



Messages

MYASTHENIA GRAVIS ASSOCIATION OF QUEENSLAND INC.

FEBRUARY 2018

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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PATRON

Dr Cecilie LANDER
Neurologist
Founder Member, of Brisbane

PRESIDENT'S REPORT

Welcome to what I hope will be a healthy and happy New Year. The members of the management committee also hope that everyone had a wonderful Christmas with family and friends.

The hot weather everywhere has certainly not been kind to Myasthenics and I am sure everyone will be dreading those huge electricity bills.

Given the lack of attendance at the March function, the committee has resolved not to organise a get-together/picnic this year. If you have any ideas for something different we would love to hear from you at info@mgaq.org.au or on the **1800 number**.

During the second half of last year Shirley Johnston, Susan White and Bill Synott, three of our long-standing and very active members, worked with students from QUT on a project to raise awareness of MG in the general community as well as working to increase donations for particular projects.

We have the results of these assignments and there are certainly some interesting and

innovative suggestions for the management committee to consider, particularly in the 'world' of technology. As we progress some ideas we will keep everyone informed.

In the December newsletter the MGAQ explained it is in the process of broadening our range of technology and we asked you for feedback about the types of devices and options members use to access the Myasthenia Gravis Association of Queensland Inc. Resources.

You can still complete this Questionnaire on Facebook if you are a member of the MGAQ Facebook Closed Discussion Group OR detach the page and post, OR scan and email. (See *page 7 for for information*).

This data will help the committee make decisions about what is best for members to access information. The use of information by mail will still continue as well.

Thanks, Carol

Supported by



Queensland
Government

Ausenco

Myasthenia Alliance Australia

MAA News -

The Alliance Committee will recommence work in late February and look forward to keeping our community abreast of issues via emailed broadcasts to individuals registered on the Alliance website as well as via the State Association newsletters.



Rare Diseases Day on February 28th each year highlights the lives of people who have rare conditions. Myasthenia is one such condition. Do look out for radio programmes and other stories about this day and also events which may be occurring in your area. Collectively, people with rare diseases are found in numbers equivalent to those with major conditions such as heart disease and diabetes. You may like to read more about rare diseases and the campaign in Australia to support people who fall into this group. www.rarevoices.org.au

MSBase Update Neuro-Immunology Registry

As at the end of January 2018, Dr Reddel has reported that the MG software coding work has been delayed. No cost implications are expected as a result of the delay. Planned upgrades to the MSBase data system which is the underlying support for the MG platform, continue to be behind schedule. These upgrades were initially due for completion April 2017 and revised to August 2017. The final stages of the MSBase update are being done now and ENID-MG will follow that.

Dr Reddel also advises that key specialised staff have moved institutions which has contributed to the delay but this is a one-off factor. Whilst the coding work could be created for the existing system, it would need to be re-done when the change over occurs and this seems an ineffective use of the moneys raised. The funds remain securely allocated and the IT company is ready to proceed as soon as the upgrade is completed. Dr Reddel is communicating regularly with the key project personnel and, whilst disappointed, remains confident that the work will proceed and that waiting is the best approach. This additional time is allowing for discussion with the MSBase Board members regarding subsequent stages of the project. The Myasthenia Alliance Australia Committee will continue to liaise with Dr Reddel and will keep the MG community fully informed on progress.

Follow the work of the Alliance by registering at the website - www.myastheniaallianceaustralia.com.au



MG Friends Victoria



MG Friends in Victoria had their second get together on the 3 December at the Springvale RSL. The weather was absolutely terrible with wind and driving rain. Despite that we had 28 MG people and carers attend which was fantastic.

We had a great lunch and chatted and swapped stories.

We are a young group and are growing in leaps and bounds which proves that there are people in Victoria who will benefit from joining our support group.

Any Victorian reading this is most welcome to contact me via email or mobile.

MG FRIENDS VICTORIA

For more details please call Greg Bowman on **0407 371 877** or email him at glen.star@bigpond.com

Do find the group on Facebook by searching MG Friends Victoria.



Visit us on facebook

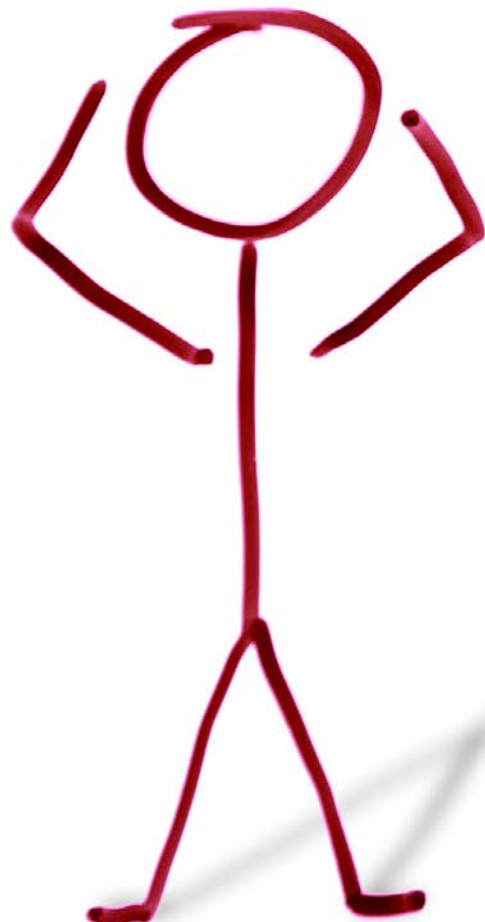
www.facebook.com/MG-Friends-Victoria-1418317788251750/



THE VALUE OF MEMBERSHIP!



WHY BECOME A MEMBER OF THE MGAQ?



- ✓ Support and guidances is just a phone call away.
- ✓ Provides access to a local support network.
- ✓ Provides access to information in the form of:
 - *Printed Material*
 - *Books*
 - *Guest Speaker Presentations (DVDs)*

To help me best manage my MG

- ✓ Provides a structure which works with Government and the medical community to address and improve treatment options for me as a MG sufferer.
- ✓ Provides services to help me with day-to-day life including:
 - *Monthly Newsletter*
 - *Access to a Medi-Alert Card*
 - *SMS Network*
 - *Facebook Discussion Forum*
 - *Internet-based knowledge*

- ✓ Gives us as individuals an organisation with a voice at a State and Federal Government level to continue subsidising drugs and treatment regimes critical to my health.



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.

I would like to know about the "Auto Immune Protocol Diet" please?

...Rosalyn



Welcome to our new members

Barry C
Bli Bli
Qld

Jeanette C,
Bli Bli
Qld

Liz S,
Coomabah
Qld

Vic A,
Bundaberg
Qld

John C,
Maroyong
NSW



MURIEL'S DID YOU KNOWs?

- 90% of the crime in Helmand Province is committed by the Afghan police
- 50% more U.S. soldiers committed suicide in Afghanistan in 2012 than were killed in action
- As it grows, Sweetcorn makes a squeaking noise like two balloons rubbing against each other
- An octopus can ooze through an opening no bigger than its own eyeball
- Humans and elephants are the only animals with chins
- There are 1000 times as many bacteria in your gut as there are stars in the Milky way

If You Transfer Money to the Association . . .

As more people are using online banking services to send money to the Association, we ask when using the direct deposit method, it would help if you could email us at info@mgaq.org.au to advise that you have paid directly into our bank account and the date of the transaction. This will assist the Treasurer in reconciling with the Bank Statement.

A payment was made on **11 Dec from Ahl for \$40**. If this is your payment, would you kindly contact our **Treasurer, Denise**, to info@mgaq.org.au Your receipt will be emailed or forwarded to you by mail. For future reference, our bank details are:

BANK: Bank of Queensland

BSB: 124 032 ACCOUNT NUMBER: 10263772

ACCOUNT NAME: Myasthenia Gravis Association of Qld Inc.

REFERENCE: Your Name and Initials



MG CHAT LIST

If you are a financial member and would like to be on the chat list, contact us - Freecall 1800 802 568 or email info@mgaq.org.au

MGAQ SUPPORT LINE 1800 802 568

Queensland Regional Coordinators

Donna.....	0414 397 462	Cairns
Daphne.....	4773 3695	Townsville
Bill	4954 1221	Mackay
Garth (Gladstone)	0408 155 954	Wide Bay/Burnett
Colleen	0409 491 789	Sunshine Coast
Debbie	4657 5974	Darling Downs
Nader.....	0415 834 401	Gold Coast

Queensland Regional

Rosemay.....	0418 686 180	Tully
Carol.....	4773 7122	Townsville
Daphne.....	4773 3695	Townsville
Jo.....	4723 8721	Townsville
Maree	4740 439	Townsville
Ron.....	0428 826 180	Townsville
Laurie	0488 738 601	Mount Pleasant
Helen	4947 1553	Proserpine
Lillian	4933 4281	Gracemere
Pam	4151 5499	Bundaberg
Vic.....	0407 797 618	Bundaberg
Lynn.....	0448 796 079	Maryborough
Leslie	0437 324 077	Kilcoy
Debbie	0407 374 883	Postmans Ridge
Vicki	0409 895 668	Pine Mountain
Vicki.....	0411 146 898	Sadliers Crossing

Sunshine Coast

Scott.....	5446 3894	Coolum Beach
Barry.....	0407 797 618	...	Bli Bli
Kerri.....	0427 425 975	Peregian Springs
Vino	0448 688 102	Palmview

Gold Coast

Elsie.....	5520 0921	Burleigh Waters
Mary.....	5564 1308	Coombah
Angela	0427 752 956	Hope Island
Marie	0418 781 526	Labrador
Richard.....	0418 249 640	Paradise Point
Kath	5573 0439	Upper Coomera
Lynette.....	0401 077 157	Runaway Bay

Brisbane

North Brisbane

Catherine.....	0402 281 671	Deception Bay
Diane	3300 4519	The Gap
Frederick	0433 024 848	Petrie
Rosalyn	0407 697 206	Zillmere
Robyn.....	0434 532 853	Kedron
Mark	0433 911 210	Eatons Hill
Nicole	0417 796 648	Albany Creek
Dennis	3855 9379	Gaythorne
Susan	3358 1056	New Farm
Karen.....	0414 312 022	Boondall
Sandi	0437 530 233	Grange

South Brisbane

Carol.....	3390 1788	Capalaba
James.....	0417 634 275	Capalaba
Kris	3822 1832	Birkdale
Marie	3349 3813	Mt Gravatt
Bill & Jitlada.....	3399 9984	Norman Park
Lynne.....	3398 4407	Norman Park
Anita	07 3800 4913	Regents Park
Sybil.....	3219 9535	Springwood
Poppy	3288 4484	Springfield Lakes

Interstate Members

Julius	02 9365 5828	Bellevue Hill NSW
Trevor	02 6679 5507	Uki NSW
Max.....	02 6621 6386	Lismore NSW
John.....	0407 181 139	Marayong NSW
Anthony	03 9480 6317	Preston VIC
Edmund.....	03 9509 8920	Caulfield Nth VIC
Bob	0419 591 204	Vermont Sth, VIC
Joel (Parent).....	0422 904 394	Oakleigh Sth VIC
Helen	08 9297 3528	Ellenbrook WA
Robert	0400 868 245	Gidgegannup WA
Sheila	0403 915 524	Mindarie WA
Greg	0419 536 517	Kings Meadows TAS
Toni (Parent).....	0417 015 486	Ulverstone TAS
Paul	0488 525 276	Kambah ACT
Colleen	0274325829	Christchurch NZ

Puzzlers

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

Sudoku

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

Word Search

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

Bamboozable

TRO BLE TRO BLE TRO BLE	MOV 4 IE	rough rough rough
LATE LATE	YENOMRUOY YENOMRUOY	SOMETH BI

Answers

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

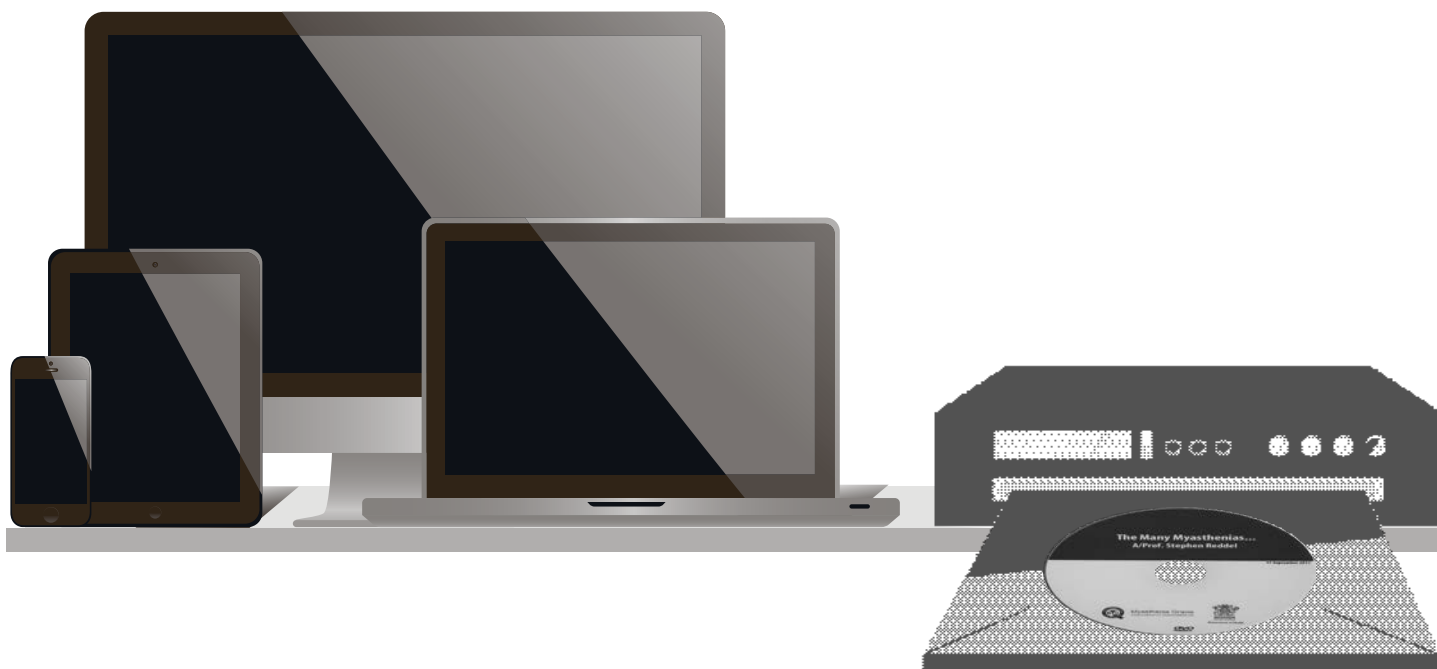
Bamboozable 15 Answers: 1. Keeping You Out of Trouble; 2. Foreign Movie; 3. A Little Rough Around the Edges; 4. Too Little, Too Late; 5. Double Your Money Back; 6. Start of Something Big.

Word Search Famous Female Singers

- | | |
|----------|-----------|
| BLIGE | NICKS |
| CAREY | PARTON |
| CASS | REDDY |
| CLOONEY | RONSTADT |
| CROW | ROSS |
| DION | SIMON |
| ESTEFAN | STREISAND |
| FLACK | SUMMER |
| FRANKLIN | TURNER |
| HILL | TWAIN |
| HOUSTON | WARWICK |
| JACKSON | WINEHOUSE |
| LAUPER | WOMACK |
| LOPEZ | |
| LOVE | |
| MADONNA | |
| MCENTIRE | |

We are still conducting the survey about the types of devices and options members use to access the Myasthenia Gravis Association of Queensland Inc. Resources.

If you haven't responded already, please take the time to help us help you!



Have you accessed any MGAQ Resources? Yes No

If yes, how did you access the MGAQ Resources? (Tick all applicable)

Mail eMail Freecall Online DVD Other

If online, what type of device(s) did you use? (Tick all applicable)

Computer Laptop Tablet Smartphone Other.....

Do you use a DVD player to view our Guest Speaker presentations?

Yes No

Would you prefer to view presentations online?

Yes No

You can complete this Questionnaire on Facebook if you are a member of the MGAQ Facebook Closed Discussion Group OR detach this page and post, or scan and email. Alternatively, save the extra email attachment, select the relevant answers and return by email.

Send your completed Questionnaires to:

PO Box 16, Mt Gravatt, Qld 4122 or Freecall 1800 802 568 or Email: info@mgaq.org.au

NEWS FROM AROUND QUEENSLAND

News from Cairns

Rare Friends Far North Queensland are once again hosting the **Rare Disease Day Fun Run & Walk 2018** in Cairns on **Sunday, 25 February**.

For more information or to Register www.rarefriends.org

The first get together for 2018 will be on **Saturday, 17 March at 11.00am at the Cairns RSL Club Boardroom**.

For more information about the Cairns group, call Donna on 0414 397 462

News from Townsville

Thanks to everyone who came to our December lunch. Your company and gifts were appreciated by all.

Next lunch: The Avenues Hotel (07 4723 8000), 270 Kern Bros Drive, Kirwan, Townsville **on Saturday, 17 February, 2018 at 12 noon**. Please RSVP -Daphne 0400 778 637.

For more information about the Townsville group, call Daphne on 0400 778 637 or email daphclay@gmail.com

C News from Mackay

Our get-togethers for 2018 to the end of June will be held on **Sunday, 25 February, 2018 at 12 noon for lunch, at Southern Suburbs Bowls Club** and on **Sunday, 20 May, 2018, at North Mackay Bowls Club, 12 noon for lunch**.

T For more information about the Mackay group, call Bill on (07) 4954 1221.

News from Gladstone-Wide Bay Region

There will be a **"Meet members of the Committee"** at Rocksalt Restaurant on **Saturday, 7 April at 11.00am**.

For more information, call Garth on 0408 155 954 or (07) 4973 7983 For local support in the Gladstone – Wide Bay region, call Garth on 0408 155 954 or (07) 4973 7983.

M News from the Sunshine Coast

Hi MG Gang - Let's hope that 2018 has started well for you and we all continue to enjoy a healthy year.

For more information about the Sunshine Coast group, call Colleen on 0409 491 789 or email colleen4551@gmail.com

G News from Darling Downs and Beyond

The Darling Downs area is huge, but I am just a phone call away if you would like any assistance.

Call Debbie on (07) 4657 5974 or 0457 148 486.

SC News from the Gold Coast

The Gold Coast MG group had their regular, friendly coffee chat get-together, exchanging experiences in Kurrawa Surf Club in Broadbeach.

Our next MG meeting will be on **Saturday 21 April, at Southport Sharks Club at 10am, cnr Olsen & Musgrave Avenues, Southport**. A table has been booked under Ms Cherie Parsons (Myasthenia Group)

I look forward to seeing you all again.

For more information about the Gold Coast group, call Nader on 0415 834 401.

what's coming up

The management committee feels it is important for members from across the state to meet and chat with some of our committee.

Therefore, over a period of time, two members from the management committee will travel to each of the areas.

The regional co-ordinators will negotiate with the committee re the most suitable time of the year and these will be advertised in the newsletter. The first round is listed below.

MEET THE COMMITTEE DATES	
WHERE IS IT?	WHERE IS IT?
BUNDABERG - 6.00pm FRIDAY, 6 APRIL	The Old Bundy Tavern, 20 Quay St, Bundaberg Table booked under MGAQ
GLADSTONE - 11.00am SATURDAY, 7 APRIL	Rocksalt Bar & Restaurant, 22-24 Roseberry St Gladstone Central. Table booked under MGAQ.
MACKAY - SUNDAY, 20 MAY	North Mackay Bowls Club, 74-76 Malcomson St, North Mackay