inc.**

P.O. Box 16, Mt Gravatt, Qld 4122 • Freecall: 1800 802 568

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