



Myasthenia Gravis Association of Queensland Inc

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Messages

MYASTHENIA GRAVIS ASSOCIATION OF QUEENSLAND INC.

NOVEMBER 2019

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.

PRESIDENT'S REPORT

One more month and we will be into Christmas mode even though it seems the shops have had Christmas displays for quite a while now.

Do not forget the
MGAQ Christmas Lunch
that will be held on
Sunday, 15 December at
Southport Sharks Club,
Olsen Ave &, Musgrave Ave,
Southport Qld.

We hope to catch up with as many people as possible at this event.

Please RSVP to Susan on
1800 802 568 so we can let
the venue know possible
numbers.

It is fantastic that we now have a full complement of members of the management committee. Our updated Rules (Constitution) which were accepted at the AGM have been forwarded to the Office of Fair Trading and the Australian Charities and Not-for-Profit Commission for ratification. The work of our association continues to grow along with that of the Myasthenia Alliance Australia. I hope that

members took the time to read the reports from the AGM booklet to get a full appreciation of the scope of projects and activities currently being undertaken.

Thanks to Dr Blum working in conjunction with the MAA (Myasthenia Alliance Australia), the new guidelines for "Drugs to be used with caution in Myasthenia Gravis" has been produced. All financial members will have received a hard copy as part of the member services from the MGAQ. Please think about keeping a copy of this pamphlet with your medical paperwork.

The management committee is still looking for a venue to hold its monthly meetings. If anyone is prepared to offer their home eleven times a year or knows of a venue we could use free of charge, **please phone Susan on 1800 802 568** and chat to her about it.

Hope as many people as possible come to the Christmas party. Apologies from me as I am incapacitated.

Thanks, Carol

The Committee greatly appreciates the generosity offered by both Anita and Donna as they work to bring people together via the Coffee and Chat programme.

Sharing experiences and building friendships in this informal way is proving to be highly valued.

Supported by



**Queensland
Government**

Ausenco



MYASTHENIA ALLIANCE AUSTRALIA NEWS

The MAA Committee remain very active and focused on the following projects.

- Rituximab and the PBS
- Improved patient access to Plasma Exchange Therapy
- The eNID Project
- Website enhancements
- Supporting Research
- Post Conference conversations
- Developing awareness at a Federal level.
- Supporting State Association initiatives.

Regards, Susan

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



You are invited to the 2019 MGAQ Christmas Function

Sunday, 15 December - 11.30am for 12 noon

at Southport Sharks Club, Olsen Ave & Musgrave Ave, Southport QLD 4215



R.S.V.P.



Tuesday, December 10 - Susan

Freecall 1800 802 568 - E: info@mgaq.org.au



COMPETITION

**LAST
CHANCE**

“Tell us about your unexpected highlight from attending the 3rd National Myasthenia Conference!”

This competition is open to everyone who attended the conference. All attendees will be notified of this opportunity.

The prize offered by Enjo Australia, Conference Sponsor, in conjunction with the MGAQ is an Enjo Kitchen Bundle valued at \$179.00.



Please write a response to this question and submit it to **info@mgaq.org.au** or post to

PO Box 1287, New Farm 4005 by 10 December, 2019.

No minimum or maximum length is suggested.

A condition of entry is that your item may be used in the Members' Forum section of the MGAQ newsletter.

The winner will be selected by Lara Hudson from Enjo.

The closing date is 10 December and the prize will be posted in time to be a Christmas treat!

MAA MYASTHENIA CONFERENCE ATTENDEE HIGHLIGHTS



The unexpected highlight was just how damn good it was. It's remarkable how far things have come in Oz with the MAA. Or should I just have expected that!
Cheers, **Stephen Reddel**



My highlight was the discovery of Enjo cleaning wipes. Use them all the time now.

Rosalyn





Myasthenia Alliance Australia – Conference 2019

Break-Out Session from the MAA Conference



Tahlia Alsop
UQ Physiotherapist
and Researcher

Keeping Active is Important to your Mind and Body

Tahlia explained, ***“Keeping active is important for your mind and body and is associated with a wide range of health and wellbeing benefits that can lead to a longer, healthier and higher quality of life. However, physical activity can be challenging when also managing Myasthenia symptoms”.***

This session aimed to address the what, why and how of physical activity in the context of Myasthenia Gravis.

Some of the topics covered included:

- What is physical activity and what are the benefits?
- How much physical activity should I be doing and how can I fit it into my lifestyle?
- How can I make sure I don't make my symptoms worse?
- What is the evidence for movement in people with Myasthenia Gravis?

Tahlia highlighted that lack of physical activity has a similar effect as smoking and obesity and is the 4th leading risk for mortality.

Physical Activity involves:

Incidental Activity – Everyday activities such as walking, gardening, making the bed and carrying the groceries.

Deliberate Activity – Planned Exercise

Sedentary Activity, sitting, lying down, not moving including watching TV.

Tahlia showed graphs of the changes to life longevity for being more active. Just by increasing our physical activity, we can increase our life expectancy.

Limitations to exercising with Myasthenia:

- Those imposed by the illness itself
- Results of complications from MG
- Consequential issues resulting from therapies employed.
- Cycle of deconditioning, fatigue, fear of exacerbation.
- Lack of support and encouragement.

Fatigue leads to task overload and participation. However exercise/movement reduces fatigue, increases strength and improves functional mobility.

Achieving Activity Goals –

- Exercise should be safe and include balance training, strengthening movements and aerobic training as is possible.
- Achievable tasks should be chosen.
- Pace yourself, build up gradually and most importantly; listen to your body, stopping/ changing muscle groups before fatiguing.
- Perhaps do it with others, make it enjoyable.
- Consider your environment- eg weather conditions: if it is hot exercise mornings or night or in air conditioning.
- Seek professional help with a physiotherapist or exercise physiologist.



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.

Denise writes

After listening to Physiotherapists, Tahlia and Kristen, at the Conference, I was motivated to do something about my own fitness, (or lack of it) as I have had a few nasty falls in the last year, and my movement and flexibility have certainly been a huge concern for me.

There is only 1 physiotherapy centre in Bundy that offers Clinical Reformer Classes (it isn't called Pilates anymore), and a real surprise was that the physios are all familiar with MG. They have been great. I had a one on one session to be assessed and

the Physio showed me how to breathe and explained why this is important. Next I was shown what to do and how to use the equipment. The Physiotherapist also designed a personal programme for me that I can handle. I had a Care Plan arranged by my GP and have received 5 subsidised visits as a result. My classes have a maximum of 6 people. We each do our own programme.

I have done 4 sessions now (plus some things at home), and I thoroughly enjoy it and I am starting to feel better for it. My balance has improved.

Read Terry's Forum story about his first Coffee and Chat - Next page



Myasthenia Gravis Friends Western Australia Coffee & Chat

Contact Edna on 0418 957 758

**Sunday, 17 November
at 2pm**

**Rossmoyne Waters,
Pelican Room**

(Located on ground floor))

**Freeman Drive,
Rossmoyne**

Position Available

To support the MGAQ Organisation

Meeting Host - Make a home available to host the monthly committee meetings. Meetings held every 2nd Saturday of the month (except January) from 8.30am-2.30pm. Requirements include 35 minute access to airport, landline facility (no significant costs), reasonable parking access. Not necessarily a Committee person. Back-up venues available if needed.

To register your interest or find out more, contact:

Freecall:

1800 802 568

Email:

info@mgaq.org.au



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Terry writes

“Are we at the right place?” we asked ourselves. My wife Yuriko and I were walking from table to table, looking for people who have MG. That's one thing you soon learn, we don't look very different to most people. I had read about the get-together in Messages, the MGAQ newsletter, and the Queens' Park Café is only a few minutes from our new home in Ipswich, so it was a delight to think we might meet others who know more about MG than we do.

Then I saw a small group arranging themselves around a table and one person was wearing the MGAQ badge. I recognised the name “Anita” on the badge as the contact for the meeting. The welcome was wonderful, and I felt like a lost sheep being returned to the flock. I have probably had MG for ten years or more, but was only told what it was five years ago when it was picked up by a perceptive eye surgeon. I have never fully understood the complexities of my own condition, so this was my chance to find out more from those with more experience.

Anita, who is also an MGAQ committee member, told us about her long-term struggles with the condition and was full of advice and hard facts. Vickie, who was there with her husband, is an enthusiastic and confident source of strategies, and lives not far from us, so a wonderful new contact. Hanna, also with her husband, is a quiet gentle soul who inspired me with stories of all that she has had to cope with. Dee seemed to glow with good health, so we were surprised to hear that she has suffered very much from her condition and Anita said that Dee has improved so much since she last saw her that



Friday, October 25th, “Coffee and Chat” at the Queens Park Café in Ipswich

she could hardly believe she is the same person. Dee was also with her carer.

Yuriko and I were fascinated to hear everyone's experiences – which doctor they see, what treatments work for them, how to get a disabled parking permit, can you get a droopy eye fixed by cosmetic surgery, and so much more. We took copious notes and have already acted upon some of the advice. I can confidently say that we learned more about what it is like to be an MG sufferer during that morning than everything we had learned before. I had been told a lot about the disease itself by people who don't have it, but here I was learning first-hand what it is like to live with it.

In many ways those with MG are like a secret society: we are mostly invisible, each of us has our own unique version of the disease, and even our GPs may know next to nothing about it. My own GP, a fine doctor, admitted, “We can learn about this together”. So just to sit and chat with other people who understand was a wonderful feeling. I strongly recommend any member to make the effort to join a Coffee and Chat. It wasn't just informative for Yuriko and me, it was a bit like finding distant relatives you never knew you had. Sincere thanks to MGAQ and Anita for all their work.

GET-TOGETHER ROUND-UP



MG Gold Coast Group had their October get-together sharing experiences with other members it was a pleasure to have Mr Ron Stephen (newly appointed MGAQ secretary) attend.



Anita Jackson hosts a friendly and casual 'Coffee and Chat' session in Cleveland.

NEWS FROM AROUND QUEENSLAND

News from Cairns

We will meet again **Saturday, 7 December at the Cairns RSL Club, Esplanade at 11.00am**. If you are visiting Cairns, you are most welcome to join us. For more information, please contact Donna on 0414 397 462.

News from Townsville

The Townsville MGAQ group Christmas Lunch will be held on **Saturday, 14 December, 2019 at The Avenue Hotel, Kirwan at 12 noon**. If you'd like to exchange a gift with members, please bring a gift to value of \$20.00.

Your company has been appreciated through out the year.

For details contact Daphne on 0400 778 637 or daphclay@gmail.com

News from Mackay

The next get together on **Sunday, 1 December will be the Christmas break-up at 12 noon at the Rice Buffet, 22 Gregory St Mackay**. All Welcome.

For information for the Mackay region, please contact Muriel on (07) 4954 1221.

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

We will meet again on **Friday, 22 November at Kawana Bowls Club**

at 10 am. As this will be our last gathering for this year, I hope many of you can attend.

For more information about the Sunshine Coast group, call Colleen on 0409 491 789 or email colleen4551@gmail.com

News from the Gold Coast

The MG Gold Coast group had their get-together, sharing experiences with other members. It was a pleasure to have Mr Ron Stephen (newly appointed MGAQ Secretary) attend.

Our next gathering will be on **Sunday, 15 December at Southport Sharks Club at 11.30am**. This will coincide with MGAQ Inc Christmas lunch celebration. I hope to see all Gold Coast members there. For more information about the Gold Coast group 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



Name _____ Phone _____

THE MGAQ "COFFEE & CHAT" has been a successful opportunity for people with Myasthenia Gravis or their carers to connect with others in the Brisbane area.

We are now planning for 2020 and would like to know which of these venues **you would attend**.

Brisbane North

Inner Brisbane

Ipswich

Brisbane South

Logan

Toowoomba

Brisbane West

Moreton Bay

Redland Bay

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