



Messages

MYASTHENIA GRAVIS ASSOCIATION OF QUEENSLAND INC.

NOVEMBER 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.

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PRESIDENT'S REPORT

It is hard to believe that the year had nearly come to an end and the next newsletter will be the last for 2020.

NOTE: CHANGE OF VENUE

Do not forget the MGAQ Christmas Lunch that will be held on Sunday, 13 December at the REDCLIFFE RSL, Irene Street Redcliffe. Please RSVP by Tuesday, December 8 to Susan on 1800 802 568 so we can let the venue know definitely. It would appear that, at this stage, the event should be able to go ahead with strict COVID restrictions in place. We hope to catch up with as many people as possible at this event. More details are available on page 4 of this newsletter.

At our Annual General Meeting the Annual Report for the MGAQ was presented. This report, along with the Myasthenia Alliance Australia Annual Report from Susan White, will be sent with next month's newsletter. If you receive your newsletter by email, it will come as a separate attachment. If you receive your newsletter by mail, it will be sent in a separate envelope. Please keep an eye out for these reports and take the time to read how the dedication and commitment from members of these two groups has led to

some very exciting and worthwhile results. Please also note how the MGAQ and MAA work very closely together with our key priorities.

Denise, our treasurer, is still trying to find out if people who are not up to date with their membership still want to remain as financial members of the MGAQ. If you receive any inquiries from her about this, please take the time to either reply to her email or phone the 1800 number so that she can make the appropriate changes.

While the association is still conducting its meetings via Zoom, the feedback from Queensland Health when several representatives from the association spoke with them about our key projects and activities was very, very positive. So, while we are not meeting face to face, we are still managing to keep the work of the association at a high level. I think our break over Christmas will be well deserved.

Please note Tips from Dr Johan Kuyler on page 6 which we hope you will keep as a permanent resource.

I hope that everyone is getting themselves and their families organised for Christmas so that you all can spend some quality time with loved ones.

Thanks, Carol

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MYASTHENIA ALLIANCE AUSTRALIA NEWS



MAA UPDATE

2020 has been no exception for the MAA. It has again been a very busy and very productive year. Hopefully an annual report will be published in the December

newsletter summarising the wide variety of activities which have been progressed this year. At the recent Board meeting, we took the time to reflect on the current trends in research opportunities and how the MAA is currently able to respond.

We feel that there is much new discussion around research into MG both from the Doctors and from Allied Health Providers. Researchers can be reluctant to take up a project involving a small community, as found in rare disease, as the project may fail or not have the impact hoped for due to the limited number of participants. The fact that we are attracting more conversation is very exciting and is a direct result of the Australian MG Community's willingness to respond. For this, **our sincere and heartfelt congratulations are offered to everyone who supports the work of the State Associations and the MAA.**

A key facilitator in engaging researchers has been the surveys run through the Associations

and the MAA. These outcomes have provided insight and potential which are vital to developing more major projects.

The Board considered the current process and the capacity to develop this encouraging trend further. We feel that there is much work to be done to develop research support from, and communication with, MG sufferers in Australia. We understand that surveys can play a vital part but participants will ultimately fatigue if this tool is over used. In 2021, when we are hopefully refreshed, the Board is keen to look into a more defined registration system inclusive of understanding individual's appetites and abilities to participate in a variety of research possibilities and locations.

As the Board is fully volunteer run, with three of the six MGers working full time, enlisting some talent to help us with the ever expanding demands seems sensible. If you or your family can help, please do reach out to us.

The MAA Board thanks our readers for their on-going support and for their patience as we grow our skills, capabilities and opportunities.

Susan White - Chairperson

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

Potential Clinical Trial Questionnaire - Feedback!

The South East Queensland MG Community responded very promptly and, where possible, with enthusiasm to the questions in the October newsletter. Our positive feedback has prompted the Doctors to progress this opportunity by requesting to be considered as a study site. Not much more will happen regarding this before Christmas with site selection to start early next year. The earliest time for a trial start will be mid 2021. The MGAQ will be kept updated.

Thank you to our enthusiastic MGAQ membership! Your efforts have given us a chance for a new opportunity.

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 podcast service. Currently MGAQ Podcasts have twelve podcasts available for Association members to listen to. This coming month we have one further podcast to be published. This podcast, Episode 13 will be released on December 16th and it is indeed an early Christmas gift. The podcast involves a conversation with Dr Johan Kuyler. Dr Kuyler is a neurologist based in Bundaberg and with 75 patients who suffer from Myasthenia Gravis, he is very experienced with this condition. The focus of the discussion with Dr Kuyler is on the question of how do patients who don’t live in the capital cities close to the major research based, large public hospitals get the very best treatment that is possible. Given Dr Kuyler’s experience with MG, the talk provides a host of suggestions for any MG sufferer to think about and action to get their very best personal outcomes. The MGAQ Executive committee was so impressed with Dr Kuyler’s suggestions, this newsletter includes a specific set of recommendations called 'Dr Kuyler’s Tips' for all of us to consider and action. We do hope you enjoy this information packed conversation.

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

Alternatively, you can access the podcasts via the members area of the MGAQ website.

You are invited to the
**2020 MGAQ Christmas
Function**
Sunday, 13 December
11.30am for 12 noon
Redcliffe RSL,
Irene Street Redcliffe
R.S.V.P. Tuesday, December 8 - Susan
Freecall 1800 802 568

**NOTE
CHANGE
OF VENUE**

CLOSED slack COMMUNITY OPEN TO MG SUFFERERS AGED 18-35 ONLY



YOU DON'T HAVE TO BE A MGAQ MEMBER TO JOIN!

- Specially created to meet the needs of this younger group who are thinking about careers, relationships, making a family, travelling etc.
- Discussion to be guided by the participants and supported by the Doctors.
- Find this group via the mgaq.org.au home page and look for the link under **SOCIAL INTERACTION**

Find this group by emailing info@mgaq.org.au for access.

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.

Tips from Dr Kuyler: How to get your best possible medical outcome with MG.

Dr Kuyler is a trained Neurologist (MBChB, FRACP) based in Bundaberg with extensive experience in Myasthenia Gravis.

Treatment success requires a 'Team Effort' from the Patient, Doctor(s) and any incorporated Allied Health support services.

For the Patient, the requirements should include:

1. **Taking an active responsibility** for their treatment.
2. **Not waiting** for their doctor to ring regarding your blood test results. Instead follow them up directly and seek clarification on any issues arising.
3. **Always carrying with you:**
 - A comprehensive list of your known medical conditions and symptoms.
 - Details of your current medications (including supplements), the dosages you take and any medication combinations you employ.
 - Details on any known allergic response or side effects to the drugs you take or have previously taken.
 - For some patients, especially those at risk of a Myasthenic Crisis, a doctor's letter (which your specialist can provide) that sets down the nature of your condition and what actions medical professionals (eg paramedics or emergency staff) should take in the event that you become unwell quickly.
4. **Maintaining a personal record** which details:
 - What are your symptoms.
 - When do you have the symptoms eg when you wake up, when your next treatment dose is due etc.
 - How long does it take for your medication to take effect.
 - How long before the next medication dose do symptoms return.
 - Any associations/interactions between different medications (or supplements) including what happened, when it started and what did you do.
 - If you have been diagnosed with other symptoms (eg blood pressure) or conditions unrelated to MG (eg diabetes)
 - If you are having intravenous (IVIG) treatment, when are the symptoms coming back (eg 1, 2 or 5 etc days before the next treatment). Is there a consistent pattern?
 - Any significant changes in daily behaviour (eg diet, exercise).
 - Any new treatments or medications you have started since your last Doctor's visit.

Note: The use of a diary or a calendar can be a very effective means of recording the patterns of symptoms or behaviours in relation to the medications or treatments you have, as noted above.

The above details are important to your Doctors. They need this information to ensure your best possible treatment plan.



Myasthenia Gravis Association of Queensland

1800 802 568 | www.mgaq.org.au | info@mgaq.org.au

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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.

Megan writes:

TOP TIPS FOR LIVING WITH MG

I recently posted a question on the MGAQ discussion group, seeking feedback on any life hacks people would like to share to make life easier. The following is a summary of the tips and tricks collated from my own experience, plus comments on the Facebook page; hopefully they will be helpful to others!

1. GADGETS:

- Electric toothbrush – this has been a game changer. I used to have to sit down to brush my teeth and then have a rest afterwards, from the combined effort of holding my mouth open and brushing vigorously. Electric job = much easier and less tiring.
- Mini food processor – makes it much easier to cut up vegetables and cuts down the exhaustion caused by meal preparation. It is also useful to blend soup – chop up vegetables for soup, cook then blend it in the processor and freeze in batches. This means there is healthy food available for days when it's too tiring to either prepare food or chew.
- Waist height clothes drying rack, the kind that folds up and can be stored away, plus a low table for the laundry basket. I found hanging laundry above my head height was tiring and my arms felt like lead. Hanging it on a waist-height rack and picking up wet clothes from a table, instead of bending down to a basket on the floor, is much less demanding.
- A jar opening thing from the arthritis foundation, because I have a grip strength problem when I'm really fatigued.
- Garden secateurs with a spring-loaded handle. I love my garden but can't use any tools that require brute strength. Expensive trimming tools that cut down the energy required to squeeze them, have been sanity-saving.
- If you have one on tap – use a nearby teenager to do all of these jobs, haha. That's even easier again. Personally, I need to plan ahead to accomplish this; while mine are willing to help, they aren't always home when I need them. But I do try to remember to ask for help when it's possible.

2. CLOTHES AND SHOES:

- Slip-on shoes – save energy by not having to tie shoelaces
- If you can't or don't want to wear slip ons – shoes horns are pretty useful to help get your feet into shoes
- Choose stretchy, comfortable clothes that are easy to get on and off
- Sitting on a dressing stool (lower to the ground than a standard chair height) really is helpful to avoid wasting energy while putting on socks, shoes and underpants.

3. MOVING AND GROOVING OT-TYPE TIPS:

- Kitchen trolleys or a walker are useful to carry/move heavy items around the house
- Slide heavy pots along a heat-proof bench instead of lifting
- Half fill the kettle – it weighs less!
- Rest heavy pots on the edge of the sink while draining, and use a colander
- Make meals that don't require stirring, or invest in auto-stirring cooking gadgets like a Thermomix
- Plan cooking/meal preparation ahead of time. It may be helpful to cook meals that can be prepared when you have the energy, store in the fridge and reheat later.
- Arrange home delivery of groceries or click and collect to avoid having to lift heavy items multiple times.
- If this isn't an option, shopping more frequently for a smaller number of items may be easier than trying to do a large grocery shop.
- Think first – what exhausts you the most? Work out how long you can perform that task, and rest before you get too tired.
- Yes, temperature really does make a difference to how you feel. You aren't imagining it. Plan your activities for the day according to the weather and layer your outfit to keep cool or warm.

RSVP ARE NOW REQUIRED FOR ALL FUNCTIONS DUE TO COVID-19 RESTRICTIONS

news from around Queensland

News from Cairns

Our final get-together for 2020 will be held on the **Tablelands, 11.30am on Saturday, 5 December at Gallo Dairyland, 9E Barron Road, East Barron**. All are welcome to attend and need to RSVP.

For more information or to RSVP please contact **Donna** on **0414 397 462** or donnaformosa64@gmail.com

News from Townsville

The Townsville MGAQ Christmas Lunch will be held on **Saturday, 28 November, at The Avenues Hotel, Kern Bros Drive, Kirwan, Townsville, 12 noon**.

If you'd like to be part of the secret Santa gift exchange please bring a gift to the value of up to \$20.00. Family and friends are welcome and are welcome to join in the gift exchange. Looking forward to your company. Please RSVP email: daphclay@gmail.com or text: **0400 778 637**.

For more 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

The next Sunshine Coast coffee and chat will be held on **Monday, 7 December** at **10.30am, Kawana Bowls Club, 476 Nicklin Way**.

Hope to see you all there. Call **Vicki** on **0411 146 898** or email avlplummer@gmail.com

News from the Gold Coast

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**.



WHERE IN QUEENSLAND?

Last month:

Charters Towers

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

Toowoomba, Wednesday, 16 December at 10.30am

Picnic Point Restaurant, 164 Tourist Road

HOPE TO SEE YOU THERE!

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



Welcome to our new members

Daniella,
Richmond,
SA

Merle,
Manoora,
QLD

Barbara,
Gold Coast
QLD

Deborah,
Warwick
QLD