



MessaGes

MYASTHENIA GRAVIS ASSOCIATION OF QUEENSLAND INC.

JUNE 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,

Welcome to the new look MessaGes under the guidance of Greg Breaden as Editor. I'm confident Greg will have some surprises in store coming up. Please send any contributions for the newsletter to the email address shown in the bottom of the left hand column of this page.

A conclusion to the search for a new Treasurer is near as discussions are under way with a member who has expressed an interest in taking on the job. There are some logistic issues to sort out as the prospective Treasurer lives in Bundaberg, but is travelling to Brisbane for the July Management Committee meeting to talk through these issues.

The mid-year function on Sunday, 12 June was a great success enjoyed by all who were able to attend. This function was timed to also celebrate the 25th anniversary of the MGAQ and to acknowledge that June is MG Awareness Month. It was great to meet with some recent new members and with Paula

Lamey, representing *Ausenco*, the MGAQ's first corporate donor. Also present was Rachel Grant, who was engaged by the Committee to arrange a program of publicity and public awareness of Myasthenia Gravis and the Association, the links to which were published in previous editions of MessaGes.

We welcomed our Regional Coordinators as well, and thanked them for taking the time to come to Brisbane for a meeting amongst themselves to talk over ideas and thoughts for going forward. As mentioned in last month's newsletter, because of privacy concerns of some of the material presented, we are not able to produce a DVD of Dr. Pane's presentation. However a summary of Dr Pane's presentation is included as part of June's issue.

Finally, I would remind members to please renew their membership of the Association as any organisation is only as strong as the members who support it.

Cheers, Graeme

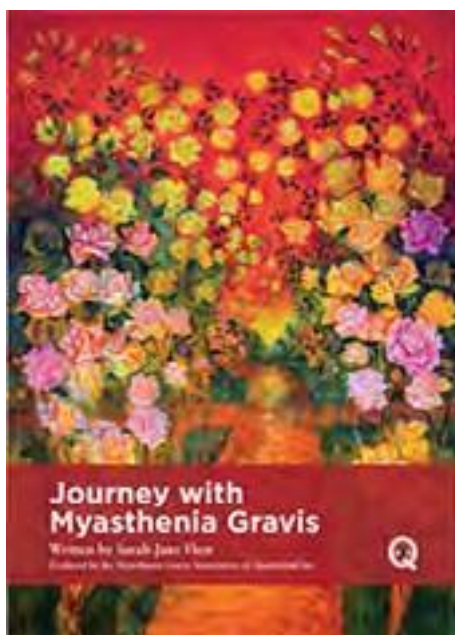
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"JOURNEY WITH MYASTHENIA GRAVIS" - A BOOK BY SARAH-JANE FLEER



Raising awareness of Myasthenia is as important as always and every opportunity to do so should be considered. The book is such a great tool for demonstrating the uniqueness of each journey with the condition and for bringing support to those affected as well as their families. Thank you to all those who read and share this book.

Contact the Association on 1800 802 568 or email at info@mgag.org.au to arrange for your copy to be sent out.

MYASTHENIA ALLIANCE AUSTRALIA



Three alerts were successfully issued via the MAA register. They shared concerns and items which apply to everyone in Australia.

- The first item reminded us all to acknowledge the Myasthenic conditions during the month of June as it is National Myasthenia Month. Feedback about what people did to feel a little special and to share this time with their family and friends who offer them support would be welcomed by the Associations over the coming months. Please send stories to info@mgag.org.au or PO Box 16 Mt Gravatt 4122 with your permission to publish.
- The second item is a reminder that our medications are not mainstream and issues with supply can occur from time to

time so be vigilant and maintain an adequate supply of your drugs.

- Thirdly, a member would like to make people who may have had a thymic cancer aware of a cancer research project currently being conducted through the Victorian Cancer Council. Called the 'Forgotten Cancers Project www.forgottencancers.com.au', they are looking for people with more rare types of cancer. After completing an online questionnaire, DNA samples are taken from saliva and information is gathered. If anyone in the MG Alliance has or has had Thymic cancer, perhaps they might be interested in participating.

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



"Two things are infinite: the universe and human stupidity; and I'm not sure about the universe."

— Albert Einstein



ABOUT YOUR EDITOR

Hello all, as you're probably aware by now, I've taken over as the editor of the MGAQ Newsletter, so here's a bit about me:

I'm married to my very supportive wife Maria (also co-Editor) and we have 2 children, Ebony 21 and Isaac 18.

I enjoy playing golf and look forward to resuming playing a few holes and hopefully 9 holes in the near future (in a buggy). I also enjoy motorsports and gardening and a Carlton supporter.

I had worked in the Printing industry since 1977 and had to retire from my last position at The Examiner Newspaper (Fairfax owned) after 28 wonderful years in the graphic design/pre-press department.

I was diagnosed with MG in August 2013, starting with a droopy eye, then a Thymectomy



in March 2014. All was going well until a crisis in June, with another couple of hospital stays over the next 9 months. Touch wood, it's been 18 months since the last stay and now off Mestison and tapered Pred to 5mg alternate days, and now on Mycophenolate.

I also produce a newsletter for an AFL Supercoach League I'm a coach in as a bit of fun, so another newsletter is a great way to fill in time and keep the mind active. I've started looking for some part-time work.

I look forward to hopefully meeting some members in the near future.

Any suggestions for some more types of articles/puzzles etc, or dislikes, please send me an email.

Thanks, Greg



This month, we welcome the following new members:

Lynne – Norman Park, Qld

Stephen – Tewantin, Qld

Annette – Tewantin, Qld

GOT YOUR THINKING CAP ON?

Answers Page 5



1. You are a cyclist in a cross-country race. Just before crossing the finish line you overtake the person in second place! What place did you finish in?
2. In a year there are 12 months. 7 months have 31 days. How many months have 28 days?
3. A plane crashes on the border of the Western Australia and the Northern Territory. Where do they bury the survivors?
4. I do not have any special powers, but I can predict the score of any football game before it begins. How can I do this?
5. Please add the following numbers in your head.
Start with 1000. Add 40. Add 1000. Add 30. Add 1000. Add 20. Add 1000
Add 10 - Write down your answer.
6. What are the next 3 letters in the following sequence?
J, F, M, A, M, J, J, A, __, __, __
7. Jimmy's mother had 4 children. She named the first Monday. Named the second Tuesday. The third is named Wednesday. What is the name of the fourth child?
8. Before Mt. Everest was discovered, what was the highest mountain in the world?

WORD SEARCH

Created with TheTeachersCorner.net Word Search Maker

K	B	S	B	Y	C	N	E	G	R	E	M	E	D	M	AMBULANCE
P	S	M	Y	A	S	T	H	E	N	I	A	N	P	D	ANTIBODIES
V	R	E	C	S	S	R	A	X	W	U	E	T	R	S	AUTOIMMUNE
Y	A	T	A	N	M	B	K	R	Q	U	S	U	E	T	AWARENESS
A	U	A	L	O	X	G	O	Z	R	T	D	A	D	C	CALCIUM
N	T	X	C	I	W	V	W	O	A	R	I	W	N	E	DISEASE
T	O	E	I	T	E	F	L	I	E	K	S	A	I	F	EMERGENCY
I	I	R	U	A	I	O	R	S	I	F	E	R	S	F	EXERCISE
B	M	T	M	C	G	S	T	N	R	M	A	E	O	E	GRAVIS
O	M	O	M	I	H	G	R	A	V	I	S	N	N	E	MEDICATIONS
D	U	H	S	D	T	G	H	K	Z	N	E	E	E	D	MESTINON
I	N	T	I	E	G	E	X	E	R	C	I	S	E	I	METHOTREXATE
E	E	E	U	M	A	G	X	G	W	K	Z	S	F	S	MYASTHENIA
S	C	M	H	Z	I	A	N	O	N	I	T	S	E	M	NEUROLOGIST
R	E	T	A	W	N	A	M	B	U	L	A	N	C	E	PREDNISONE
															REST
															SIDEEFFECTS
															STAIRS
															WATER
															WEIGHTGAIN

SUDOKU

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

www.theteacherscorner.net
printable Sudoku

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

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

MYASTHENIA GRAVIS FOUNDATION OF AMERICA



The Myasthenia Gravis Foundation of America Inc. have posted the following on their website

MG Research Update Presented at 2016 National Conference, Dr. Jeffrey T. Guptill (MD, MA, MHS), assistant professor of neurology at Duke University Medical Center, delivered an update on Myasthenia Gravis research and clinical findings, at the 2016 National Conference, held May 1-3, in Raleigh, North Carolina.

Dr. Guptill discussed the updates on clinical trials for Methotrexate, CFZ533, Rituximab and Eculizimab, and also updates from the 2015 Scientific Session in Hawaii. **(see link below)**

Whilst the presentation is a summary of the talk and is quite technical it may be of interest to those who attended the National Myasthenia Conference last year when Dr Reddel referred to current research. It is certainly a conversation starter!

Please click here for presentation: www.myasthenia.org/#sthash.saXT184l.dpuf
or use this link: myasthenia.org/LinkClick.aspx?fileticket=tolxUsvtKQg%3d&tabid=103



MGAQ Discussion Forum is a "Closed Facebook Group" which allows like-minded people to communicate between each other in a safe forum. New members need to JOIN and then be approved by Admin before they can join the conversation. Only members who also belong to the group can see the posts or chats within it. This is a wonderful forum to share your MG Journey and chat to others on their MG Journey.

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

The **MGAQ Facebook Page** is an "Open Facebook Page." The difference is that this page is Public and can generally be seen by anyone on Facebook. The Facebook page allows the MGAQ to communicate broadly with people who "Like" the page. When the MGAQ publish a post or an announcement it appears in the newsfeed of people who "like" the page. To spread the awareness of MG we need as many people as possible to "Like" the page. Help us to achieve this by visiting the MGAQ Facebook Page and click "Like" at www.facebook.com/mgqld/

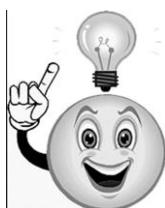
DID YOU KNOW??



- August has the highest percentage of births
- Unless food is mixed with saliva, you can't taste it
- The average person falls asleep in 7 minutes
- A bear has 42 teeth
- Ostrich's eye is bigger than its brain
- Lemons contain more sugar than strawberries
- 8% of people have an extra rib
- 85% of plant life is found in the ocean

THINKING CAP ANSWERS?

From Page 3



1. **Answer:** 2nd Place. If you pass the person in second, you take second place, and they become 3rd.
2. **Answer:** They all do.
3. **Answer:** You don't bury the SURVIVORS!
4. **Answer:** I can predict the score BEFORE it begins. Well, the score before any football game is always zero to zero!
5. **Answer:** Many will get 5000. But the actual answer is 4100!
6. **Answer:** S, O, N. The sequence is first letter of the months of the year. September, October and November are the next in the sequence.
7. **Answer:** Jimmy. "JIMMY'S MOTHER had 4 children"!
8. **Answer:** Mt. Everest. It was still the highest in the world - it just hadn't been discovered yet!



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@mgag.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.

Lin Powell writes about MG from a Carer's Perspective

My wife and I were married just over 30 years ago when I was 46 and she was 39. It was a second marriage for both of us. My wife gave up a career as a successful Travel Agent to care for me who had recently had a heart attack and was in a highly stressful job.

She had been diagnosed with MG 12 years before our marriage and was familiar with the symptoms. To me she was a bright caring, busy person, who sometimes tired easily but generally was able to work quite hard at bringing up three active children and look after a new husband whose diet and exercise regime had to be catered for.

As time went by and I entered a less stressful position, my wife began to show signs of tiring more easily and not wanting to rise as early as she had.

We consulted a neurologist who merely did some simple tests and increased her dose of Mestinon. I noticed that if she did not keep up the Mestinon and take it at the recommended intervals, she 'wound down'. At times her speech became a little slurred as if she had been drinking alcohol to excess. As neither of us is a drinker, that excuse could not be used.

However, we led a fairly active life including camping, fishing, walking and gardening together, whilst my wife did a fair bit of sewing and embroidery. We had a year in Canada where my wife really 'blossomed'. She enjoyed the experience, joined a Hospital Auxillary and immersed herself in the life of a French Canadian City. She loved the cold weather and if you think there is cold in Australia, you have seen nothing until you experience the Canadian cold!

As we have grown older the usual pangs of age have caught up with us. Arthritis is a constant companion and that makes it harder for the MG sufferer to remain mobile. We have found that regular walking is ideal to lessen weight and generally keep our metabolism working.

My wife had a serious accident in September 2014 and that has magnified the effects of MG. As the age related ailments accelerated, the accident caused

other problems and ones that the carer must be very alert to. Up until my wife's accident my caring was fairly minimal. It generally was to make sure that she took her medication on time, an iPhone has helped, the alarm is great; to make sure that she was safe walking and kept in a reasonably straight line.

Medication is a major issue now. Not only is it important to make sure that she takes her MG medication on time but also to make sure that doctors and chemists know that she has MG. It is astounding the ignorance of doctors and nurses with the ramifications of various medications on an MG patient. Because my wife was a trained nurse, she is very aware of the dangers of various drugs and their interaction with one another, therefore she is ultra-sensitive to the prescribing of drugs. However, as those of you with MG know, you get tired and do not at all times make yourselves clearly heard. That is one of the biggest challenges for a carer. It is important to be there, but not to mollycoddle. The patient must be kept safe but must not lose her self-esteem, sometimes a fine line to be made.

Speech is one of the first casualties of MG and when you are hard of hearing as am I at times, it is said that I am deaf, I am not really, words not formed clearly are hard to hear. The MG sufferer gets tired of repeating themselves and understandably become very cross. The carer must turn the other cheek and try to listen more attentively to adequately keep the sufferer's spirits up.

If I had to sum up the attitude of a carer of a MG patient, it would be love. The carer must at all times realise that even though the MG sufferer tries to do things and fails, it is with love that she should be encouraged but not roused on or belittled. There is a fine line between doing tasks and encouraging the sufferer to do them. It is easy for one not impaired to accomplish things but it is hard to stand by and watch and encourage. That is where the love of the sufferer is paramount.

Thanks, Lin

NEWS FROM QUEENSLAND

News from Cairns

Cairns group will meet again on Saturday 18th June at the Cairns RSL Club, Esplanade in the Boardroom at 11.00am. This is a great opportunity to catch up with fellow Mgers. If you happen to be holidaying in the beautiful far north, you are most welcome to join us.

For more information, please contact Donna on 0414 397 462

News from Townsville.

Our next lunch is Saturday 23rd July 2016.

For details, contact Daphne 0400 778 637

News from Mackay

Our next get-togethers will be held on the following dates:

Sunday, 17 July, 2016 at 12 noon for lunch at Harrup Park Country Club.

Sunday, 18 September, 2016 at 12 noon for lunch at Mt. Pleasant Tavern.

Sunday, 13 November, 2016 for the Christmas lunch at 12 noon will be held at Souths, Milton Street.

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

Our next gathering will be on Saturday 6th August at the Buderim Tavern at 12 noon. Hope to see you all there.

Please contact me if you have any queries. Colleen McLean 0409 491 789.

colleen4551@gmail.com

News from the Gold Coast

Our next get together will be on 26th of June. The venue will be mailed to all Gold Coast members by one of our members Angela, who will kindly be taking care while I'm overseas.

Angela's contact number is 0427 752 956.

I look forward to seeing you all again when I return in August.

Cheers Nader

News from Debbie, Darling Downs' Co-ordinator

Hi all

My role as a co-ordinator for Darling Downs and beyond, has been both rewarding and fulfilling. Due to the large area I cover, my support is done mainly by phone contact, which is moving forward very quickly. I have extended my contacts to further out to Western Qld, eg Longreach and places in that vicinity.

I have decided to embark on some road trips soon to spread the word on the wonderful job that the MGAQ Society Qld do and offer any support that I can as co-ordinator. I have sent a covering letter with info booklets on Myasthenia Gravis, and contact details to medical centres, to inform doctors and people, who are either diagnosed with this condition or caring for someone with it, that there is support no matter how geographically isolated they may be. Any questions are great questions, so send them through.

I was lucky enough to be able to attend a co-ordinator's gathering in Brisbane on the weekend and also attend the MGAQ meeting. Very positive and interactive time spent networking together and making new friends. 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.



“Good friends, good books, and a sleepy conscience: this is the ideal life.” — **Mark Twain**



IT'S MEMBERSHIP SUBSCRIPTION RENEWAL TIME

MEMBERS CAN NOW ALSO PAY THEIR ANNUAL FEES VIA THE MGAQ WEBSITE
www.mgaq.org.au/membership-application-form

It's that time of the year again when Membership Subscriptions for the financial year 2016/2017 are due.

As voted at the 2015 Annual General Meeting, membership fees have increased this year by \$5 for each type of membership. The envelope in which this notice was enclosed will advise you when your membership expires. If you look along the top line you should see "YOUR NAME" followed by some figures in smaller print than your address. If you receive the newsletter by email and are unsure whether or not you are currently financial, please phone our 1800 802 568

freecall number to enquire.

The majority of members will have 6/16 which tells you (and us) that you are financial to 30 June 2016. Others may show 6/17 or even 6/18 to indicate they have saved time and postage by paying in advance. If you are unfinancial, please take a minute to phone on the FREE call number, 1800 802 568 and advise whether or not you wish to retain your membership and receive "MessaGes". LIFE MEMBERS and PAID-UP LIFE MEMBERS do not pay further subscriptions. We are also giving you the option of paying your subscription directly into our bank account.

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

If you use 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.

Your receipt will be forwarded to you with the next available issue of "MessaGes" following receipt of your payment. If you do not receive your receipt, please ring us on the toll free number 1800 802 568. We thank you in anticipation of you renewing your membership.

If you wish to pay by Cheque or Money Order, please use the following form and forward to:
The Myasthenia Gravis Association of Queensland Inc.
PO Box 16
MT GRAVATT Qld 4122

Herewith please find my cheque / money order / cash for the sum of \$_____ being annual subscription \$_____ and/or Donation \$_____.

NAME _____ **Category A Myasthenic \$20**
(or) Category E – Supporter \$20

ADDRESS _____

And for _____ **Category D – Carer \$10**

ADDRESS _____