



Myasthenia Gravis Association of Queensland Inc.

MessaGes

OCTOBER
2022

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 OCTOBER 2022

What a wonderful opportunity it is to have the AGM undertaken using both Zoom and face-to-face. Our guest speaker after the AGM, Dr Geraldine Moses, "*The Seven Things Everyone Should Know About Their Medicines*" really made members who were listening think about what medications they are taking and why. A big thank you to Geraldine for her highly relevant presentation and for having us all think about what each medication contains and what benefit it provides.

The work of the new management committee has already started with everyone trying to manage the workload from so many projects. Remember that, if you have a bit of spare time to give, it would be appreciated as every little bit of time helps. We are also looking for project managers for some smaller activities which will have a start and end date attached so people know the level of commitment required.

A big thank-you must go to the representatives from Queensland Health who made the time to meet with three of our management committee members prior to our AGM. They were amazed at the work of the association and the outreach we have achieved across the state and beyond. As well as the management committee the Region-

al Co-ordinators and Coffee and Chat co-ordinator work hard to ensure that both new members and the ones who have been with the association for many years are provided with opportunities to meet and chat with people and share 'stories'.

At this stage, things are looking good for our

**Christmas Get-together at the
Club Southside,
76 Mount Gravatt-Capalaba Road,
Upper Mt Gravatt,
on Sunday, 11 December,
11.30am lunch sitting.**

Please remember to RSVP on the 1800 number so the venue can cater for our numbers. It would also appear that we need to send our Christmas gifts sooner rather than later and buy gifts when we see them as they may be gone tomorrow. I am sure that the children and grandchildren in particular have already informed you about their very long list.

Wishing everyone a safe lead up to the festive season and hope that all loved ones are organising to have a joyful time together.

Thanks, Carol

Myasthenia Gravis Association of Queensland Inc

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Your Association is your **VOICE** with Government.



MYASTHENIA ALLIANCE AUSTRALIA

NEWS UPDATE

Our first "Art with Heart" auction is now complete. Well done everyone who supported this activity in the various ways.

This thank you is inclusive of the

- Administration efforts - in particular committee members - Denise, Natalie and Donna
- The amazing, generous and talented artists lead by Lyn Church.
- The Myasthenia Gravis community who spread the word and 'talked about' this campaign.
- The wonderful people who bid making it fun, showed support to the crafters and who are ensuring the success of the MAA.

Bringing greater awareness about Myasthenia is an important goal and this campaign was heavily focused on this objective. This campaign was also important to the MAA as adding funds to ensure sustainability must remain a focus. It is becoming apparent that we need to be a presence

in the Health community. There are significant reviews and hopefully subsequent reforms occurring throughout the Federal Government Health sector. The MAA devote many hours to writing submissions, answering questionnaires and attending webinars in an effort to ensure that the rare disease of myasthenia gravis has a voice. In the post Covid era, face-to-face communication has rebounded strongly as it is an important tool in having our targeted requirements understood. To attend face-to-face requires funding for airfares and accommodation. At times, these costs can be high especially to Canberra when Parliament is sitting. To date, the MAA have not attended without support. This needs to change and your contributions will be well purposed.

It is hoped that this Art Auction will become an annual event and will, in time, to be seen as the fundraising face of the Australian Myasthenia work via the MAA.

Rare Voices National Summit

The MAA have been invited to attend this significant event with Susan requested to present during the Care and Support Session on Day 1. There will be a gala event on the Friday night in celebration of RVA's work and the MAA are keen to be there recognising the amazing work done by this

small organisation during the past ten years. It will be two full days of mixing and mingling - a rather scary first for someone with a suppressed immune system - and so great to be present showing our support and encouragement to the people who give so much to the rare disease community.

Survey Feedback

Enclosed in this newsletter is the first of the feedback about research conducted this year through the survey format. It is very positive and very appreciative letter to our community. Thank you to everyone who participated. By having the MAA register, the State Association contacts and via the more casual contact via Facebook our community have been able to gather in a way that is uncommon in the rare disease sector. Researchers cannot progress a research project without participants. Typically, lack of numbers has proven to be

a huge hurdle to progressing projects. By showing how we can muster sufficient numbers and by utilising the survey model, the projects successfully completed this year show that research within the myasthenia patient cohort can be successful. We are finding a model that gives a voice to our condition. This voice will only grow as more projects come along. The feedback provided today will ensure that we are considered in the future.

Read the survey feedback on Page 4.

Kind regards Susan White - MAA Chairperson

If you are not already registered with the Alliance please go to www.myastheniaalliance.org.au

ART WITH HEART AUCTION

THANK YOU!

The Auction has finished, and we've raised over \$3000!

A big thank you to all of the wonderful donors and bidders who have supported the Art with Heart Auction and helped to raise vital funds for **Myasthenia Alliance Australia**.

THE AUCTION

The auction has now finished with great success. We look forward to seeing you at next years auction.

Together, we have made an impact.

Thank you to all of our wonderful donors and bidders, who now own some truly unique and remarkable pieces. We'd also love to thank everyone that supported the auction by raising awareness about Myasthenia Gravis and the auction.

Also a very special thank you to Lyn Church for instigating the event by donating her magnificent painting - Ocean Views.



**Myasthenia
Alliance Australia**
myastheniaalliance.org.au



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of Queensland Inc.**
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“THANK YOU - PATIENT VOICES MATTER”



theAlfred



Myasthenia
Alliance Australia

FEEDBACK ON RECENT SURVEY THE IMPACT OF THE CORONAVIRUS DISEASE (COVID-19) PANDEMIC ON MYASTHENIA GRAVIS PATIENTS IN AN AUSTRALIAN POPULATION

Dear MAA members,

We want to extend our sincerest gratitude to all of you who took part in the survey looking at the various impacts of the COVID-19 pandemic on your lives. We received 229 responses which is an excellent number. Our preliminary analysis has shown that, on average, the pandemic had a mild impact on your myasthenia control and treatment but had a more substantial impact on other aspects of your life.

The results of the survey will be published in the coming months in an international peer-reviewed journal, where we will explore the impact of the pandemic on your myasthenia control, treatment choices, other medical conditions, as well as financial and emotional wellbeing. The results of this survey are of great importance to the general and medical community, as those who are immunosuppressed have been at the forefront of the pandemic. We anticipate the results of the survey will guide medical practitioners to focus on areas that may have previously received less attention and provides important lessons in the event of future global health events.

Thank you and best wishes,

Dr. Pakeeran Siriratnam, Dr. Katherine Buzzard, A/Prof. Stephen Reddel, Dr. Ben Chen, Dr. Wen-Wen Zhang, & Dr. Laura McArthur.



MGAQ Website

Members Only Access

Only current financial members have access to the Members Only feature of our website and member login details are changed annually.

All current members will receive their new login details via email by the end of October.

If you haven't received yours by then, please email treasurer@mgaq.org.au



TOWNSVILLE COFFEE & CHAT

RECIPE CORNER

GRILLED CHICKEN BREAST WITH ROASTED SWEET POTATOES, CHERRY TOMATOES AND SEARED SPINACH

INGREDIENTS:

- 4 x 150gm chicken breasts, no skin
- 500gm sweet potato, cut into 1cm discs
- 1 punnet (200gm) cherry tomatoes
- 200gm spinach
- 30ml pure vegetable oil or olive oil

METHOD:

1. Preheat the oven to 180°C. Lightly toss the sweet potato and cherry tomatoes in half of the oil, and lay out in a single layer on a roasting tray lined with baking paper. Roast for 20 minutes or until soft and lightly coloured.
2. Fry the chicken breasts in the remaining oil in a heavy based pan until golden all over. Transfer to the roasting tray with the vegetables for the last 8 – 10 minutes of cooking.
3. Heat a large frying pan and cook the spinach until it is lightly wilted then give it a little squeeze with your tongs to remove any excess water.
4. Arrange the cherry tomatoes, sweet potatoes and spinach on four plates, slice the chicken breasts into 2 or 3 pieces and arrange on top and season with salt and pepper.

RECIPE NOTES:

Give your sweet potato a good scrub and you don't need to peel it. Peeling results in loss of some of the good stuff like fibre, antioxidants and nutrients.

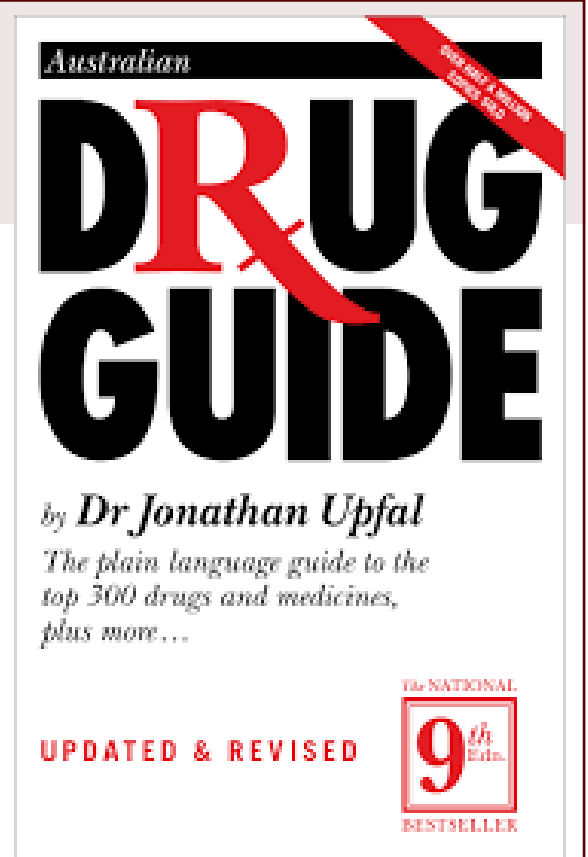
Serves 4



NEW LIBRARY RESOURCE AVAILABLE TO MEMBERS

At the recent September MGAQ meeting, fantastic speaker Dr Geraldine Moses AM, Pharmacist, referenced this book. The Association has purchased a copy to share with members. As usual, the Association will post it out and members are required to pay the return postage. Please call 1800 802 568 or email info@mgaq.org.au if you would like to take advantage of this opportunity.

The full presentation of Dr Moses talk is now available in the video section of the Members Only resource area of the website. She is highly qualified and very passionate about consumer knowledge. Viewing this video at your convenience is highly recommended. As with all the videos, a second viewing can be extremely helpful.



You're invited to the
MGAQ Christmas Function

to be held at

Club Southside

76 Mount Gravatt-Capalaba Rd, Upper Mt Gravatt

on

Sunday, 11 December

11.30 am for 12 noon

For more information / RSVP - Contact Susan

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



SUPPORT your Association by **VOLUNTEERING.**

MEMBERS' FORUM

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.

Inspiration, planning and the right tools

We are reestablishing our garden again after years of neglect from when I was physically unable to do the work. Finding the right medication/treatments for my experience of Myasthenia Gravis (MG) has meant that after 10 years I am now more able bodied and ready to get on with the things that I love; and so, I return to my garden.

I was once frenetic in my gardening technique, but we all know that energy with MG is defined by our strength limitations on any given day. Gardening is not something I can just 'hack away' at anymore, I need inspiration, planning and the right tools. Now I choose an area of my garden, I sit and contemplate, then slowly tackle how I can make improvements. The cultivating takes time because it takes lots of energy, but slowly and surely our garden is looking tended once again.

These years have taught me to slow down and calmly tackle the tasks ahead. I no longer approach things with a frenzied energy expecting change immediately. Like when changing medication, improvements don't necessarily happen quickly but require time, sometimes years in my experience. In all things, I look to others who are experiencing similar journeys for inspiration, I then plan a way forward and ensure I have the right assistance. Slowly and surely my life feels and looks more tended.

You could say I am reestablishing my life with a new attitude. I've decided that focusing on what makes me happy, makes everything work better. I make it my days' work to do things that are fun, or I find the fun within what I must do. I laugh a lot. I take joy in what I am doing and share cheer with my family. When I do this, everything seems to go well and even, dare I say, takes care of itself. Fun, laughter, joy and cheer – we can all do with more of this, right?

Helen T

About the Author: I was diagnosed with Myasthenia Gravis in 2012. I live on the Far South Coast of NSW with my Husband and our big black Labrador. I enjoy creative endeavours like painting, crochet and knitting, reading and watching old movies, and writing.

WELCOME TO OUR NEW MEMBERS

Rodger & Janina,
Marsden, QLD

Graham,
Trinity Park, QLD

Chona,
MacDowell, QLD

NEWS FROM AROUND QUEENSLAND

News from Cairns

Please join us at the **Cairns RSL Boardroom on Saturday, 19 November at 11.00am** for our regular catch up. If you are visiting Cairns, you are also welcome to come along. This will be our last gathering for 2022. For more information, please/text **Donna on 0414397462**.

News from Townsville

Thanks for attending our August Lunch. Our next Lunch is on **Saturday, 29 October 2022, 12 noon at Kirwan Sports Club, 159 Bamford Lane, Kirwan**.

Looking forward to your company. Family members are welcome. I will let you know if COVID conditions change.

For details and if you can come please RSVP **Daphne on 0400 778 637** or email daphclay@gmail.com

News from Mackay

For more information, please contact **Mary on 4959 5251**

News from Bundaberg

For more information, please contact **Denise on 0431 571 399**.

News from the Sunshine Coast

Please join us for our next Coffee and Chat on **Monday, 5 December at 10.30am - Kawana Club, 476 Nicklin Way Kawana**. All are welcome.

For more information, please contact **Vicki on 0411 146 898** or email avplummer@gmail.com

News from the Gold Coast

Hi Everyone. MG Gold Coast group had their get-together sharing experiences with other members on Saturday 8th of October at Broadbeach Kurrawa Surf Club. Our next meeting will be at 10am on Saturday, 3 December at Southport Sharks Club. I hope to see all there.

Kind regards Nader Amiri, Gold Coast Coordinator **0415 834 401**.



COFFEE & CHATS

RSVP Anita on 0414 588 312

WELLINGTON POINT

**Thursday 3rd November at 10.30am, Farmhouse Restaurant and Coffee Shop
625 Main Road, Wellington Point**

what's coming up

What's On?	When Is It?	Where Is It?
MGAQ CHRISTMAS FUNCTION	SUNDAY, 11 DECEMBER 11.30am for 12 NOON	Club Southside, 76 Mount Gravatt- Capalaba Road Upper Mt Gravatt

Become **INVOLVED** - make a **DIFFERENCE** to yourself and others.