



Messages

MYASTHENIA GRAVIS ASSOCIATION OF QUEENSLAND INC.

OCTOBER 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

What a wonderful experience we had with using Zoom to allow members from near and far to join our AGM and the wonderful presentation by Dr Kirstine Schrubsole which followed. While many people who would normally travel from within the Brisbane area joined, we also had people from all over Queensland, most other Australian states and even New Zealand. The total number of 30 was outstanding and those who joined really embraced the technology with some even managing to post questions for Kirstine during her presentation which she kindly answered at the end of her talk.

It is very pleasing that we have a full complement of members for our executive committee. The work of the association now involves both social aspects and political agendas that are of vital importance to acquiring the best outcomes in terms of quality of life for our members. Our work with the National Alliance Australia is an integral part of this ongoing advocacy.

Christmas is approaching quickly with the shops overflowing with decorations, toys and

well-advertised gifts for one and all. We are still hoping that people can come together for our usual Christmas lunch but, at this stage, we just have to wait and see what eventuates. The association will keep everyone informed.

A new project aimed at young people under 18 years of age who have Myasthenia Gravis is the "My MG Journey" competition. There are some great prizes on offer and the association has deliberately made the closing date well after the Christmas school holidays. So, if you qualify or have a child in that age group we urge you to peruse the information and have a think about what you can produce. A covering letter and the poster will also be forwarded to neurologists. Our young people are the future of this organisation and having them tell their story and also be a part of the youth forum will greatly benefit both themselves and others.

There is more information about the competition on page 3 of this newsletter.

Thanks, Carol

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MYASTHENIA ALLIANCE AUSTRALIA NEWS



MAA UPDATE

Dr Stephen Reddel, of the MAA Medical Advisory Board, has flagged the need for anybody who has previously had or currently has a thymoma to take extra care protecting against exposure to COVID 19 as they may be more seriously affected. The following relevant article is technical but included here for reference:

<https://science.sciencemag.org/content/early/2020/09/23/science.abd4585>.

For people who have had a thymoma, it is recommended that you keep this reference handy and share it with your treating doctors should you become infected with Covid 19. Your doctors will seek out the required understanding in regard to the references in this paper. Please continue to take the necessary government recommended steps to assist in avoiding contact with the virus.

For further conversation please contact Susan on 1800 802 568.

New website address for the Alliance

The MAA website remains unchanged but the hosting has been shifted to a new address. Whilst there is an email redirection visible with the old web address, it would be great if members could open the new address and save it to their list of favourite addresses.

Please go to www.myastheniaalliance.org.au

**Follow the work of the Alliance by registering at the website
www.myastheniaalliance.org.au**



TAKE THIS 1 MINUTE SURVEY TO FIND OUT!

- Question 1.** Do you have AChR+, mild to moderate Myasthenia Gravis and your regular treatments DO NOT include IVIg or PLEX.
- Question 2.** If you answered yes to Question 1 please indicate if you would be able to access the Princess Alexandra Hospital at Wolloongabba Brisbane.
- Question 3.** If you answered yes to Questions 1 & 2, would you be interested in the opportunity to receive the drug Sartalizumab as part of a clinical trial to treat MG? This drug is an IL-6 related medication. IE> it is a humanised monoclonal antibody that targets IL-6 receptors.

**Please participate in the Survey by visiting www.mgaq.org.au or call MGAQ 1800 802 568
Further information will be made available if the trial gains enough support to proceed.**

ARE YOU UNDER 18?

In 2021, the MGAQ will celebrate 30 years supporting people with Myasthenia Gravis in Queensland as a volunteer Association.

As part of our celebrations, we are offering our YOUNGER PEOPLE a competition to help raise awareness by telling a story about their journey with MG.



THE COMPETITION IS OPEN TO THREE AGE CATEGORIES

Junior (5 to 8 years); Primary (9-13 years); Young Adult (14-18 years).

There is a prize of \$500 for the best entry in each age category plus consolation prizes.

Entries open 1 December, 2020 and close 10 March, 2021.

For more information download flyer from

<https://tinyurl.com/y4xavcfx>

Email: info@mgaq.org.au or Freecall 1800 802 568.



MGAQ Inc. podcast series

UPDATE

"Greetings" and welcome again to another update on the MGAQ's new podcast service. Currently MGAQ Podcasts have eleven podcasts available for Association members to listen to.

This coming month we have one further podcast to be published. This podcast, **Episode 12** which is to be released on **November 4th**, involves a conversation with a member whom has suffered from not just one auto-immune condition but three, her journey and how she has managed what MG and the other conditions have presented. It is a wonderful story and again shows the level of strength and resilience within our membership community.

Also, please remember, if you are a member who would like to join this service but are not quite sure what is required... help in connecting up is available.

Just contact Dr Podcast at: podcast@mgaq.org.au

MGAQ Videos and Podcasts AVAILABLE NOW via the MGAQ Website

A wide range of informative Videos, Podcasts and Journals items can now accessed by visiting the **'members only'** section of the MGAQ website at www.mgaq.org.au/members-only Once you have access to the members-only area, you'll be able to view, listen or read on your smart phone, iPad, tablet or PC.

All members will need a username and password to login and access the members only pages. Financial members can request a password by visiting www.mgaq.org.au/user/register and completing the online form.

IMPORTANT: Please be sure to use an email address that is known to the MGAQ. This will allow us to verify that it is indeed you that is making the password request!

As the MGAQ website is administered by volunteers, please understand that it may take a little while to receive your login credentials via email.

Follow up with info@mgaq.org.au if you don't receive your password within a week or so.



MURIEL'S DID YOU KNOWs?

- Melbourne was the capital city of Australia for 26 years between 1901 and 1927 before the capital shifted to Canberra
- There are three times as many sheep than people living in Australia
- The Australian Emu – a large, flightless bird – can run as fast as 45km/h (28mph)
- Platypus are highly poisonous, and have enough poison to kill a dog or make a human seriously ill
- The Box Jellyfish – which is found in the waters of the Great Barrier Reef – is responsible for more deaths than snakes, sharks and saltwater crocodiles combined

MG Gold Coast Group Get-together Saturday, 19 September



The MG Gold Coast group had their get together sharing experiences with other members on Saturday 19th of September at Kurrawa Surf Club.

Our next meeting will be at 10am on Saturday 28th of November at Southport Sharks Club. I hope to see all there. Kind regards Nader Amiri (Gold Coast Co-ordinator).

Nundah Get-together

Roslyn, Amanda,
Clive, Anita and
Karen.

And Trevor our
photographer.



Hello all, I would like to introduce myself as the new Sunshine Coast Co-Ordinator for the MGAQ Coffee and Chat mornings.

Firstly, I would like to thank Colleen McLean for all the tireless work she has done as the previous Co-Ordinator of this wonderful group. I hope I can live up to her wonderful reputation and dedication.

I was diagnosed with MG 9 yrs ago in Victoria and it's certainly been a journey. My husband Alan and I have recently moved to the Sunshine Coast for retirement. Alan, who is my carer usually joins us for the coffee and chat mornings, so it will be nice to get some men along to join the group and have a chat.

As yet the next coffee and chat morning has not got a firm date, however it will be on a Monday in early Dec at 1030am at the Kawana Bowls Club.

Feel free to contact me for a chat on **0411 146 898** or email avlplummer@bigpond.com

Regards, Vicki



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.

HANDY TIPS FROM OUR MGAQ CARER MEMBERS

Judy writes: “With Myasthenia Gravis, the journey of providing extra support can start from the start of symptoms, not just diagnoses. In fact, a lot of extra support is given before diagnosis because the unknown cause of the symptoms mean that carers are the only ones providing treatments and trying their best to help their loved one feel OK. The unknown also means fighting for answers, fighting through the web of the medical jargon, protocol and timing; a fight where you wish that your person will be taken seriously, listened to and heard, hoping one medical practitioner will eventually request the right test or click onto the things that are happening. Sometimes the carer is the only other person to understand, or in some cases believe, what is happening because they see even the smallest changes. Because of this, the kinds of support end up being physical, emotional and in some cases financial if the symptoms have prevented the warrior from working”.

Judy

Linda writes: “The highs and lows of being a carer...My Warrior is a very patient, loving man who blesses me with his gorgeous smile every day. Some days it takes a bit of work to get that smile, but it's worth it. He covers his frustration of not being able to do what he used to do, his lack of enthusiasm for day to day activities, his chronic fatigue, his apathy with coping now he has Parkinson's, and this week the stunned realisation of bladder cancer. His poodle Barney Boy is his close companion and of course the love of me, his carer and soul mate. We do enjoy each day and every day is a delight”.

Linda

Toni writes: “Carer's Your Wellbeing is just as Important! It is all too common for Carers to put the needs of their loved ones above their own even when it impacts on their own health and wellbeing. It's of great benefit to both yourself and those you care for to take time to look after yourself. You can't pour from an empty cup. Fill your cup in order to be able to fill someone else's cup. Caring takes an equal toll on both levels emotionally and physically. I feel the emotional toll is sometimes ignored because we don't want to be seen as not coping. IT'S OK for you to look after yourself. When you are physically and mentally healthy you are able to provide care and also keep caring longer. Your body will provide you with little subtle warning signs that you need a break. If these signs are ignored your body will make you listen. For me, if I keep pushing and ignoring the signs I end up with a migraine which puts me to bed and I am no good to anyone. Taking care of yourself everyday can include having little breaks, doing something that's just for you that ignites you. Did you know 1% of your 24hr day is just 14mins. Is there 1% of your day you can spend investing in your own self care? Know your limits and don't push beyond them, however much pressure there is to be the perfect Carer”.

Toni

The MGAQ would like to acknowledge and thank our Carers during National Carer's Week 11-17 October 2020

AGM ZOOM FEEDBACK

"I would encourage any members of the MGAQ community to join in on future zoom meetings. Living in Victoria and unable to attend meetings, I have found it an invaluable and simple option to connect to Zoom. Being a "dinosaur with technology", I found it easy to connect to! The meetings are informative and it has been interesting hearing from guest speakers addressing various issues with mg.

For those not current members, I would also encourage you to join. The yearly MGAQ \$20 membership for those with mg provides additional privileges including informative podcasts, etc. Please refer to the website or contact the Association on 1800 802 568 for further information ."

Pauline

"I live in Victoria and although we had a couple of weeks of stage 4 lockdown to go I together with others from SA, TAS and WA attended the AGM using Zoom. This was followed by a short talk by one of the members, a speech pathologist who explained some of the difficulties people have with talking and swallowing. It was both heartening to put faces to the names we regularly see in this newsletter and reassuring to hear of the work that is underway to make our lives easier.

To join the meeting was simple

- About a week before the day I advised the office **info@mgaq.org.au** I wanted to join in and waited for instructions which arrived a couple of days before the event
- I loaded ZOOM onto my device,
- a few minutes before the start time I clicked on the link provided by MGAQ, followed a few prompts and I was connected

If you do not want to connect using a device call 1800 802 568 and arrangements can be made for you to join in by phone.

Have a go it is easy."

Tony, Vic.



Welcome to our new members

Kristie, Eatons Hill

QLD

Cheryl, Habana

QLD

news from around Queensland

News from Cairns

We are back and will be meeting once again on **Saturday, 24 October at 11am at the Cairns RSL Club, Esplanade.**

It would be appreciated if you could RSVP your attendance so that we can abide by the venue's covid restrictions.

For more information or to RSVP please contact **Donna on 0414397462** or donnaformosa64@gmail.com

News from Townsville

We had a wonderful gathering in August and am looking forward to our next lunch at **The Avenues Hotel, Kirwan on Saturday, 17 October at 12 noon.**

To RSVP, contact **Daphne on 0400778637** or daphclay@gmail.com

Note: Incorrect date advertised in August newsletter.

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

Call **Vicki on 0411 146 898** or email avlplummer@gmail.com

News from the Gold Coast

Hi Everyone. The MG Gold Coast group had their get-together, sharing experiences with other members on Saturday, 19 September at Kurrawa Surf Club. Our next meeting will be at **10am, Saturday, 28 November at Southport Sharks Club.**

I hope to see all there. Kind regards, **Nader Amiri, Gold coast Co-ordinator, 041 “5 834 401.**



Mackay Harbour

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**



Brisbane - Coffee & Chats

Please contact **Anita on 0414 588 312.**

what's
coming
up

What's On	When Is It	Where Is It?
MGAQ CHRISTMAS FUNCTION	Sunday 13th December 2020	SANDSTONE POINT HOTEL BRIBIE ISLAND

Please note that due to COVID-19 the MGAQ committee will determine if this event will change closer to the time.