



Myasthenia Gravis Association of Queensland Inc

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Neurologist

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Messages

Myasthenia Gravis Association Of Queensland Inc.

MARCH NEWSLETTER

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

It is hard to believe that already nearly ¼ of 2021 is over. So much is still happening in our lives with questions about when people with Myasthenia Gravis will be eligible to receive the Covid vaccination. Be assured that our top neurologists here in Australia are working closely with others overseas to ensure that the vaccine is safe for people with Myasthenia Gravis and that we are able to access the vaccine in a timely manner.

As soon as the MGAQ receive any relevant information it will be passed on to members through a variety of media.

I hope that everyone took the opportunity on Rare Diseases Day to talk with someone about Myasthenia Gravis, how you manage it and what symptoms affect you the most.

Rare Voices Australia is doing a wonderful job, not only in raising awareness about the multitude of rare diseases, but also making people aware of these conditions as well as agitating in the political arena for better access to resources and support. The MGAQ is very active within this organisation.

Please make sure that you circle **13 June** on your calendar for our get-together which will also be a celebration of 30 years of our association. A number of articles and photos will be in each newsletter leading up to this event. If any of our long-term members have photos or memories to contribute we would really appreciate it if you either phone the **1800 number** or email info@mgaq.org.au

Your association will, at our AGM, be seeking someone for the position of Secretary. We already have a minutes secretary so the workload of the secretary itself would not be very onerous. Our committee members are a very dedicated and hard-working group and we need to ensure that we have enough people on the committee to manage the wide range of projects in which we are involved plus the general administration of the association. We ask people to think carefully about being able to donate time to this position. There are people on the committee who are more than willing to support and help anybody who is prepared to put up their hand.

Thanks, Carol

Supported by



Queensland
Government

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MYASTHENIA ALLIANCE AUSTRALIA NEWS



MAA UPDATE

Discussion Paper Regarding COVID VACCINATION

In response to the many and varied conversation from the MG Community in regard to the safety and considerations to be made in evaluating the suitability of the MG community for COVID vaccination, the MAA are indebted and extremely thankful to Associate Professor Stephen Reddel (neurologist), and also to those as listed by Dr Reddel, for bringing to us a highly informed discussion paper, inclusive of data, aimed to provide informed guidance on these many questions.

Dr Reddel has put a great deal of time into sourcing the best possible information. An example of this includes joining International Conference meetings at 3am in the morning. The Discussion Paper, will be made available to all Australians in electronic form via the MAA website www.myastheniaalliance.org.au. We invite you and your families to read the information gathered.



For MGAQ and MGNSW members, every financial member will receive a hardcopy of this 10 page document and where details are provided, an electronic copy will be sent. The MAA Board aim to reach out to as many patients as possible via every known communication source. Please do share the information with fellow MG friends and with your Doctors.

The Discussion Paper is designed in two parts to provide a document suitable for the Patients and also for Clinicians. Please read the introduction from Dr. Reddel to understand more. We strongly recommend that people share this document with their Specialists and with their General Practitioners as they seek information regarding the best choice for their individual situation. Providing the document to your clinicians in advance of your appointments will allow them adequate time to consider the information carefully and to do further research as required.

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Question?

Why do we have the State Associations and also the MAA? Can you answer this question?

I think some members are a little confused so a brief outline is given here and if you would like to discuss issues or learn more or get involved, please call Susan on 1800 802 568.

The State Associations operate to provide a more personal experience and more direct support.

As Health Departments are managed at a State level (how obvious is this during this COVID experience) contact with these bodies can only be made via a registered State Association.

The MAA is a formally drafted and signed Alliance of the State Associations and facilitates recognition at a Federal level.

The Alliance deals with Health Policy matters drafted by the Federal Government. These are overarching frameworks that the State Health Departments are guided by. The TGA, the NDIS are both examples of Federal policy. Under law, State Associations are not recognised by Federal Departments.

MAA Update continues Page 3 >

MAA Update continued from Page 2 >

The Alliance does not provide information that relates to seeking Medical support within a State.

All research opportunities are supported and encouraged by both the MAA and the State Associations. Some projects are better suited to broad community and this is important when larger numbers are required. Where patient contact is required, it may be best to be a local project. Research presents in many forms and we are well covered to capture every possible opportunity.

Enhancing available treatment options is a priority. Bringing together the limited number of Specialists and Researchers across Australia who have a keen interest in this particular rare condition is an important part of bringing about best outcomes for patients. The MAA can help with this.

Raising Awareness of MG and the Patient journey is a priority that should be covered at every opportunity and is a collaborative goal for all the organisations.

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Research Opportunities in 2021

It was flagged in 2020 that MG Australians should expect the opportunity to participate in survey based research. The MAA is still hopeful that projects will come on line soon.

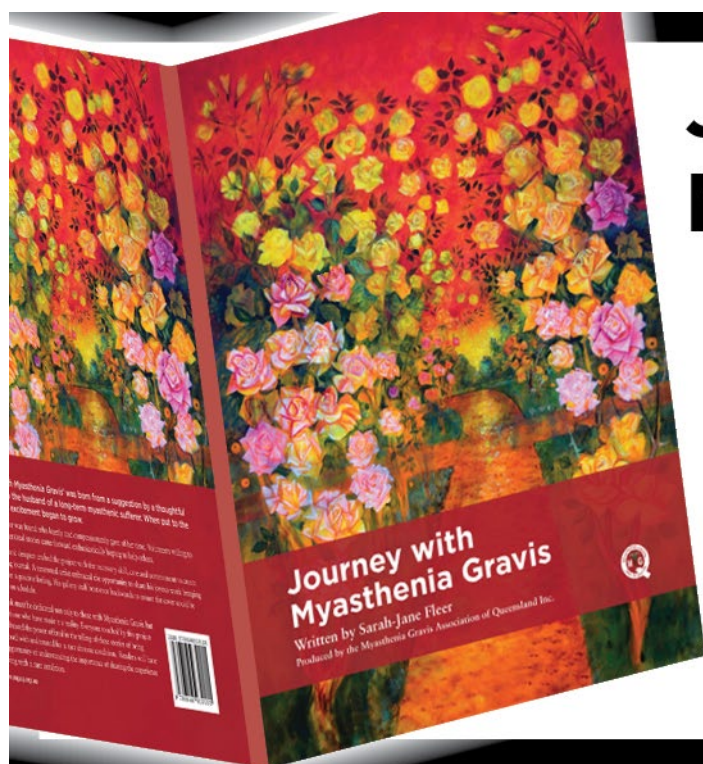
MGBase (previously known as eNID) is progressing slowly but very steadily and when our community help is needed we will let you know!

Working towards a "Patient Reported Outcomes Survey" to look at side-effects from MG related treatments has been a priority for the past 12 months. The MAA is confident that we will bring this opportunity to our members in 2021. More details will be given as they become available.

Regards

Susan White, Chairperson

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



Journey with Myasthenia Gravis

A book by Sarah-Jane Fleer

Raising awareness of Myasthenia is as important as always. The book demonstrates the uniqueness of each journey with the condition.

It aims to support those affected as well as their families and friends.

If you would like to purchase a copy,

Contact the Association

Freecall: 1800 802 568

Email: info@mgaq.org.au

Website: www.mgaq.org.au



MGAQ Inc. podcast series

UPDATE

THERE IS A NEW FEATURE FOR OUR PRIVATE PODCASTS

Now, subscribers can get an email every time we publish a new episode.

EVEN BETTER: Subscribers can listen to the episode in their web browser!

Your MGAQ Podcast Team have noticed that some of our members have had difficulty adding the private podcast feed to a player like Apple Podcasts. Plus, some popular players (like Spotify) that members may prefer don't support private podcast feeds.

To address this problem we have a new feature which circumvents all of that: subscribers get notified by email and can listen right away on the web. As shown below, giving an excerpt from the email, one simply clicks on the *'Play this episode in your browser'* button. Once you click this button, the system opens up a window in your browser, which allows one to play that podcast.

You will still be able to have the same existing functionality, that is you can listen using your favourite podcast listening app as shown below by clicking *'Listen in your favourite podcast listening app'*.

Also via the browser window, one can view any and all the previously published podcasts. So if you are a new member and haven't had previous access or you simply haven't been able, then you can play whatever previous podcast grabs your interest. A nice feature of this service is the system will show you when, if at all, you last

listened to each available podcast.

Don't want to receive emails each time the MGAQ publishes a new podcast! No problem, simply click the button on the first or any subsequent email which says *'Unsubscribe from these emails'* and the emails will no longer be sent to your address but podcasts will still be available on your podcast player if you have set that up.

So if you have been holding back from joining the MGAQ Podcast Subscriber List because of needing a Podcast Player, well there is no need now. Simply email me, Dr Podcast, at the following address podcast@mgaq.org.au and simply say **"Add me to the Subscriber List"**. That's all any member needs to do and when we publish each new podcast you'll get an email. We trust you will find this additional set of features useful.

Regards, Dr Podcast

How to listen

On the web, in your browser:

Play this episode in your browser →

Follow these instructions to listen in your favorite podcast player:

Listen in your favorite podcast listening app →

How Did We Continue as an Association with Workloads, Funding and Recruiting New Members.

The Association started with membership fees were \$10.00 with the first name of the association being The Australia Myasthenic Assoc in Qld. Our name changed to our current one in June 1995 when we were registered as a Charity Organisation. We also received permission from NSW Association to use their logo. Our current logo was implemented in 1997.

To keep things informal they held car rallies, picnics and bus trips. This gave us all a chance to meet people who had Myasthenia Gravis and to hear their stories and to form a bond with each other. There was also a raffle going at each event to help boost our funds.

They also held Garage Sales to raise monies and also awareness plus had stands in fairs and one was as the Racecourse Road Carnival. Hand made Rag Dolls were made to sell as they represent MG. There has been organised Radio Talks as well as placing pamphlets in Doctors' Rooms, Ambulance Stations, Hospitals and Chemists.

The committee has been on numerous trips throughout Queensland to raise awareness and

to put names to faces in Queensland as at first we were just doing things in Brisbane. They started up support groups in Cairns, Townsville, Mackay and Rockhampton. We also had meetings in smaller areas Ipswich, Mooloolaba, South Coast, Gladstone, Tamborine Mountain and Bundaberg.

The committee was relying on the generosity of members and friends who had been providing their own personal office equipment to use. It was decided to apply to Qld Health for Grant Monies to purchase equipment and it was received and we continue to receive it today.

The membership fees rose to \$15.00 from July 1995 and then rose to the present figure of \$20.00 in 2015 so they have been kept at a minimum rate.

We still have some of the founding members in the Association today. The association started with the drive to find out more about Myasthenia Gravis and also to find others with the disease and we still focus on these values today.



Fundraising at Racecourse Road Fair



Welcome to our new members

Gary E,
Maryborough,
Qld

Joan C,
Ipswich
Qld

Steve V,
Kingsford
NSW

David N,
Tweed Heads South,
NSW



Brisbane - Coffee & Chats

SUNNYBANK HILLS

The Coffee Club Sunnybank Hills,
Corner Compton Road and Calam Road
Thursday, 8 April at 10.30 am

Please contact Anita on 0414 588 312.



LUNCHEON

Shepparton RSL Club,
88 Wyndham Street, Shepparton,
Sunday, March 21 at 12 noon

RSVP necessary for Reservations by March 19.

For further information, please call Pauline 0419 332 260.

Bundaberg Coffee & Chat



We had a lovely get together this morning here in Bundy at the Waves Sports Club. Seven attendees, Dennis, Christine, Garry, Carol, Stephen, Wendy and Denise.

Enjoyed the company and food and everyone was happy to tell the story of their journey, each so different. Had some laughs, thanks Dennis, and some serious conversation.

How good does it feel to talk to people who understand what you are saying, can feel the same frustrations and relate to the trials we all deal with daily. Bundaberg will host another Coffee and Chat in a couple of month's time. Thank you to all who came and made this such a worthwhile event.

Puzzlers

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

Word Search - Asian Countries (1)

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

AFGHANISTAN
ARMENIA
AZERBAIJAN
BAHRAIN
BANGLADESH
BHUTAN
BRUNEI
BURMA
CAMBODIA
CHINA
GEORGIA
HONGKONG
INDIA
INDONESIA
IRAN
IRAQ
ISRAEL
JAPAN
JORDAN
KAZAKSTAN
KOREA
KUWAIT
KYRGYZSTAN

Answers

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

Bamboozable 34
Answers: 1. High IQ;
2. Misunderstanding;
3. Backwards
Somersault; 4. No
One is Perfect; 5.
Upwards Battle; 6.
Times Up
Word Change 24
Answers
cost
coat
cowl
bowl

Sudoku

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

Word Change

cost
bow

Bamboozable

I Q	STANDING MISS	WAS REMOS
ONE ONE ONE	BATTLE	TIMES

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

News from around Queensland

News from Cairns

Looking forward to catching up once again at **Cairns RSL Club, Boardroom** on **Saturday, 17 April at 11 am.**

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

News from Townsville

Next lunch for Townsville MG group will be held on **Saturday, 17 April 2021** at **The Avenue Hotel** at **12 noon.**

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.**

News from Bundaberg

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

News from 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.**

News from the Sunshine Coast

The Sunshine Coast group will meet again on **Monday, 12 April at 10.30am** at **Kawana Club, Nicklin Way.**

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

News from the Gold Coast

Our next meeting will be at **10am, Saturday, 27 March** at **Southport Sharks Club.** I hope to see all there.

Kind regards **Nader Amiri**, Gold Coast Co-ordinator, **0415 834 401.**

WHO is this?



ANSWER NEXT EDITION

SAVE THE DATE

30 years
anniversary
1991~2021

Celebration

Sunday, 13th June 2021 - 10am
at **Hornets Football Club, Graham Road, Carseldine**