



Myasthenia Gravis Association of Queensland Inc

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Messages

Myasthenia Gravis Association Of Queensland Inc.

FEBRUARY 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

Welcome to the new year and I hope that everyone is keeping safe and well. It sometimes seems that we cannot cope with any more problems and issues being put upon us. We are very lucky to be living in Australia and have such a great medical system and wonderful volunteers who are prepared to just keep going to support our country when it is in need.

The information that we are getting about COVID-19 makes it appear that it will be part of our lives for a considerable time to come. Some top neurologists from across the country are constantly evaluating the information about vaccines and, as soon as they feel satisfied about the correct one for people with Myasthenia, this will be communicated to all members.

We still have quite a few members who are unfinancial. As this money is used for things like producing and sending 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.

A number of projects in which the MGAQ is involved have continued to evolve during the past few months. We look forward to being able to share information about our current projects with you plus those in which the Myasthenia Alliance Australia is taking the lead. Projects such as eNID are progressing well.

Rare Diseases Day is on 28 February. Please take a minute 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 are a similar number of people living with a rare disease as there are people who have diabetes or asthma.

2021 is a significant year for the MGAQ as we celebrate thirty years as an association. Our patron, Dr Cecilie Lander, has written a very interesting article about how the association grew out of a need for people with Myasthenia to get together and support each other - the same applies to our association thirty years later. Member Welfare is still an important aspect of the MGAQ's work.

Let us all hope that 2021 is more positive than 2020.

Thanks, Carol

Supported by



Queensland
Government

Ausenco

MYASTHENIA ALLIANCE AUSTRALIA NEWS



MAA UPDATE

Welcome to 2021!

There is hope for a better year ahead as the vaccinations are to commence. Sudden border closures and surprise exposure to the virus remain a constant concern.

The MAA will publish comment from our Medical Advisory Board as soon as full commentary on the vaccines is made available.

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The eNID project has progressed well over the past few months with a "Go Live" for the Pilot Phase happening. A Domain name has been secured plus Logos and Launches are being discussed.

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In a latest partner event with Rare Voices Australia, the MAA has participated in a forum to discuss how the NDIS is functioning for people with rare disease. NDIS Assistant Directors for Community Engagement attended the meeting which was chaired by RVA CEO, Nicole Millis. The directors took notes and asked many questions. In summary of the feedback to the MAA from people with Myasthenia and from others attending the forum, it seems that distinguishing between permanent disability and chronic/acute/palliative impacts is causing difficulties when applying for access to the NDIS. Validating access is the first step to a successful application. Seeking professional support in writing an application is very helpful but many plan managers don't always grasp the complexities of more chronic conditions such as Myasthenia so it can be a difficult process. There is on-line support available to help understand this access process

Accessing the NDIS - Providing evidence of your disability

This link will take you to information to help you provide strong evidence of disability <https://tinyurl.com/2j4v8xc6>

Documentation from Doctors and service providers is also required and again, discussion reflected how ill prepared Professionals are to address the questions adequately. Of note, the NDIS is available to people from 7-65 years. Application for support must be lodged prior to turning 65 years. It does not require an approval for funding to be provided by this date.

With the support of Terumo BCT, a tailored public affairs toolkit has been developed entitled "*How can patient organisations ensure their voices are heard in public policy?*" The aim is to help Australian patients in their advocacy efforts. This toolkit contains practical and easy-to-follow steps to facilitate outreach activities and discussions with public stakeholders.

Please link to this publication via <https://bit.ly/3cEsBbj> (you will be prompted to save the PDF to your computer). This booklet was produced as patients and patient organisations can add value to health care planning and can be directly involved in the healthcare decision-making process. Advocating takes much time, effort and an adequate approach to ensure that the right people are engaged at the right time and this booklet may be helpful.

The authors of this toolkit are considering offering a supplementary training webinar. Get in touch via **1800 802 568** if you are interested!

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Rare Diseases Day will be celebrated around the world on **February 28**. Susan will again represent the Myasthenia community at a Virtual Rare Disease Day Parliamentary Event to be hosted in early March.

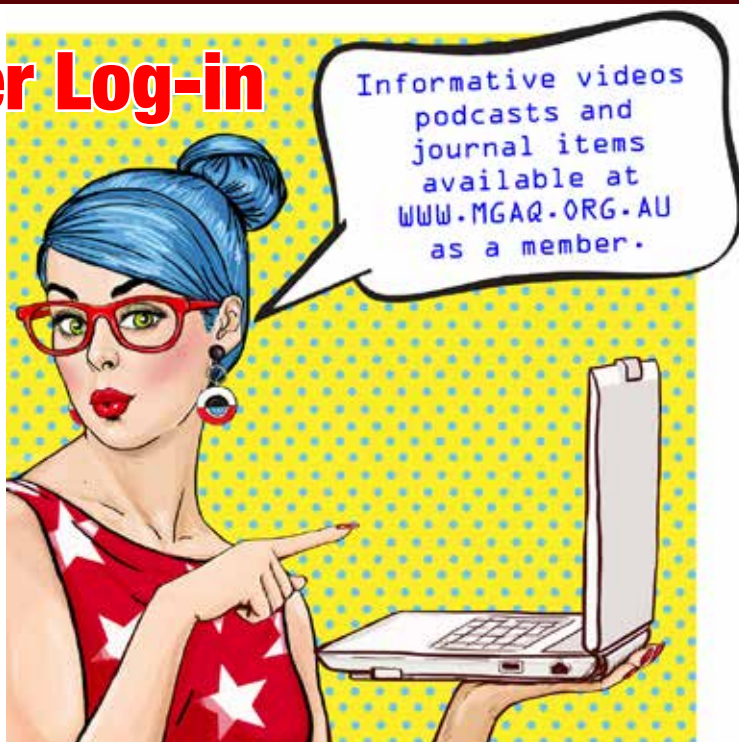
Regards**Susan White, Chairperson**

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

MGAQ.org.au Member Log-in

A wide range of informative videos, Podcasts, and Journal items can now be accessed by visiting the **"members only"** section of the MGAQ website at www.mgaq.org.au/members-only

All members will need a username and password to login and access the members only pages. Financial members can request a password by visiting www.mgaq.org.au/user/register and then completing the online form. Once you have access to the members-only area, you will be able to view, listen or read on your smart phone, iPad, tablet or PC.



Brisbane - Coffee & Chat

"IN RECOGNITION OF RARE DISEASE DAY"

WHERE Ipswich, Queens Park Café, 10A Merle Finimore Avenue

WHEN Saturday 27th February at 10.30am

Please contact Anita on 0414 588 312.



RARE DISEASE DAY®

28 FEBRUARY 2021

RAREDISEASEDAY.ORG

#RAREDISEASEDAY



RARE IS MANY RARE IS STRONG RARE IS PROUD

Rare Disease Day is organised by EURORDIS-Rare Diseases Europe and 62 National alliances of patient organisations for rare diseases.

Meandering Memories

On the origins of the Myasthenia Gravis Association Queensland (MGAQ)

The year that comes to mind is 1989.

I had returned to Brisbane from London as a qualified neurologist exactly a decade earlier and I was thoroughly enjoying the diversity of people with neurological conditions who were coming to my rooms on the Terrace in Brisbane. There were lots of challenges, but treatments were changing and so much more could be offered in every neurological discipline.

Myasthenia Gravis (MG) is a relatively uncommon neurological disease but one that attracted my interest. Treatment could be difficult. Anticholinesterases were used since 1934; thymectomy was endorsed from the late 1960's; azathioprine and prednisone were added in the 1970's.

The uncovering of the immunological origins of MG gradually occurred through the last decades of the twentieth century. Professor Iain Simpson had hypothesised an immunological basis in 1960; in the same year, the first tissue specific antibody to striatal muscle was reported. The existence of anti-acetyl choline receptor antibodies was demonstrated in 1973 and Lindstrom in 1977 reported a reliable assay. When I lived in London, I had the good fortune to meet Professors Angela Vincent and John Newsom-Davis who published their seminal findings concerning anti-acetylcholine receptor antibodies and MG in 1980.

So, it was with this background, that in 1989, I had the privilege to meet Gerald Hancock and a short time later, Kathleen Ross. Both wanted MG information and support to be readily available. Remember that in 1990, the world had not yet arrived at the computer age when information was merely a click away on a webpage, a word not yet invented! It was apparent that there was no community MG body in Queensland. I had personal experience of the Epilepsy Queensland Association and I suggested, independently, to both Kath and Gerald that a lay support body would be a valuable resource for this relatively rare disorder in Queensland. They both jumped at the possibility. They chatted and agreed to start the project—and the rest, as they say, is history!

Kath was a quiet, determined, and efficient or-

ganiser. Gerald was an ideas man with enthusiasm and flamboyant energy. They surrounded themselves with a vibrant team and together, they began the hard work. Connections were made with the MG lay body in NSW. The first Queensland Committee meeting took place at the Early Street Historical Village at 75 McIllwraith Avenue, Norman Park (which at the time belonged to the Hancock family) on the 1st of May 1991. Kathleen Ross was elected President, Gerald Hancock Secretary, Helen Carmosina Assistant Secretary and Treasurer, Robert Kubler Vice President and Rob Wallis Assistant Vice President. Attendees whose names appear in the first Minutes are Kathleen and Frank Ross, Gerald Hancock, Jenny and Robert Kubler, Kathy and Robin Wallis, Pearl and Bill Bennet, Joy Duggan, Shirley Langshaw, Ray Middap, Patricia Johnston, Shirley Johnston, El-laha Shahidi and Helen Carmosina.

The newly formed Committee and members gradually built-up contacts and developed a data base of MG sufferers and their supporters. My involvement remained as medical advisor and I was not involved with the functionality or structure under which the original MG Association operated. The AGM each year however was a pivotal educational event and became a time to invite a guest speaker to update members on the latest MG news. Quite often in those early years, the MG Association Executive would invite one of my colleagues or myself to give a medical talk and update. I have always believed that having a dedicated lay support group offered valuable education and support and I strongly encouraged my Neurological Registrars as well as Allied Health professionals to visit the MG Association, offer talks and discuss strategies for effective management.

WHAT DO I REMEMBER OF THE EARLIEST MGAQ MEETINGS?

I recall being astonished when Gerald, ever the entrepreneur, came in carrying a large wooden box about the size of a large carton of coke. It contained an early prototype of a truly mobile

phone, certainly the first I had ever seen! I recall Kath's wonderfully good humour as she tried diligently to get her team back to work and to keep them on track; she was such a skilled organizer. And yes of course there were some occasional disagreements too.

But what I recall most is the laughter! Joviality. Care and compassion. MG meetings were always fun. And lots of hard work. In those features, nothing has changed in this regard. The good humour,

the care and compassion for each other and the hard work all continue to the present day.

Congratulations MGAQ on achieving 30 years and may you long continue to support Queenslanders who suffer from Myasthenia Gravis and their carers. It has been an honour to be your Patron.

Thank you MGAQ!

Cecilie Lander



Cecilie and Kath



Shirley and Kath



First meeting.



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.

**Do you recognise anyone from the photo of the 1st meeting?
We would love to hear from you!**

18-35 PRIVATE slack COMMUNITY

Conversation available.



YOU DON'T HAVE TO BE A MGAQ MEMBER TO JOIN!

- Created to meet the needs of this younger group who are thinking about careers, travel, relationships, and starting a family.
- Discussion to be guided by participants and supported by a neurologist.

Find this group by emailing info@mgaq.org.au for access.



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.

Puzzlers

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

Word Search - African Countries (2)

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

MALAWI
MALI
MAURITANIA
MAURITIUS
MOROCCO
MOZAMBIQUE
NAMIBIA
NIGER
NIGERIA
RWANDA
SENEGAL
SEYCHELLES
SIERRALEONE
SOMALIA
SUDAN
SWAZILAND
TANZANIA
TOGO
TUNISIA
UGANDA
ZAMBIA
ZIMBABWE

Answers

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

moon
loon
oot
lost
last

Answers

Word Change 25

Upright Piano
Room for One More,
Old Too Learn,
Earth, 4. Never Too
Raise, 3. Peace on
Happiness, 2. Pay
1. Spread a Little

Answers:

bamboozable 33

Sudoku

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

Word Change

last
moon

Bamboozable

h a p p i n e s s	PAY	PPPPPP EARTH
Never Old Learn Old Learn	MORE MORE MORE MORE MORE	O N A I P

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

News from around Queensland

News from Cairns

Rare Disease Day - February 28 2021 - Come and join Rare Friends in Cairns on Sunday, February 28 at Cairns Esplanade and walk, run or ride to support locals affected by Rare Disease and recognise International Rare Disease Day. Fun run starts at 8.30am.

To register go to www.rarefriends.org

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

News from Townsville

Our next lunch is on **Saturday, 20 February** at The Avenues Hotel, Kern Bros Drive, Birwan at 12 noon.

For more information, 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

Bundaberg will be holding a get-together on **Sunday, 14 March** at 10.30 am at The Waves Sports Club, 1 Miller Street. RSVP to **Denise** 0431 571 399 or 1800 802 568.

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 or (07) 4973 7983.

News from the Sunshine Coast

Call **Vicki** on 0411 146 898 or email avplummer@gmail.com

News from the Gold Coast

The MG Gold Coast Group had their get together sharing experiences with other members on Saturday, 23 January at Kurrawa Broadbeach Surf Club.

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.



WHERE IN QUEENSLAND?

Let us know where you think it is:

Send to: info@mgaq.org.au
or post to MGAQ, PO Box 16,
Mt Gravatt, Qld, 4122



Brisbane - Coffee & Chats

IPSWICH

Queens Park Café, 10A Merle Finimore Avenue
Saturday, 27 February at 10.30 am

MANGO HILL

Coffee Club, Cnr Anzac Ave and Halpine Drive
Thursday, 11 March at 10.30 am

Please contact **Anita** on 0414 588 312.



Welcome to our new members

Rachel S,
West Moonah,
Tas

Tony S,
West Moonah,
Tas.

Teena T,
Pimlico,
QLD

Ian,
Biloela,
QLD