



Myasthenia Gravis Association of Queensland Inc.

Messages

**FEBRUARY
2023**

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 FEBRUARY 2023

Christmas and the holidays seem to have gone in a flash and we are back into the management committee starting on or continuing particular projects. From the messages you have received you will note that a great deal of work was done in relation to the shortage of medication. It now appears that the shortage of Mestinon 60 and Mestinon Time-span has been resolved and MG'ers can get them from their regular pharmacist at the price they had been paying prior to the shortage. Please use the 1800 number if you are still having difficulties.

Just when one problem is solved another arises. We were advised by the National Blood Authority on 19 January that the supply of Intragam 10 (IVIg) would be ceased on 30 January and that all people with Myasthenia Gravis who receive this infusion will be changed over to Privigen. This change will happen automatically through the clinical systems in place. The reason given was, because of continuing challenges arising from the impacts of Covid-19 especially in relation to changed donor behaviour, affected the availability on the availability of plasma used for the production of some plasma products. This has affected the amount of Intragam 10 that is available.

We still have quite a few members who are un-

financial. As this money is used for things such as producing and sending out the newsletter, podcasts, website updates and functions for members it is important that we have funds available to continue these services. Please take the time to check if you are financial. We only expect people to pay for the current financial year and do not ask for any unpaid fees from previous years.

Rare Diseases Day is held on 28 February to raise awareness for rare diseases and improve access to treatment and medical representation for individuals with rare diseases and their families. Queensland Rare Disease Day illuminations in Brisbane will include the Story Bridge, Victoria Bridge, Redcliffe Place Sculptures and the City Hall Annex. Please take a moment to think about the approximately 8% of the population who live with one of the 10,000 known rare diseases in Australia. Statistics show that there is a similar number of people living with a rare disease as there are people who have diabetes or asthma.

This year will again be a very busy one for the management committee and we look forward to continuing to provide the best possible service and support for our members.

Thanks, Carol

Myasthenia Gravis Association of Queensland Inc

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MYASTHENIA ALLIANCE AUSTRALIA

NEWS UPDATE

Gosh - the year is underway but the MAA team have had little rest over the past two months! There was much to be done as the team stayed on top of the ever evolving Mestinon shortage story. Particular thanks are extended to Natalie and Glenda and to all your Committee for their willingness to prioritise the distribution of information. The latest update is included on page 5 of this newsletter. As you can read, it seems that the shortage is resolved for the moment. All feedback from membership is welcomed and the MAA team will continue to monitor the situation.

Also included in this newsletter is my Annual MAA Report. Please, I ask that you take the time to read it and perhaps chat to others about how fortunate this rare disease group is to have a self-supporting network.

It is very special for any life-changing condition to have a signature awareness/fundraising event. Other conditions such as Breast Cancer, Arthritis and Asthma have created a well known, annual activity to focus on their needs so why not us too. Even though we are rare and our numbers are small, we can do it! Championed by award winning artist Lyn Church, who herself is an MG Warrior and special person, the MAA are focused on expanding your "Art With Heart" event. All help with this project is very welcomed!

Notification from the National Blood Authority informed the Associations that changes to the supply of Intragram 10 IVIg product will occur from January 30 2023. Some patients will be moved to alternate products. The shortage of this particular IVIg product has resulted from continuing challenges arising from the impacts of the Covid-19 pandemic, especially in relation to donor behaviour. This product is collected in Australia and is now in short supply. International product is not affected. If you receive Intragram 10 and are concerned, please speak with your Specialist. Our community can help all those who are reliant on this particular form of IVIg by asking our family members and friends to consider visiting the Blood Bank to donate plasma.

Warm regards

Susan White - MAA Chairperson

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



VICTORIAN REGIONAL MG LUNCHEONS

to be held on

Sunday, 26th March at 12 noon

Sunday, 25th June at 12 noon

Shepparton RSL Club, 88 Wyndham Street Shepparton

RSVP is essential. Please call Pauline 0419 332 260 - All Welcome



Myasthenia
Alliance Australia

MAA CHAIRPERSON'S ANNUAL REPORT

31 October 2021 – 31 December 2022

Susan White, **MAA President**

The past fourteen months has convincingly demonstrated why it is so important for this small patient group of approximately 2,500 people to have a strong National voice and a united stance. This is the leadership provided by the Myasthenia Alliance Australia.

Addressing medicine shortages, facilitating research opportunities, bringing awareness and community connection as well as making meaningful connections with government, health professionals and Industry have kept the MAA busy through the 2022 year.

By registering at www.myastheniaalliance.org.au and following the activities of the Australian State Associations in NSW and QLD people have been kept abreast of the work which has been undertaken throughout this past year. Given below are the highlights from an extraordinary year's work by a very small volunteer team.

- **Rituximab for Myasthenia patients.** Rituximab is confirmed available equally to all Myasthenia patients should their Specialist wish to consider this medication choice. Listing via the PBS was finally achieved on September 1st 2022. We thank the relevant Government Departments for bringing about the legislative changes required for this unique situation.
- **Art With Heart Awareness Campaign.** A first-time project was introduced to bring Australia wide conversation about the rare condition of Myasthenia Gravis. The platform of on-line art/craft/other auctioning allowed patients to come together in a fun and collaborative space. It allowed the general public to learn about the condition and to offer tangible support and it established a platform for building awareness. This year's "Art With Heart" campaign was an inaugural offering and now it needs momentum to be a signature event for the myasthenia community.
- **Mestinon supply shortages.** Many, many hours of work have been devoted to communicating with the pharmaceutical companies, Government Departments and our community as this difficult and as yet incomplete issue progresses. Thankfully, due to the on-going work of the MAA, all Government Departments including the Minister's Office are familiar with our condition and have been supportive.
- **Access to TPE.** Following a recommendation from the Health Minister's Office a submission to the MBS Review Taskforce occurred September 2022. This follows four years of effort to fully understand the issues and interactions surrounding the declining access to Therapeutic Plasma Exchange as a treatment option for people with Myasthenia Gravis. The 'Patient Voice' option proved to be the only suitable platform for raising an issue that is so multifaceted. Feedback is expected in 2023.
- **Partnering with Rare Voices Australia (RVA).** Every year the MAA reports on the collaborative work undertaken with this group. The RVA has gone from strength to strength and now celebrates 10 years. Once again, we have worked collectively on many topics. Susan was delighted

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Best **CARE** for all Australians is our **GOAL!**

to attend an amazing summit for the rare disease sector, hosted by RVA in November 2022. As an invited presenter, the MAA were able to provide a case study demonstrating the importance of partnering across the rare disease sector. This opportunity allowed the MAA to cement contacts with many Heads of Government Departments, with Industry and with our peers in the patient advocacy world.

- **Research** – The Patient Reported Outcomes Research Project in collaboration with Terumo BCT, Australian National University, MAA and the University of Sydney was completed. This project is hugely significant in both size and information collected. The data collection phase was closed off late January 2022 and data analysis progressed slowly but steadily throughout the year. Indicative results have already proved invaluable to the MAA. Some results have been generally shared. A Journal Article and a Conference Paper are expected in 2023. This work is highly credible thanks to the number of participants. A huge thank you is extended to the Australian Myasthenia community for responding so positively to this project and to other requests which occurred during the year. Fostering research remains a focus and opportunities have presented across a broad range of topics in 2022.

Foundational and follow up work continues for the MAA and the diversity of topics is noticeable. This includes on-going support for MGBase, seeking to enhance the website, communicating more deeply and keeping up with a rapidly engaging Patient Voice sector.

The work undertaken in 2022 and indeed during the previous eight years since inception of the MAA, has brought additional recognition and understanding of the experience of living with Myasthenia each and every day. This growth in knowledge is being experienced within our own community as well as with Government, Industry, Researchers and Health professionals.

The MAA is a fully volunteer run and donation funded organisation. The financial status of the Alliance has declined in 2022 due to some major expenses. Currently it remains viable, operating on low overheads. All donations are very gratefully received and can be made as designated contributions via the State Associations.

In summary, the MAA Board are keenly focused on the “What Next” and “How To” conversations for 2023. Regrettably the current operational model involves a reducing worker base and an expanding platform of work. This puts the future viability of the MAA at risk. We must find solutions for the future sustainability of this organisation. Therefore, we aim to seek out fresh ideas from everyone with an interest in supporting people affected by this condition. Funded and unfunded models need to be considered.

Please reflect on the fact that over half the MAA Board has each individually donated almost ten years of time and energy to supporting everyone around Australia. It is time for others to come forward. It is time for other State Associations to be founded. Sadly, during the medication crisis, many of the more distressed callers were Victorians – they simply did not know that the medications were becoming short and did not know who to reach out to.

As Chairperson, I deeply thank my team of four for their tireless, gracious and generous commitment to this significant work. The depth of support runs deeper with the Committees of the NSW and QLD Associations giving generously also. This year has seen an increasing number of people registered with the Alliance. Without this support our work could not be effective. Our sincere appreciation is extended to everyone involved.

2023 will be my final year as Chairperson. Ideally, the year will be spent mentoring others as they become involved. Progressing the organisation to a more enduring operational model is also a priority.

With very best wishes for people to stay strong and to find joy in 2023.

Susan White MAA Chairperson.

MAA Update on Mestinon Supply - 25 Jan. 2023

More good news about Mestinon supply improving for both 60mg and 180mg! The Mestinon supply shortage has been an evolving issue over the last few months and the MAA has been actively monitoring the situation and speaking with government and industry stakeholders to ensure we can access this important medication. We thank you for contacting us and your state associations with your feedback and we appreciate this has been concerning and sometimes frustrating. Please see the latest update below.

180mg/Timespan

The shortage of Mestinon Timespan 180mg tablets is now **expected to resolve on 31 January 2023**. The supplier iNova have confirmed they have received 180mg stock. They have despatched backorders and can now fill new orders for their wholesalers. Approximate dates wholesalers should be able to fulfil pharmacy orders are:

NSW, VIC, ACT & QLD: 1 February 2023

SA & NT: 3 February 2023

WA, TAS & NORTH QLD: 6 February 2023

Please note there may still be a few days for your pharmacist to then receive your order and get it to you.

To meet demand throughout January, Medsurge received a second Section 19A approval for another 180mg product (MESTINON-SR pyridostigmine bromide 180 mg slow-release tablets Canada) and they have confirmed sufficient supply of this product with the TGA. However, please be aware that the PBS listing for this particular product had not yet been approved at the time of writing this update.

We encourage you to speak with your pharmacist and ensure they are aware of iNova's recent stock arrival and the resumption of usual processes for 180mg supply.

60mg

The shortage issue has been resolved and supply has resumed. Pharmacists can access 60mg from their usual wholesaler.

The TGA have assured us they will continue to monitor the supply of Mestinon and facilitate patient access where possible.

Susan White, MAA Chairperson, Natalie Windle, MAA Secretary, Glenda Bidner, MAA Board Member



MGAQ Inc. podcast series

PODCASTS

Greetings All

Did you know that you can listen to the newsletter on the podcast via the Member Log in at www.mgaq.org.au

Feel free to contact Dr Podcast at podcast@mgaq.org.au

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



rare voices
A U S T R A L I A[®]

RARE DISEASE DAY TUESDAY 28 FEB. 2023

Rare Disease Day is the globally co-ordinated movement for rare disease working toward equity in social opportunity, healthcare and access to diagnosis and therapies for people living with a rare disease. Rare Voices Australia (RVA) is the national alliance that represents australia for rare disease annually.

The call for action for 2023 is
“Share Your Colours”



**MGAQ SUPPORTS THE “LIGHT UPS” IN QUEENSLAND FOR
RARE DISEASE DAY.**

BRISBANE ILLUMINATIONS

Story Bridge
Victoria Bridge

Reddacliff Place Sculptures
City Hall Annex

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.

The New Year

As we move into a new year, I reflect on the resolutions that we all make but often forget after a few weeks. I think that looking after ourselves can be a continuous habit not just something we ponder once a year.

There are many wonderful teachers and philosophies that we can incorporate into our lives to help us live a great life and feel better about ourselves. Having a chronic disease doesn't mean that it must take centre stage. Here are some ideas that I focus on instead.

I embrace who I am and don't compare myself with others - no matter where I am regarding my Myasthenia gravis (MG) symptoms I accept it so I have the energy to be with my family and enjoy the things I can do.

I connect with people – working from home I am not always around others, so I reach out and link up with those who are important to me on a regular basis. Family and friend connections create much happiness in my life.

I do something that is fun or different each day – for me the fun projects might be cooking a new recipe, brushing the dog, watering the pot plants, or phoning my sister. It doesn't have to be big or time-consuming, but the fun factor is the key.

I dress to feel good and accentuate my positives – even when I am home all day and won't necessarily see anyone else, I dress to feel happy. I rarely just put on track pants (mind you, they have their place) but choose something smart and comfortable to wear. Sometimes this means my favourite colour and it always means putting on my favourite jewellery.

I make time for myself, and I let myself stop and chill out - I learnt this habit very early in my journey with MG. There was a lot of stopping and resting in the early years. I now realise that I get far more done if I do stop rather than if I try to push through. I also feel a heck of a lot better!

Creating meaning in our life is an ongoing process, no matter where we are in our journey. I believe that it takes more than a new year's resolution to make my life work, so I include these important ideas every day. What do you do for yourself, to live your best life?

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.

BAMBOOZABLES

www.thinkablepuzzles.com

LOUD

DANCE DANCE DANCE --->DANCE	CRYING CRYING CRYING CRYING	groPOOLund	ABCD EFGH IJKLM NOPQ RS_U -WXY Z	FREQUENCY	
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SUDOKU

www.theteacherscorner.net Printable Sudoku

					3	6		
8	9	4	1	2		7	5	
7					8			2
9		6		1		2		
3	5			8		4		7
			5	6		1		
	3	9	8	7				4
		5			9			
1			2			8	9	6

ANSWERS

Bamboozable 8 Answers: 1. Last Dance; 2. For Crying Out Loud; 3. Inground Pool; 4. No TV for a Week; 5. High Frequency; 6. Sit Ups

What Word 2 Answers: 1. Stopwatch; 2. Hon-est; 3. Shoehorn; 4. Tailpipe; 5. Arkansas; 6. Car-oon; 7. Copycat; 8. Sweepstake; 9. Forefathers; 10. Detail

5	1	2	7	9	3	6	4	8
8	9	4	1	2	6	7	5	3
7	6	3	4	5	8	9	1	2
9	7	6	3	1	4	2	8	5
3	5	1	9	8	2	4	6	7
4	2	8	5	6	7	1	3	9
6	3	9	8	7	1	5	2	4
2	8	5	6	4	9	3	7	1
1	4	7	2	3	5	8	9	6



Melbourne Lunch

**Sunday, 19 February at
12.30pm**

Matthew Flinders Hotel - Bistro
(Booked under MG)

667 Warrigal Road, Chadstone Vic
(not far from Freeway exit)

RSVP: Greg Bowman 0407 371 877 or enquiries Catherine Bergin 0418 563 557

SUPPORT your Association by **VOLUNTEERING.**



Myasthenia Gravis Friends Western Australia Coffee & Chat -

Venue: **Austria Club, 46 Staniland Street, Orange Grove**

Date: **Sunday, 19 March at 2.30pm**

For more information, please contact Annette on 0413 855 077.

Join us in Perth



RECIPE CORNER

Curried Chickpea Salad

Serves: 5

Prep time: 10 minutes

Cook time: 15-20 minutes

Ingredients

Salad:

2 cans chickpeas, drained and rinsed

1 tablespoon olive oil

½ cup chopped spring onions

1 cup spinach, chopped

½ small bunch coriander, chopped

1 red capsicum, chopped

½ cup sultanas

cup cashews, chopped

Dressing:

1 tablespoon olive oil

½ lemon, juiced

2 teaspoons apple cider vinegar

1 tablespoon curry powder

1 ½ tablespoons tahini

Method

PREHEAT oven to 200°C.

DRAIN and rinse

chickpeas and place onto

lined baking tray. Drizzle

with olive oil and roast in

oven for 15-20 minutes.

PLACE remaining salad

ingredients into a large

bowl.

MIX olive oil, lemon juice,

apple cider vinegar and

curry powder in a small jar

until combined,

then drizzle in the

tahini until the desired

consistency has been

reached. Mix well.

DRIZZLE dressing over salad ingredients and toss before

serving.

1 ½ serves Veg. per portion

Recipe courtesy of www.qcwacountrykitchens.com.au



Good Gut Health

NEWS FROM AROUND QUEENSLAND

News from Cairns

If you are visiting Cairns, you are also welcome to come along. **Our next meeting will be on Saturday, 18 February at 11.00am - Cairns RSL Club, Esplanade.**

For more information please call/text **Donna on 0414 397 462.**

News from Townsville

April Lunch. Our next meeting will be held on, **Saturday, 22 April at 12 noon - Sports Club, 159 Bamford Lane Kirwan, Ph. 07 4773 1223.** Looking forward to your company. Family members are welcome.

For more information, please contact **Daphne on 0400 778 637** or email daphclay@gmail.com

News from Mackay

For more information, please contact **Mary on 07 4959 5251**

News from Bundaberg

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

News from the Sunshine Coast

Our next get-together will be held on **Monday, 6 March at 10.30am - Kawana Club, 476 Nicklin Way.**

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 11th February. Our next meeting will be at **10am on Saturday, 1 April at Broadbeach Kurrawa Surf Club.** I hope to see you there.

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



COFFEE & CHATS

RSVP Anita on 0414 588 312

WELLINGTON POINT

**Thursday, 9 March at 10.30am, Farmhouse Restaurant, Wellington Point Farm
625 Main Road, Wellington Point - All Welcome!**

WELCOME TO OUR NEW MEMBERS

Patricia,
Redland Bay QLD

David,
Chermside QLD

Stephen,
Carindale QLD

Sophia
Stockleigh QLD

Terence,
Torquay QLD

Pat,
Chermside QLD

Noel,
Petrie QLD

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