



Messages

MYASTHENIA GRAVIS ASSOCIATION OF QUEENSLAND INC.

AUGUST 2016

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.

Myasthenia Gravis Association of Queensland Inc

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PRESIDENT'S REPORT

G'day all,

I think there will be some interesting times ahead for the nation following the result of the Federal election, but let's hope that the country will continue to progress.

You will note in the Members' Forum of this issue an item from our newsletter editor, Greg Breaden, regarding a local newspaper story that he organised.

The most interesting thing about the article is the response Greg received from people who are not members of the MGAQ. This could be an idea for other members to put pen to paper (or the electronic version of it) and submit your own story to local media outlets as a way of increasing awareness of MG among the general population.

Of course, a Members' Forum item similar to Greg's would be a great follow-up.

I would again remind members who receive the newsletter directly from the Association via hard-copy or email, that if they have not yet renewed their membership,

to please renew it before 30 September if they wish to continue receiving their copy of the newsletter directly after that date. If you are not sure of your membership status, please email to info@mgaq.org.au or contact our **1800 802 568 Support Line.**

Non-financial members after 30 September, will need to register at our website www.mgaq.org.au to receive the newsletter via email.

Don't forget the Annual General Meeting on Sunday, 11 September, 2016. Guest Speaker is Nicole Millis from Rare Voices Australia, an umbrella not-for-profit organisation for groups which support people with a defined rare medical condition, of which MG is one.

Full details are on page 8 of this issue. Let's make this year's AGM a real success.

I look forward to catching up with current and new members at the AGM.

**Cheers
Graeme**

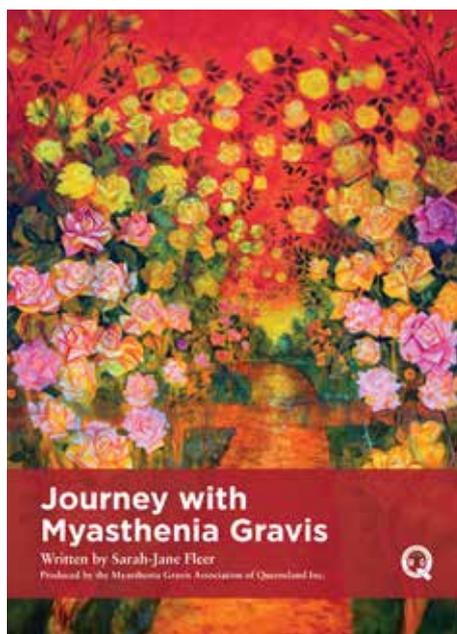
Supported by



Queensland
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Ausenco

“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.

Contact the Association on 1800 802 568, email at info@mgaq.org.au or go to our website www.mgaq.org.au if you wish to purchase a copy.

MYASTHENIA ALLIANCE AUSTRALIA



Myasthenia
Alliance Australia

who are we?

Myasthenia Alliance Australia was formed to support the needs of myasthenics from all states, particularly on issues and items of national importance. At this stage, Queensland and New South Wales have signed the agreement but any state which has a group registered as an association is welcome to apply to join this alliance.

The objectives of Myasthenic Alliance Australia are to:

Support people sharing unique and differing

experiences with the myasthenic syndrome.

Foster meaningful and distinctive dialogue amongst the associations through direct sharing of new information.

Develop and implement co-operative initiatives through a national platform that provides 'one voice' on issues pertaining to myasthenia.

Unify Australians with this condition and provide a pathway and voice for myasthenics throughout Australia

Promote an understanding and awareness of myasthenia through education and pressing for practical solutions through advocacy.

Promote and support research into this condition.

Ensure that each individual association continues to operate with full autonomy.

Follow the work of the Alliance by registering at the website

www.myastheniaallianceaustralia.com.au

PROJECT UPDATE

RESEARCH UPDATE

“eNID” (the electronic data registry project for neuro-immunological diseases being developed in Australia) continues to progress through the establishment phase.

It is in the third round build phase at the present. More details will be released when it is launched. Hopefully this will occur in the next few months.

NEWS FROM AROUND QUEENSLAND

News from Cairns

The Cairns group will next meet on Saturday, 17 September, at 11.00am at the Cairns RSL Club Boardroom (upstairs).

Visitors are always welcome.

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

News from Mackay.

On Sunday, 17 July, we held our lunch get-together at Harrup Park.

Eleven members attended. A report was given on the Co-ordinators meeting on Saturday, June 11, 2016 and the 25th Anniversary Meeting on Sunday June 12, 2016. Both of these were held in Brisbane.

All attending had an enjoyable lunch and discussion later. Our intended guest speaker was unable to attend because of unforeseen circumstances.

Sunday was a perfect day, bright and sunny, not like the previous two days, which there was very heavy rain.

Eleven members attended and a get well card was signed by all attending and posted to a member who is unwell.

The dates for our get-togethers for the rest of the year are: Sunday, 18 September, 2016 for lunch at Mt. Pleasant Tavern, 12 noon, and Sunday, 13 November, 2016 for our Christmas Party at Souths Milton Street, 12 noon.

All M.G. Association members, carers and interested people are welcome to attend .

For more information on any of these events, contact Bill, Area Co-ordinator, 07 4954 1221, Mobile 0429 729 685

News from Townsville.

Our July lunch meeting was attended by 12 members and 6 family members.

We appreciated the information given by Jo and Carol about the talk by Dr. Anthony Pane a Brisbane Neuro-Ophthalmologist at the June

meeting of MGAQ in Brisbane.

Many thanks to the couple who travel from Ayr to attend our lunches.

Our next lunch meeting is on Saturday, 24 September, 2016 at 12 noon at The Avenues Hotel, 270 Kern Bros Drive, Kirwan, Townsville.

Regards, Daphne 0400 778 637.

Email: daphclay@gmail.com

News from Rockhampton

For more information, contact Jeanne Harp. jharp08@hotmail.com or 0437 048 361.

News from Wide Bay (Hervey Bay)

There aren't any meetings scheduled for Wide Bay currently, but if you need more information, contact Jan Powell, Ph. (07) 4128 6045, Mobile 0429 622 438 or Email Janpowell3@bigpond.com

News from Wide Bay (Gladstone)

If you would like to find out if there are any upcoming functions, or get-togethers, contact Garth, the local support Co-Ordinator for Gladstone-Wide Bay on mobile 0408 155 954 or (07) 4973 7983

News from the Sunshine Coast Group

If you have any queries, please contact: Colleen McLean 0409 491 789.

colleen4551@gmail.com

News from the Gold Coast

While Nader is away, Angela is filling in. Angela's contact number is 0427 752 956.

News from Darling Downs

Love to hear from anyone whom I can be of assistance to in anyway.

Debbie Hawkins, Email debsy570@yahoo.com

phone (07) 4628 6103, mobile 0457 148 486.

Please leave a message and I will return calls or reply via email.



This month, we welcome the following members:

Anthony – Preston VIC

Sonia – Mundingburra QLD



MGAQ Discussion Forum is a "Closed Facebook Group which allows people to communicate between each other in a safe Australian forum".

To join the conversation:-
www.facebook.com/groups/mgqld/

DID YOU KNOW?

Thanks to Muriel for the facts!



- Buzz Aldrin mother's maiden name was MOON.
- Humans have the same number of hair follicles as chimpanzees .
- The average person who lives to be 75 will have spent 6 years dreaming .
- Queen Elizabeth 1 often drank two pints of strong beer for breakfast .
- Andy Warhol always wore green underpants .

BAMBOOZABLES

www.thinkablepuzzles.com

Answers below

DEAD BODY MY	NO NO RIGHT	Ci ii	LOOKING 1111	BBBBBB	BRAIN KIDNEY HOME HEART
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SUDOKU

www.theteacherscorner.net Printable Sudoku

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

And remember, no peeking at the answers unless you really have to

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

Bamboozable Answers: 1. Over my Dead Body; 2. Right Under the Nose; 3. See Eye to Eye; 4. Looking Out for Number One; 5. Be-Line; 6. Be-Line; 7. Home is Where the Heart Is



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.

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A letter from Helen

This is a list of things that I am going through and am not sure whether they are caused by old age or myasthenia gravis and am wondering if other people with myasthenia have similar symptoms.

I tire easily; don't get up as early as I have all my life till the last 2 years. I am also getting bad cramps in my fingers and legs on and off day and night.

My arm muscles are very weak. I have trouble lifting them up, but my legs are pretty good.

My eyes are very dry, but at present my sight is good in both eyes at once.

I am 84, and have no age problems with blood pressure, diabetes, heart or lungs. I do have problems holding a pen. I was only diagnosed 2 years ago which I believe is unusual.

I live in WA and would very much appreciate the contact with other sufferers.

Note: *If you would like to contact Helen, please call MGAQ Support Line on 1800 802 568*

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My newspaper article about MG Awareness Month

Some readers will be aware that I contacted my local newspaper The Examiner (Launceston), in May, to run an article to coincide with MG Awareness Month in June.

I received a response to let me know that they would be in contact.

Around mid-June and no response, I sent another email and I received a response that the message had been passed along. So waited again.

And after a few more weeks, nothing, so I decided to send an email to let them know that the idea of the article was for MG Awareness month and also mentioned I was disappointed, as other diseases get National attention (good for them though), and even Vegemite Day gets a mention on Sunrise.

And guess what! An email asking for an interview. All went well and the article appeared, less some things I'd forgotten to mention, but the message was put out there.

The best part of the article is being contacted by three people; one lady in her 60s who's had MG since her late teens, and most interesting is her father had MG, which she put down to diet in World War II times in Holland. I'll be sending out a booklet to her also.

Another call was from a lady, whose daughter, in her 50s, also has had MG since her late teens, but after a Thymectomy has been fine since.

And I received another call from a gentleman in his 70s with MG (since teens). We had a great chat and will catch-up at some stage.

It's been an eye-opener to know there's more sufferers around in Tasmania than I thought, but more importantly, others now know there's support available and they aren't alone.

Greg Breaden

COMMITTEE NOTICE BOARD

ANYONE INTERESTED?

This association has a 7ft portable projector screen that is excess to our needs.

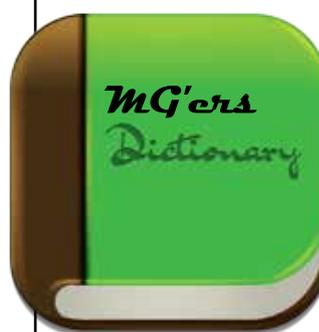
Anyone wishing to acquire this screen can contact:

info@mgaq.org and include a donation amount to be made to this association for same.

If you, or a family member, or a friend, would like to be involved in any aspect of the work undertaken by the Association, do make contact on

**1800 802 568 or
info@mgaq.org.au**

as we would be delighted to discuss options with you.



MESTINON

*pyridostigmine
bromide*

[pir-i-doh-stig-meen]

Word Origin

pyrid(ine) + -o- + (physo)
stigmine

noun, Pharmacology.

1. a cholinesterase inhibitor, $C_9H_{13}BrN_2O_2$, used in its bromide form in the treatment of myasthenia gravis.
2. Mestionon is also used in military personnel who have been exposed to nerve gas.



MEMBERSHIP SUBSCRIPTION REMINDER

**For more information, call the toll free number
1800 802 568 or email: info@mgaq.org.au**

AGENDA FOR THE ANNUAL GENERAL MEETING

of the

MYASTHENIA GRAVIS ASSOCIATION OF QLD INC.

to be held on

SUNDAY, 11 SEPTEMBER, 2016

at the

SOUTHERN CROSS SPORTS CLUB, MT GRAVATT
commencing at 10.15am



1. **OPENING**
2. **APOLOGIES**
3. **CONFIRMATION OF QUORUM**
4. **MINUTES OF THE PREVIOUS AGM HELD AT SOUTHERN CROSS SPORTS CLUB ON 13 SEPTEMBER, 2015**
5. **BUSINESS ARISING FROM MINUTES**
6. **PRESIDENT'S ANNUAL REPORT**
7. **TREASURER'S REPORT**
8. **ELECTION OF MANAGEMENT COMMITTEE 2016/17**

NOMINATIONS:

PRESIDENT	(Vacant)
VICE PRESIDENT	John Noble
SECRETARY	Carol Buchanan
TREASURER	Denise Hannay
COMMITTEE MEMBERS (5)	Shirley Johnston, Anita Jackson, Donna Formosa, Susan White, Rosalyn Holland

As no accepted nomination for President was received, nominations will be called from the floor at the AGM.

9. **APPOINTMENT OF AUDITOR**
Notice of Motion – That this meeting agrees to the appointment of BDO Australia Ltd as Auditors for the year 2016/17.
10. **BANK AUTHORITY**
11. **GENERAL BUSINESS**
12. **GUEST SPEAKER – Nicole Millis, Executive Officer, Rare Voices Australia**
Nicole will talk about the formation of Rare Voices Australia, and the important role it has played in putting rare disease on the agenda. She will talk to the need for a National Plan for Rare Disease in Australia, always making the link between individual stories and broader policy issues. Nicole will tell the group how they can participate in the 'Fair for Rare' campaign and join the push for a fairer go for those living with rare disease.
13. **CLOSE**

NOTE – the AGM will be followed by a short general meeting to set membership fees and present the association's Annual Operational Plan 2016-2017

2015/2016 ANNUAL GENERAL MEETING

**Sunday, 11 September,
10.00am for 10.15am sharp!**

WHERE

**Southern Cross Sports Club
Corner Klumpp and Logan Roads, Mt Gravatt**

(vehicle entry to club is via Klumpp Rd).

Lunch is available at the venue with a varied and reasonably priced menu.
Tea and coffee will be available prior to the meeting.

GUEST SPEAKER

Nicole Millis, Executive Officer, Rare Voices Australia

WHAT DO I NEED TO BRING?

Yourself and whomever else you wish to bring along – the more the merrier.

HOW DO I GET THERE?

UBD Map 201 Reference D7

RSVP

Ring our **FREECALL 1800 802568**

and tell Shirley if you are coming, how many and if you are staying for lunch.

Please let her know by **Friday, 2 September, 2016**

GUEST SPEAKER BIOGRAPHY

Nicole Millis has recently been appointed to the role of Executive Officer for RVA. This follows a period of nine months where Nicole held a position on the board of RVA and impressed with her strong contribution.

Nicole, qualified in Social Work, has both professional and personal experience of rare disease. Nicole spent the last three years as the National Manager of the MPS and Related Diseases Society of Australia, and in that role had significant experience responding to a range of patient and family support enquiries and clinical care issues.

She is also an experienced advocate for an improved orphan drug access system.

About Rare Voices Australia...

Rare Voices Australia is a national, not-for-profit organisation established in 2012 with a vision to be 'the unified voice for ALL Australians living with a rare disease

The RVA team will retain the invaluable services of former Executive Director Megan Fookes who has moved to a part-time role focusing on policy and stakeholder relations.

The new team at RVA is working hard towards a brighter future for Rare Diseases in Australia.