



Myasthenia Gravis Association of Queensland Inc.

Messages

**MARCH
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 MARCH 2023

Welcome everyone to the March newsletter. You will find some very important information about Intragam no longer being processed with Privigen now being used for infusions, information about the 2023 Covid injection, a message from the MAA and the need for people to pay their yearly membership of this association.

For patients receiving **IVIg**, we have become aware of **changes to the supply of Intragam 10 from 30 January 2023 and that MG patients will move to the alternate equivalent IVIg product, Privigen.**

We appreciate that a change like this can cause some distress or concern so please discuss any concerns with your neurologist or treating clinician. You can also see the pamphlet:

Switching Immunoglobulin Products – What Should I Know? What Can I Do? at

www.blood.gov.au/sites/default/files/Switching_Products_FactSheet.PDF

It seems that Covid will now be a part of our lives so it is important to ensure that you are up to date with vaccinations. ATAGI recommends a COVID-19 vaccine booster dose for people who have medical comorbidities or complex health needs, so this applies to all adults with MG. Please speak with your doctor or pharmacist about having one of these booster vaccinations.

On page 5 you will see a call out for people to support the Myasthenia Alliance Australia. This very small

group is involved in a wide range of high level activities that are very time-consuming. Also, there are many projects that do not require a high skill level but rather just need time devoted to them. Please consider carefully and, if you are interested or want more information, please phone Susan on **1800 802 568**.

While MGAQ provides much free information, we certainly still need to have members who are financial so that the association can continue to operate. The \$20 membership fee barely covers the cost of producing, printing and mailing out the newsletter 11 times a year. The association has many ongoing activities and commitments such as running face-to-face and zoom committee meetings, ensuring we provide the best two-way communication with members, continuing to produce and provide extra resources such as podcasts and brochures, being involved with research so that we have data and important information about the best treatments available, conducting meetings and get-togethers across the state – and the list goes on! So please, if you are not a financial member, think about paying the \$20 for category A membership and/or for Carer/Supporters and help support YOUR association.

Thanks, Carol

Myasthenia Gravis Association of Queensland Inc

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



MYASTHENIA ALLIANCE AUSTRALIA

NEWS UPDATE

Denise Hannay, representing the MGAQ, and myself were fortunate enough to attend a Parliamentary luncheon celebrating Rare Disease Day in recognition of the Rare Disease Sector. It was organised by Rare Voices Australia (RVA) and was well supported by key politicians and your local Federal Government Representatives. It was another excellent opportunity to make people aware of our condition and our needs. This trip was supported, in part, by your donations to the MGAQ and the MAA - an example of making funds work for the benefit of all. I thank Denise for giving her time and embracing the chance to network, learn and converse and also for supporting me so that I could physically attend and continue my chosen engagement.

On Page 7 of this newsletter you will see a **'Save The Date'** advertisement. Thanks to the generous time offered by the Specialist Doctors from the MAA Medical Advisory Board, the MAA are planning a conference style event for our community to be hosted at **Concord Hospital Sydney on 21 October**. It will be a smaller event than the previous national conference so please note the date, register with **www.myastheniaalliance.org.au** in order that you receive prompt notification, and mark the week-end in your diary. Perhaps consider a holiday in Sydney to make it all worthwhile. Available places will be limited and more information will follow when details are formulated.

A serious call out has been made in regards to strengthening the MAA team. The MAA team does know how hard the journey with Myasthenia can be, we do get unwell and very tired at times but we are passionate about the value of the work undertaken and are reluctant to see it fall away. Please consider the possibilities of someone you know or yourself possibly contributing.

Dr Reddel (MAA Medical Advisor) has offered very welcome clarity around keeping your Covid Vaccination current. These details can also be found in this newsletter on **Page 5**

Best regards

Susan White - MAA Chairperson

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



- **Dr Mike Freeland MP and Susan White at Rare Disease Day Parliamentary Event.**



**GOLD
COAST
11 February**



**SUNSHINE
COAST
6 March**

RECIPE CORNER

Donna's Shortbread

Ingredients

250g butter, softened
3/4 cup caster sugar
1 teaspoon Vanilla extract
2 cups plain flour, sifted
1/2 cup rice flour, sifted

Method

1. Using an electric mixer, BEAT butter, sugar and vanilla until light and fluffy.
2. STIR in sifted flours.
3. Roll into small balls and place on a baking tray. Flatten slightly with the back of a spoon.
4. Prick the top of the rounds with a fork and sprinkle with extra sugar.
5. Bake in the oven on 160 deg for approximately 15 minutes or until light golden.
6. Remove from the oven and allow to cool.

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

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.

Dealing with grief

Recently our Mum passed away. People deal with the passing of a loved one in different ways. Of course, there is no right nor wrong way. I have found kindness to myself is the key to helping me work through my grief.

We all try to make peace with this very natural occurrence, it obviously leaves a big space in our lives. I have found solace in my writing and would like to share with you something I wrote for Mum.

Look for me in beauty

*You wish for me to be near you.
And I can be. On all days and in all ways,
look for me in beauty and I will be there with you.
For as you love me, I will be loving you.
Look for me in rainbows
and in each morning's sunrise.
Find me amongst the stars at night
and in the colours as the day subsides.
I will be among the birds in your garden
and in every blossoming tree.
See me in the view over the mountains
and in the flowers shifting in the breeze.
I am there in the ocean that returns to the shore
and amongst the footprints in the sand.
You will hear me in your favourite song,
and in every whistled tune.
I share in our family fun and laughter,
in the jokes and joy and tears.
You may think I am away, but I am not truly.
For when you look for me in beauty, I am there with you.
And as you love me, I am loving you.*

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.

UPDATED COVID BOOSTER UPDATE 2023

ATAGI have recently released updated COVID booster advice for 2023 which has been accepted by the Government and includes availability of new bivalent vaccines. These contain both the original COVID-19 variant and also an updated vaccine against Omicron variant.

Overview:

- ATAGI recommends a 2023 COVID-19 vaccine booster dose for adults in the following groups, if their last COVID-19 vaccine dose or confirmed infection (whichever is the most recent) was 6 months ago or longer, and regardless of the number of prior doses received:
 - o All adults aged 65 years and over.
 - o Adults aged 18-64 years who have medical comorbidities that increase their risk of severe COVID-19, or disability with significant or complex health needs.
- MG would reasonably be considered a medical comorbidity that increases the risk of severe COVID-19, so this applies to essentially all adults with MG.

ATAGI also recommends: bivalent mRNA booster vaccines are preferred over other vaccines.

The bivalent vaccines include: Pfizer Original/Omicron BA.4/5, as well as Pfizer Original/Omicron BA.1 or Moderna Original/Omicron BA.1. Note: Moderna Original/Omicron BA.4/5 is currently under evaluation by the Therapeutic Goods Administration.

Kind regards to all, Stephen Reddel



**WORK WITH A GREAT TEAM!
MAKE A DIFFERENCE!
LEARN AND GROW!**

The work of the MAA continues to grow and develop. It is expanding rapidly with Government and Industry seeking us out for community engagement feedback. Opportunities to develop services, awareness and research for the MG community continue to present. The MAA need more volunteers if it is to take up everything that is offered.

If you have a passion to bring about change, if you have health or industry experience, this could be an exciting addition to your interests. If you have a connection to this condition and want to make a difference for yourself or a family member or close friend then please enquire about joining the team. Maybe share this with someone who might be willing.

What is required? An interested person will need to become a member of a State Association committee. This will involve participating at the grass roots level. The MGAQ committee meets 9 times per year, via ZOOM, teleconference or in person. There are no out-of-pocket expenses and meetings are 4 hours in length. From there a sub-committee interest is taken with the MAA. These meetings are solely via ZOOM or teleconference and email communication is used effectively. Meetings times are by mutual agreement and occur each 4-6 weeks for 2-3 hours. Project time follows and is generally very flexible.

Please do phone Susan on **1800 802 568** if you can help or would like further information. Don't think someone else will volunteer – we need you. Ask about it now.

Susan White, MAA Chairperson

SUPPORT your Association by **VOLUNTEERING.**

Rare Disease Day 2023: Ensuring Equity for Australians Living With a Rare Disease



• Hon Keith Pitt MP with Denise Hannay.

It was such a privilege to be a participant in **Rare Voices Australia Parliamentary Event** held at Parliament House in Canberra on 8 March. I was there to represent the Myasthenia Gravis community with Susan White, Myasthenia Alliance Australia. There was a lot of opportunity to network and chat with Federal Members of Parliament and other RVA Ambassadors.

Congratulations to Nicole Millis and her amazing RVA team for everything they do on behalf of all rare conditions.

Denise



• RVA Ambassadors
L to R: Andrew Bannister; Tim Fulton; Renae Wood; Lachy Beckett; Denise Hannay; Dr Mike Frelander MP; Susan White



• L to R: Nicole Millis; Hon Mark Butler MP; Dr Mike Frelander MP; Dr Monique Ryan MP



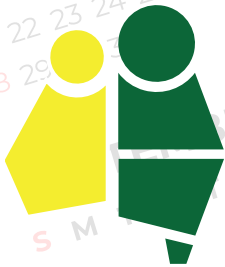
SUPPORT your Association by **VOLUNTEERING.**



**“SAVE THE
DATE”**

**Saturday October 21 2023
Myasthenia Conference
Sydney**

“Attendance by Application”



**Myasthenia
Alliance Australia**

myastheniaalliance.org.au



FOLLOW US ON

Instagram

@myastheniaqueensland

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A COLOURED VIEW

PILL POPPING MAYHEM – No Thanks. At age now 87, 30 months after MG diagnosis, I've designed a simple **"Personal/Medication Record"** that can inform any Medical/Hospital Advisor - which, when, and how much - medication I have consumed since it all began. Critical medical notes can be included too (if you choose). I'm prescribed for classical MG meds, and also other pain management for chronic back and abdominal challenges, culminating in around 18 separate medications for consumption daily at different intervals. I use an MS Excel spreadsheet, self-designed to accommodate my/our needs. (Audrey my partner also takes 2 insulins x 3 times daily plus prescribed meds).

Now before the reader shudders at a computer driven application – read on. I will happily consult, customise, and email a personalised MS Excel spreadsheet file to any MG mate who would care to make pill popping (and all selected personal records such as weight, blood sugar, blood pressure, cryptic notes, etc) an easier daily task. This Record is easily updated and can even be reduced in size, printed and laminated to carry in your purse/wallet. See the illustrations. Just make sure that your PC has Excel (MS Office). Then all you do each day is begin colouring in. It may take a few trial attempts to customise your Records. Send it all to me at djkl157@gmail.com

My visiting RN, GP, RBWH Staff, Specialists and Pharmacist, are all highly complementary of my system, that in effect leaves out nothing that might be required for ongoing medical diagnosis. No personal information is required except an email address, Proper name of Meds, Dosage, Times. The rest is up to you to complete as desired. Webster packs do not work for me and this alternative has proved beyond measure to be 100% effective (for me).

Derek, QLD

WELCOME TO OUR NEW MEMBER

Donna S, Varsity Lakes, Qld

Puzzlers

Puzzles by
www.thinkablepuzzles.com
www.theteacherscorner.net

Word Search - Books of the Old Testament (2)

X E K K M H U L L Z V S I Z
S K Z O A A E L E E E D S E
N D U N C I L C E T O K A P
W A O K K H H A S U I J I H
N J H E K A R A C N M S A A
O J Z U R A I O G H P A H N
M E N I M S B S N B I A S I
O L A M E N T A T I O N S A
L H X L U D U E H Q C I I H
O M C H A I M E R E J L A J
S C R N O B A D I A H S E Z
E S I A G G A H G N O S S S
C E B M I C A H C M T B O H
L J I M V K K Z A H N U H W

- AMOS
- CHRONICLES
- DANIEL
- ECCLESIASTES
- EZEKIEL
- HABAKKUK
- HAGGAI
- HOSEA
- ISAIAH
- JEREMIAH
- JOEL
- JONAH
- KINGS
- LAMENTATIONS
- MALACHI
- MICAH
- NAHUM
- OBADIAH
- SAMUEL
- SOLOMON
- SONG

Answers

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

- 1. Musically Inclined; 2. Overcome the Odds; 3. The Underdog; 4. Cut Above the Rest; 5. One Thing After Another; 6. Waving Goodbye
- Answers:
stare, stale, stille,
smile.

Sudoku

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

Word Change

stare

smile

Bamboozable

MUSICALLY	13579... COME	DOG
cut rest	another one thing	THE
		GOODBYE

NEWS FROM AROUND QUEENSLAND

News from Cairns

Cairns - Get togethers are held regularly and visitors to Cairns are most welcome to attend. For more information, please contact **Donna on 0414 397 462.**

News from Townsville

We are looking forward to our next lunch on **Saturday, 22 April at 12 noon - Sports Club, 159 Bamford Lane Kirwan.** Family members are very welcome. Look forward to seeing you there. For more information, please contact Daphne on **0400 778 637.**

News from Mackay

For local support please contact **Mary on 07 4959 5251**

News from Bundaberg

For local support in Bundaberg, please contact **Denise on 0431 571 399.**

News from Hervey Bay

For local support, please contact **Jan on 0429 622 438.**

News from the Sunshine Coast

Join us at our next get together which will be held on **Monday, 8 May at 10.30am - Kawana Club, 476 Nicklin Way.** For more information, please contact **Vicki on 0411 146 898** or email avlplummer@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

ASPLEY

**Wednesday 22nd March at 10.30am, Stellarossa Cafe,
Robinson Marketplace, 605 Robinson Road,**

- All Welcome!

MURIEL'S DID-YOU- KNOWS

- Australia is the only continent in the world without an active volcano
- The termite mounds that can be found in Australia are the tallest animal-made structures on Earth
- Melbourne has the largest public tram system in the world
- The Gold Coast has the world's largest canal system, which is larger than those of both Venice and Amsterdam combined

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