



Myasthenia Gravis Association of Queensland Inc.

MessaGes

APRIL
2024



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 APRIL 2024

The management committee hopes that everyone had a healthy and safe Easter filled with laughter, family and friends.

Some executive members will meet with Queensland Health later this month. This meeting is to review the workings of the association in light of the upcoming expiration of our funding. We certainly hope that the untiring work done in member welfare, research, awareness and advocacy is conveyed to the team at Community Services Funding Branch and that we are successful in securing much appreciated funding into the future.

Members with access to the computer would have received an Email in relation to possible inclusion in any upcoming surveys. Both the MAA and MGAQ endeavour to ensure that any avenues to further the 'needs' of our members through research are supported. Please take the time to respond to this email so that you can be contacted if you are willing to be involved into the future. If you are unable to find this email please phone the freecall number 1800 802 568.

Our Light Up Project for June Awareness growing even bigger and more places around the state are becoming involved. More information will be in the next couple of newsletters and we hope that, if you get the opportunity, please take

a photo and then send it to info@mgaq.org.au for possible inclusion in our newsletter. Also, please remember that not all photos might appear in the newsletter but they will be saved digitally for future use.

Please take the time to read the Art With Heart information on pages 4 and 5. Then, take the time to view the articles for auction.

In next month's newsletter you will see the membership renewal information. We are always grateful to those people who make a donation at the same time as they renew their membership. Because the MAA does not have any direct line to donate to this very busy and worthwhile group, you will find boxes which ask you to which group you want your donation to go – to the MGAQ or to the MAA. Please make sure that, if you add a donation with your membership fee, that you tick the appropriate box. If you wish to share the donation please write the amount next to each box once you have ticked same. I also must stress that one membership fee does not even cover the printing and posting of the newsletter so your management committee really does appreciate membership renewals which seem to be becoming less and less each year. We need your support so we can support you.

Thanks Carol

Myasthenia Gravis Association of Queensland Inc

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



MYASTHENIA ALLIANCE AUSTRALIA

NEWS UPDATE

Check it out!

Some wonderful **items have been donated to the Art With Heart campaign** and you can see them by visiting www.myastheniaalliance.org.au. Information about the campaign, how to donate and what is available can all be found here.

We are so very grateful for the amazing support received from two renown Australian artists who have gifted paintings to support people living with this rare disease. These artists are Herman Pikel and Chris Seale. Information is provided about them or you may prefer to google and see the wonderful works they have produced and read about the many awards they have received.

If you receive this newsletter by traditional mail, please ask a friend to log on to the Myasthenia Alliance Australia website so that you can take a look. It won't be hard for them and everyone will enjoy viewing the growing list of items.



The Pharmaceutical Benefits Advisory Committee (PBAC) will assess a new treatment called Zilbrysq® (Zilucoplan) for generalised Myasthenia Gravis patients at its meeting in July 2024. Zilucoplan is a once-daily subcutaneous (an injection into the tissue between the skin and the underlying muscle), self-administered peptide inhibitor of complement component 5 (C5).

Submissions expressing interest in accessing this new medication are now being accepted with a closing date of May 29th 2024. The MAA will make a submission on your behalf as the organisation representing all MG patients in Australia.

The Myasthenia Alliance Australia (MAA) encourages MG patients and carers or families/friends to **consider making a personal submission highlighting the lived experience**. Individual submissions add great impact and help demonstrate the diversity of our experience with MG and the importance of having different treatment options to give us all the best care and quality of life. It is also an opportunity to share your voice and experiences with the national decision-makers.

This is the same process we recently did for another new treatment (Ravulizumab). It is fantastic to have yet another opportunity for a new treatment mode.

Please stay tuned for updates from the MAA (make sure you are registered at www.myastheniaalliance.org.au and state associations, as we will again provide useful information and guidance if you would like to make a submission.

Thankfully the summer heat has now passed and this may make life a little easier.

Kind regards

Susan White - MAA Chairperson.

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

BECOME INVOLVED - MAKE A DIFFERENCE

For membership payments and donations, the MGAQ account details are:

BSB: 124032

A/C: 10263772

CONVERSATION CONNECTION COMPANIONSHIP

ASPLEY

A fantastic response with 17 people attending the recent Coffee and Chat at Aspley in Brisbane. Those who attended enjoyed the opportunity to share experiences about their journey with MG. It was decided that future Aspley Coffee & Chats would be held at Hornets Football Club.



IPSWICH



GOLD COAST



Scan to apply for
Membership or to
renew your existing
Membership



Scan to make a
donation to the
Myasthenia Gravis
Association of Qld Inc.



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

Creativity *for* Positivity

ART WITH HEART AUCTION IS NOW LIVE

**DARE YOUR FRIENDS AND FAMILY TO CARE ABOUT MAKING A
DIFFERENCE FOR PEOPLE WITH MYASTHENIA GRAVIS.**

You are the difference that drives us!

The Myasthenia Alliance Australia (MAA) is very proud to continue the good work occurring with International June MG Awareness Month and delight in announcing the launch of an **Australia wide "Art With Heart"** Auction in support of our condition. This has been a major undertaking of the MAA with its second year running.

MAKE AN IMPACT

Wondering how you can get more involved to help and support the MG Community?

The first step in this awareness endeavour requires us, our strong and committed Myasthenia community, to reach out to our families, friends, neighbours, workmates, health professionals, government representatives at all levels and everyone to ask for contributions to the auction. This event is targeted towards strengthening our MG community by providing interaction as a group in a fun and positive manner.

It is also very much about raising awareness of Myasthenia Gravis throughout the broader community. Build community awareness by reaching out to social groups and NGOs.

Become a sponsor. If we want to ask for understanding from others or acknowledgement from medical providers, they need to be familiar with our condition.

What are we asking you to do to make this event successful?

Contributions of all types (large, small, service based or tangible object) will be greatly appreciated.

- Please donate items or ask others if anyone would like to contribute.
- Share the news as widely as possible. This can be done by:
 - Focused conversation
 - Via emails
 - Sharing on Face-book/Instagram etc.

We will be starting off this year with some great donations from our wonderful members and supporters.

We now have a range of items including paintings, crafted wooden items, beautiful quilts but we require more items! ...

We are extremely grateful for the paintings received from some award-winning artists.

Herman Pekel Artwork - Oil painting by Hermen Pekel

Herman Pekel is an Australian artist born in Melbourne in 1956 of Dutch parents. He held his first solo art exhibition in Melbourne at the age of 17, which was a sell-out success. Pekel is a multiple winner of the prestigious Camberwell Rotary Watercolour prize and the Camberwell Rotary Travel Scholarship. His tonal works in oil and watercolour range from city to landscapes, to café and bar interiors, to dynamic industrial scenery. Herman is an artist of energy and enthusiasm, able to see a painting in almost any subject matter and capable of producing award-winning work. His work is featured in many

CONTINUED NEXT PAGE

books and is exhibited widely, and regularly in the USA.

Herman is a multi-awarded painter: a three-time winner of the coveted Camberwell Gold Medal Art Prize and a winner of the prestigious Alice Bale Award in 1989 and 1993.

His works are featured in several books: 'Australian Impressionist and Realist Artists', compiled by Tom Roberts and which features Australian artists, '120 Years of Watercolours' by the Australian Realist Artists, 'Artists and Galleries of Australia and New Zealand' by Max Germaine, and 'Profile on Contemporary Watercolours'

He is a painter of immense talent and insight and continues to actively exhibit across Australia and internationally. Herman is represented in Artbank, Castlemaine Regional Gallery, Grafton Regional Gallery, Bathurst Regional Gallery plus public and private collections in Australia and overseas.

Country Charm - a stunning oil canvas by Chris Seale

Living in Kurrajong Australia, Chris is a member of the Plein Air Painters of Australia and is working towards the next solo exhibition.

Coming from a very talented family, Chris developed love for painting developed at a very young age. Chris first gained recognition in 1965, at the Parramatta Agricultural Show with a 1st prize in drawing and a 2nd prize in watercolour.

Pursuing a love of nature, Chris is particularly well-known for countless contemporary-impressionistic bush, land and seascapes.

Over the years, Chris has developed a unique painting technique in both modern and traditional works. Has had numerous solo and joint exhibitions; is privileged to have been frequently requested as artist in residence and has also presented numerous live demonstrations.

In brief, Chris' career highlights include two 1st prizes at the Sydney Opera House Art of Sydney Awards 1996/1997. More recently a prize winner at the d'Arcy Doyle Art Awards Qld. 2014. Multiple awards at Royal Queensland Art Society in 2015. 3rd Sydney Royal Show 2016, 2nd and 3rd Prize in the Hawkesbury Show 2016/ 2017, 1st prize and people's choice in Macquarie Towns Arts Society 2017, 1st prize in Sydney Royal Show 2017. Best in show Hawkesbury Show 2018. Winner Ardency Art award 2018, Springwood Art Show Rose Lindsay award winner 2018, 1st traditional, 1st drawing Castle Hill OBF awards 2018. 2nd in Open and 2nd Local Artist Hawkesbury Show Richmond 2019. 1st and commended Macquarie Towns Autumn exhibition 2019. "Award of Excellence" 1st Sydney Royal Show 2019. Highly Commended Royal Art Society of NSW 140th Celebration Exhibition 1880 to 2020 and 1st "Award of Excellence" Sydney Royal Show 2021. ...

And Prints from original canvas by **Skye Elizabeth Carroll**

- Underwater
- Beautiful Parrots
- In Port
- Bathtime

It is time to dig deep for the Art with Heart Auction proudly hosted by the Myasthenia Alliance Australia. All the pieces that you see in the auction have been lovingly donated by Myasthenia Gravis Warriors and their supporters. Please see the flyer and auction kit for specific details. Call 1800 802 568 to discuss if you are uncertain.

Finally, we need people to bid at the Auction now that it is open

An Artist Kit can be downloaded here www.myastheniaalliance.org.au/wp-content/uploads/2024/04/MGAQ-Artist-Kit-2024-v1.0.pdf

<http://www.airauctioneer.com/art-with-heart-auction-myasthenia-gravis>

#myastheniagravis #MGNSW #MGAQ #RareVoicesAustralia

Please do get behind this MAA campaign. Together we keep working for a better life for all.

As Pablo Picasso said, 'Art washes away from the soul the dust of everyday life.'



www.myastheniaalliance.org.au

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

MYASTHENIA AWARENESS

QUEENSLAND LIGHTS UP for MYASTHENIA



The Myasthenia Gravis Association of Qld has currently secured 28 sites around the State to illuminate in teal in recognition of International Myasthenia Gravis Awareness month in June.

The locations and dates will be available in the May Newsletter.

Have you seen the MGAQ Billboards on the Bruce Highway?



Site No: LS105A

Southbound Glenorchy

Located near Glenorchy, south of Maryborough on the Bruce Highway. It's on the left hand side as you travel south toward Tiaro & Gympie.

6.00m x 3.000m

+25.640846, -152.639038



Site No: LS145A

Outbound Rockhampton

Located 15km north of the Rockhampton (Yepoon turn-off) on the Bruce Hwy. It's on the left hand side as you travel north out off Rockhampton. (Approx. 1km south of the Caves)

6.00m x 3.000m

+23.189922, -150.467833



The Myasthenia Gravis Association of Queensland banner will be displayed on the
Story Bridge
in Brisbane (inbound) from
27th May to 9th June.



SUPPORT your Association by **VOLUNTEERING.**

What does it mean to live with a rare disease?



Opportunities for change

Accessing reliable information

Although no health professional can be an expert in all rare diseases, partnerships can be formed between health professionals and patients and patient support groups to learn more about the condition. You can do so via the QR code below to the RARE Portal.

Support for all people living with rare diseases

Rare diseases often impact people's mental health and wellbeing, and can result in out-of-pocket expenses.

Checking in on people's wellbeing and helping facilitate access to appropriate mental and socio-economic supports is important. You can do so via the QR code to the RARE Portal.



Scan to visit
the RARE Portal

What is a rare disease?

A rare disease is a chronic and complex condition that affects **less than five in 10,000** people.¹

How many rare diseases are there?

Over **7,000 known rare diseases** exist with more yet to be named. Unknown or unclassified diseases are referred to as **undiagnosed diseases**.¹

What are the types of rare diseases?

80% are of genetic origin, however, other non-genetic rare diseases include rare cancers, infections, and autoimmune disorders.¹

How many Australians live with a rare disease?

An estimated two million Australians currently live with a rare disease which is **approximately 8% of Australians**.¹

The health system and rare disease



Inequitable access to healthcare, **limited referral pathways**, and lack of **care coordination** make navigating the health system challenging.¹



By virtue of being rare, rare diseases can often result in **delayed diagnosis and misdiagnosis**. Education and awareness are important factors in ensuring people living with a rare disease receive a quicker, more accurate diagnosis.¹



Specialist clinicians, health services, medicines and therapies are often **not available** or **accessible**.¹



Rare disease **data is not captured** in health information **systems or registries**, with no strategy to collect, measure and translate data.¹



Scan the QR code
for more information.

1. Australian Government Department of Health. National Strategic Action Plan for Rare Diseases. Canberra; 2020. 63 p.
Accessed from: <https://www.health.gov.au/resources/publications/national-strategic-action-plan-for-rare-diseases> on 9 October 2023.

Puzzlers

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

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

Number Block

Try to fill in the missing numbers.

The missing numbers are integers between 0 and 12. The numbers in each row add up to totals to the right. The numbers in each column add up to the totals along the bottom. The diagonal lines also add up the totals to the right.

								35
8	6		1		4	1	3	34
	8	2	5	1		0	2	29
4	11		1	11	11	2	0	46
9	4			9	9	5	1	53
8		12	1		5	8	4	50
8	7	8	9	7	3	8	12	62
3	1	6	4	11		8	7	44
2	3	7	4	2	9	0	1	28
51	44	54	32	56	47	32	30	49

Mad Cabs

They are a group of words, that at first glance and first saying don't make sense... but say them SLOWLY and LISTEN to what you hear to figure out what the phrase is. Example: Common Firm Their Rain = Come In From The Rain

1. Abe An An Ap-
peal
2. Abe Autumn
Lisp Hit
3. Abe Ax tree
Tally
4. Abe Hair Heat
Rash You're
5. Abe Hum Pen
Thin Height

U can 1,2,3,... IT	DO ¹² OR	CAN'T DO CAN'T DO CAN'T DO CAN'T DO
GOODNESS GOODNESS NEST	WEIGH PRICED	living SHOESTRING

Answers

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

49	30	32	47	56	32	54	44	51
28	1	0	9	2	4	7	3	2
44	7	8	4	11	4	6	1	3
62	12	8	3	7	9	8	7	8
50	4	8	5	8	1	12	4	8
53	1	9	9	7	9	4	9	9
46	0	2	11	11	1	6	11	4
29	2	0	2	1	5	2	8	9
34	3	4	7	1	4	4	6	8
35								

bamboozable 17 Answers: 1. You can count on it; 2. Foot in the door; 3. No can do; 4. Honest to goodness; 5. Way overpriced; 6. Living on a shoestring;

Mad Cabs 1 Answers: 1. A Banana Peel; 2. A Bottomless Pit; 3. A Back Street Alley; 4. A Buried Treasure; 5. A Bump in the Night



This is an ongoing request to the MG community.

Please REACH OUT to your Local, State and Federal Representatives

both formally through a requested meeting or informally at a Meet and Greet event to:

- ♥ Tell them that you have a rare disease and that getting care is time consuming and hard;
- ♥ Tell them that Centres of Excellence would be ideal;
- ♥ Tell them that it is a long and chronic condition where little assistance is offered through NDIS;
- ♥ Show them the website details:
- ♥ Tell them that greater awareness is needed to improve care;
- ♥ Show them the Art With Heart flyer explaining how we are trying to help ourselves;
- ♥ Talk about the depth of work undertaken by your MGAQ and MAA committees;

www.mgaq.org.au and www.myastheniaallianceaustralia.org.au

**DUE TO THE MANAGEMENT COMMITTEE NOT MEETING IN APRIL,
ALL APPLICATIONS FOR MEMBERSHIP WILL BE HELD
OVER UNTIL MAY MEETING.**

NEWS FROM AROUND QUEENSLAND

Please remember to bring empty Mestinon bottles to all MGAQ gatherings to support Chloe's art project.

News from Cairns

The Cairns group will meet at **The Bluewater, 7 Harbour Drive Trinity Park** on **Saturday, 18 May** at **11.45am**. Look forward to catching up with everyone and also visitors to Cairns.

For more information, please contact **Donna** on **0414 397 462**.

News from Townsville

Our next lunch is **Saturday 20 April Sports Club** at **12 noon**, **159 Bamford Lane, Kirwan**.

Please RSVP to **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

For more information please contact **Michael** on **0447 887 652**.

News from the Gold Coast

We will be meeting at **10am** on **Saturday, 11 May** at **Southport Sharks Club, Corner Olsen and Musgrave Ave, Southport**. I look forward to seeing you all.

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



ALL WELCOME

**SPRINGWOOD - Saturday 18th May 2024 at 10.30am, More Cafe,
Shop 1/34 Fitzgerald Ave, Springwood Shopping Mall**

RSVP Anita on 0414 588 312

WHAT'S ON?

What's On	When and Where	Topic
June Awareness Function GUEST SPEAKER, ASSOC. PROF. JAN SANSONI	SUNDAY 9th JUNE Aspley Hornets Football Club, 50 Graham Road, Carseldine	Myasthenia Gravis Research: Capturing Health Outcomes and Patient Perspectives

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