



Messages

MYASTHENIA GRAVIS ASSOCIATION OF QUEENSLAND INC.

APRIL 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

P.O. Box 16

MT. GRAVATT QLD 4122

NATIONAL FREECALL:

1800 802 568

ABN 92 055 613 137

Email: info@mgaq.org.au

Internet: www.mgaq.org.au

COMMITTEE MEMBERS

President

Carol BUCHANAN

Vice-President

Susan WHITE

Secretary

Ron STEPHEN

E: info@mgaq.org.au

Treasurer

Denise HANNAY

E: 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

PATRON

Dr Cecillie LANDER

Neurologist

Founder Member, of Brisbane

PRESIDENT'S REPORT

Welcome to another newsletter written in these very difficult, uncertain times. Despite the isolation, I hope that everyone had some joy bestowed on them over the Easter period. For those of us lucky enough to have the use of technology, a familiar face on a phone or computer screen can bring so much joy, particularly as the light at the end of the tunnel is not very bright so far. What a dreadful few months it has been with drought, bushfires, floods and COVID-19.

I would like to take this opportunity to praise and thank the amazing people on the front line and also those who have just carried out acts of kindness. I decided to phone one person per day to just see how they are going and have a chat. It is amazing just how many people we lose touch with because of our normally busy lifestyle and how wonderful it is to hear their voice and sometimes surprise at the end of the phone. I am sure that many of our members will be helping in a variety of ways and, if one of our family members is carrying out essential services, please say thank-you from the MGAQ.

Now we have our new Rules (Constitution) we do not have

to advertise for nominations for the Management Committee for 2020/21 until the July newsletter. However, please think about this in two ways – if you are interested in nominating or if there is someone you wish to nominate.

The management committee is very busy keeping in touch by phone, email and computer. At this stage, no future face-to-face meetings have been planned. Luckily, it is not a very busy time of the year but there are always things to be done or followed through so our work can continue.

One huge undertaking that has come to fruition is the eNID project. The coding work is complete and paid for and some of our recognised Australian neurologists are testing the functionality of the program. Please read the Myasthenia Alliance Australia News with interest as this is a very exciting step forward.

Stay safe and well, look after yourself and be assured that the MGAQ is there for you at the end of the phone, via the website or Facebook or through your regional co-ordinators.

Thanks, Carol

Supported by



Queensland
Government

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MYASTHENIA ALLIANCE AUSTRALIA NEWS

UPDATE APRIL 2020

THE eNID PROJECT

It is with extreme gratitude that the MAA can announce progression of the eNID Project to the testing phase. This means that the coding work has been undertaken for Version 1 and the key Specialists are exploring and fine-tuning the functionality. There is much hope for an April launch. This would then see the programme available for use by participating Specialists. We are very grateful to MSBase for continuing with this project and for providing the required data technology to make it happen. We are grateful to Dr. Katherine Buzzard, A/Professor Stephen Reddel and Dr. Stefan Blum for their keen interest in initiating and developing this opportunity for people affected by Myasthenia Gravis.

The MAA Board wishes to draw attention to the great contribution the MG Community has made in bringing about this outcome. When the initial call went out to raise \$40,000 for this project, supporters across Australia reached into their pockets with very few questions asked, and endorsed this project. This money was raised by the end

of the 2017 Conference. Encouraging support continued to be received from a handful of very generous donors. When MSBase confirmed that work could continue but with a changed financial proposition the MAA were able to respond very quickly and with a 'No Problem' response! We did not want this project to stall. With assistance from both the MGAQ and the MGNSW Associations, the requested funding was achieved and the cheques were sent in February 2020. The MG Community of Australia have contributed \$105,000 towards this invaluable project.

More updates will be provided as information becomes available. With so little research focused on chronic management of this condition, this database will allow clinicians to look for trends in their use of the available treatments and therefore bring enhanced patient care. We hope all Australian neurologists will be keen to participate.

Regards Susan White

Follow the work of the Alliance by registering at the website
www.myastheniaallianceaustralia.com.au

“

Community is much more than belonging to something; it's about doing something that makes belonging matter.

Brian Solis

”



WHAT'S NEW FOR THE MGAQ

Over the past couple of months we have discussed five series of new services, podcasts and vodcasts, to be delivered to members. For two of those series, namely **'My Journey with Myasthenia'** and **'Ask the Expert'** podcasts, *we need help from each and every member.*

The **'My Journey with Myasthenia'** series records the experience and learnings of members on their individual journey with MG. To enable us to record your journey and therefore help others, please contact the **MGAQ Helpline 1800 802 568** or **email our Podcast Team** at podcast@mgaq.org.au giving your name and contact phone number.

The **'Ask the Expert'** series is underway. It commenced last month with questions regarding speech, swallowing and related matters impacted by MG. We have received a host of great questions and our expert, Dr Kirstine Shrubsole, will be answering them this month. A podcast will soon follow.

The next specialists facing your questions will be a Neurologist and a Psychologist. So get in

touch and voice those questions either through your **Regional Coordinators**, on a **MGAQ Facebook** site, call the **MGAQ Helpline 1800 802 568** or send an email to info@mgaq.org.au

To deliver these new services, the MGAQ website has been rebuilt. It will be completed this month. Also, the new podcast delivery system will be implemented.

Members who have given the MGAQ their mobile phone numbers will directly receive the podcasts to those phones.

This will allow members the opportunity to listen to the podcasts at a time of their choice. This could be when sitting in your favourite chair or going for a walk.

... Remember, we need help from each and every member. Dr Podcast is waiting for volunteers who will share their MG Journey story. **Contact us!**



'Ask the Expert' podcast series

Send us your questions.

FreeCall **1800 802 568**

Email: podcast@mgaq.org.au



What I do on an Isolation Day!

Carol

Repotting Herbs



Let's see if we can get 3 pictures for May's Newsletter?

Karen

Music



Send your Isolation Day picture to:

PO Box 16, Mt Gravatt 4122, Qld or info@mgaq.org.au



MURIEL'S DID YOU KNOWs?

- 1. Australia has 19 World Heritage Listed sites
- 2. The country holds the Guinness World Record for the most amount of Christmas lights on a house - over half a million!
- 3. Australia's richest woman Gina Rinehart earns \$1 million every 2 hours
- 4. 91% of the country is covered by native vegetation
- 5. Australia invented the world's first seat belt law in 1970



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

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.

Joel writes...

I have a daughter, Linnea, who has MG and I'm happy to share her story.

It started off with a droopy eyelid back in December 2016. The GP thought it was just an allergic reaction. One week later when it got worse, we found ourselves in the emergency department of Monash Hospital, watching her whisked off to the MRI urgently, to see "if there was anything nasty in her brain".

When I look back it's ironic that it was with a great sense of relief that the neurologist arrived the next morning, did some tests, and told me she had something called "Myasthenia Gravis". Great, she did not have brain cancer. He wandered off shortly thereafter and said he'd be back tomorrow. What the hell is Myasthenia Gravis I asked myself? I thought she'd take a few tablets and be back to normal in no time. It was Christmas Eve, she was nine years old, and she wanted to make sure she was home in time for Santa. Only as the hours passed and I googled some more, the seriousness of the situation dawned on me gradually.

The next months were a blur of hospitals, tests, various treatments (including IVIG), worry and anxiousness. In a matter of weeks my daughter had gone from winning 5km fun runs, to not being able to see or talk properly or even walk

up a set of stairs. Many aspects of her life were affected including socially, school and psychologically. There was an emotional and financial strain on our family life as well. When I look back it dawns on me that out of all of us, I think Linnea was the strongest and bravest.

After a difficult period I'm pleased that, thanks to the treatments available and the doctors she's been lucky enough to see, that over three years later her health is good and her life has returned to a kind of normal. She has just started high school, is doing well with her marks and even playing a little sport. We keep our fingers crossed that long may it continue. I'm aware that not everyone is so lucky, but I also think it's important for us not to lose hope either.

Finally, I'd like to say that the support I received from some members on the MGAQ when she was diagnosed was invaluable. Hospitals and doctors can be a bit impersonal and although we got medical explanations, it was really difficult to know where to turn to for practical advice and support. A couple of people in particular took the time to call and talk to me when I needed it most. They gave me their experience, suggestions and practical ideas that the doctors couldn't or wouldn't.

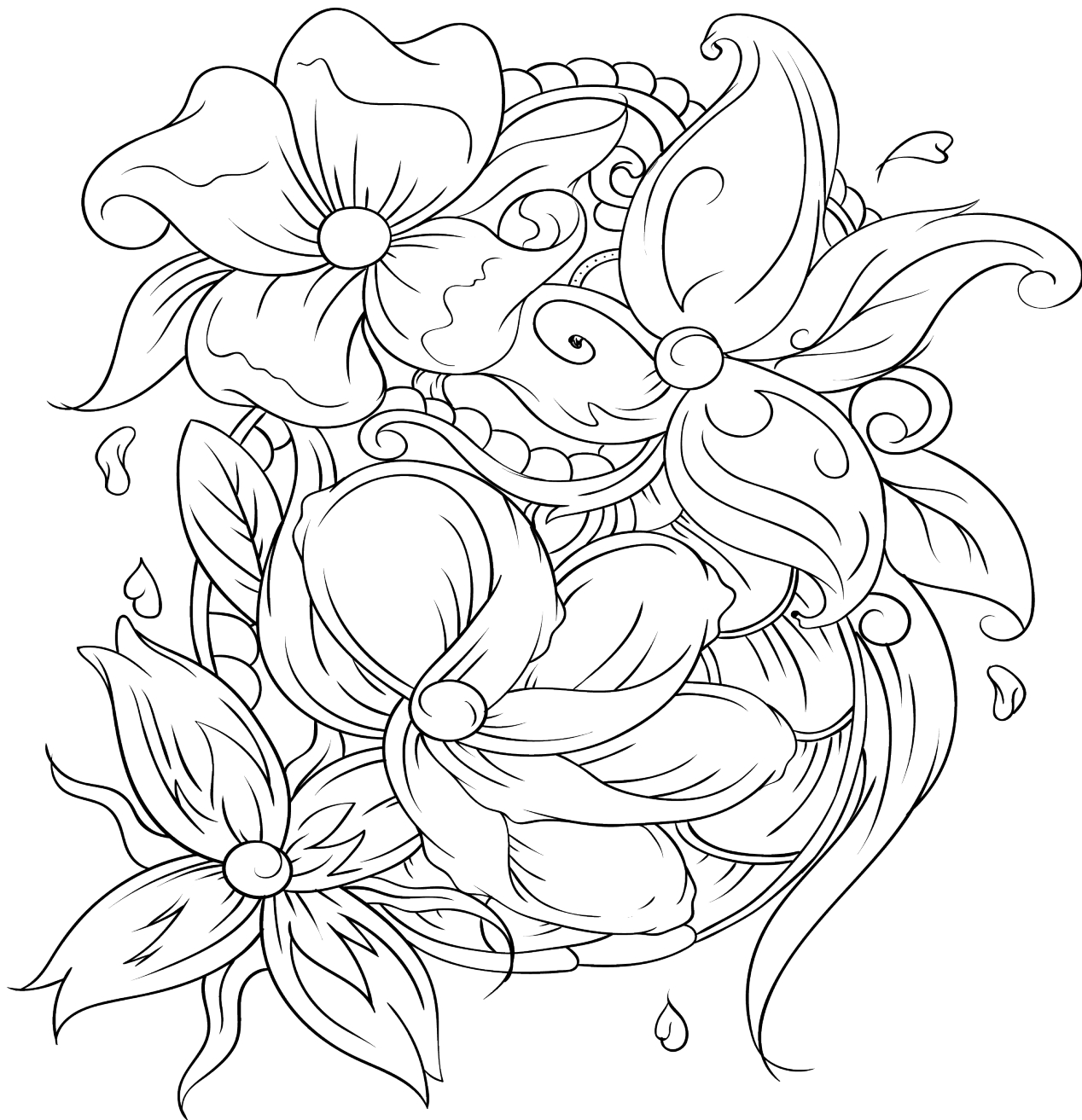
Joel is one of the Admins on the Myasthenia Gravis Australia Parents & Grandparents Facebook page.

Myasthenia Gravis Australia Parents & Grandparents



COLOUR-IN TO WIN

Colour-in the picture and have a chance to win a **Woven Wall Hanging** courtesy of Denise. Take your pick, or Denise will create one in the colours to suit you! **Entries close 30/5/2020**



Send your entry to:

PO Box 16, Mt Gravatt 4122, Qld or send to **info@mgaq.org.au**

(A photo of your entry is also accepted)

Name:

Address:

.....

Telephone: Post Code:



Myasthenia Gravis Association of Queensland Inc.

JUNE MEETING

Because of the social distancing restrictions, the June MGAQ Members' Meeting will still go ahead using technology instead of face-to-face.

We have organised a *Guest Speaker, Dr Angelo Contarino, Clinical Psychologist*. His talk is **"My Metropolis Journey with MG"**. He will present via zoom webinar and there will be the facility for participants to ask questions of the presenter.

Please try to be involved with this interactive session if you have access to a computer and are a financial member.

The presentation will also be videod and sent out to all financial members in the usual manner.

Watch out for further information in the May newsletter.



June 2020

International Myasthenia Gravis (MG)
Awareness Month

June 8 & 9, 2020

With Queensland taking a particular focus on 8 June.

International Myasthenia Month aims to raise awareness about this rare auto-immune disease.

Brisbane is contributing to MG Awareness Month, with the Brisbane City Council lighting up both the Story Bridge and the Victoria Bridge in the Teal colours of recognition.

This will occur on the evenings of 8 and 9 June 2020.

NEWS FROM AROUND QUEENSLAND

News from Cairns

I hope you are keeping well in these times of uncertainty. Although the face to face catch ups have been cancelled until further notice, please feel free to pick up the phone and call me if you would like a chat.

For local support in the Cairns region, please contact Donna on 0414 397 462 or donnaformosa64@gmail.com

News from Townsville

For details contact Daphne on 0400 778 637 or 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

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

News from the Gold Coast

Hi Everyone. Hoping this finds you well. I am sure that you would have already noticed that we are in a grip of deadly Corona virus. Given anyone that would likely attend are vulnerable, the Committee decided to cancel all Coffee and Chats and Regional get-togethers for March and April with a review after that.

At this stage we can't organise our next meeting, I will inform you as soon as we know. Of course you are welcome to contact me for a chat during this difficult time. I hope that you are keeping yourself safe. Kind regards, Nader.

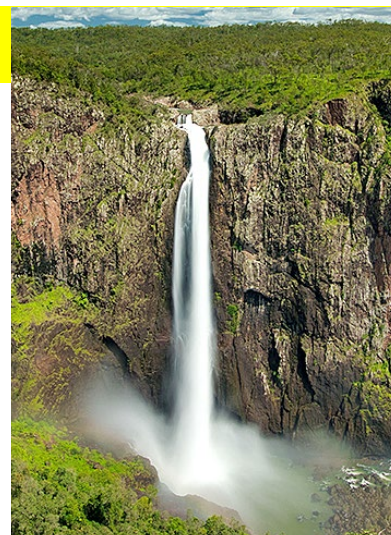
For more information on the Gold Coast group, please contact Nader on 0415 834 401.

News From Brisbane

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



For more information,
Contact Anita on 0414 588 312



WHERE IN QUEENSLAND?

MARCH: Lizard Island

Let us know where you think it is:

Send to: info@mgaq.org.au
or post to MGAQ, PO Box 16,
Mt Gravatt, Qld, 4122

If you
would like a chat,
pick up the phone
and call your
local regional
Coordinator.



Welcome to our new members

Brian E, Mannum SA
Kevin D, Denmark SA

Sharon S, Leppington NSW
Dianne M, Eight Mile Plains Qld