



Messages

MYASTHENIA GRAVIS ASSOCIATION OF QUEENSLAND INC.

SEPTEMBER 2019

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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Neurologist

Founder Member, of Brisbane

PRESIDENT'S REPORT

Our Annual General Meeting was held on Sunday, 15 September with approximately 30 people in attendance. A big thank you to those who made the effort to come and support your association.

I am pleased to report that we have a full complement on our management committee. A big welcome to our new Secretary, Ron Stephen, our Minutes Secretary, Kirstine Shrubsole, and committee member, Karen Downes.

Also discussed at the AGM was the extension of our funding from Queensland Health until 2022 with the option of another two years beyond that. This funding guarantees the continued operation of the management committee. Three members of the committee met with a Queensland Health representative on the Friday prior to the AGM to discuss recent achievements plus our future priorities. It was a very positive meeting with acknowledgement of what has been achieved in the past year and the extensive projects and work outlined in this year's Annual Operational Plan. The comment that such a lot of work is being done by such a small organisation was received with thanks.

A vote was taken on our new Rules which will replace the cur-

rent Constitution which was very dated. The essence of the old constitution has not changed but the wording and some additional information was necessary. Thanks go to the project manager, Veeta Bassi, and McCullough Robertson Lawyers for their pro bono work.

Our Annual Operational Plan was also presented at the meeting. This was accepted and the ongoing and new projects listed in the document are already progressing.

After the formalities were over, people got into groups to hear from management committee members and those who attended the conference about some of the topics of interest. The feedback from the conference was very, very positive and we must thank the presenters and people who helped pull the conference together for the first time in Brisbane.

It was great to see that most people took the opportunity to stay for lunch and chat with friends old and new. Do not forget that the committee organises Coffee and Chat get-togethers throughout Brisbane as well as those that are organised by the regional co-ordinators.

Thanks, Carol

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MYASTHENIA ALLIANCE AUSTRALIA NEWS



The MAA Board remains focused on its range of objectives which include:-

- Supporting local Myasthenia communities and State Associations in all states of Australia as they deliver camaraderie and local knowledge to others. Fostering research, including the new opportunities which have resulted from the Conference, and working with various Government bodies to ensure best possible treatment options for each and every situation with Myasthenia.
- A recent addition to the MAA website is the newly released **"Drugs to be Used With Caution"** flyer (see home bar). Prepared in conjunction with Dr Blum, it is available directly on the website and in 'pdf' form for printing out and sharing. There is a reference site included for your Doctors to explore more details and to understand more about the concerns of the many drugs. The key message from creating this flyer is that many drugs may affect the neuro-mus-

MAA Update

cular junction and hence, the Myasthenia also. Treating Health Professionals need to be aware of the risks, consider choices carefully and take appropriate management steps. It does not mean that the drugs must be avoided as they may be essential for other reasons. The individuals need to be very aware of personal responses to medications and communicate promptly with treating clinicians. https://myastheniaallianceaustralia.com.au/drugs_and_mg/

- The annual MAA President's report will be published in November. A full outline of the work of the Alliance over the past twelve months will be made available via the MAA website and news events listing. Typically, we are all very amazed by what has been achieved in just 12 months. This year will not disappoint.

Kindest regards to all the very important followers of the MAA. Without registered followers and active supporters we could not be making such remarkable achievements.

Susan White - President

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

Thanks

to Dr Blum working in conjunction with the MAA (Myasthenia Alliance Australia), the new guidelines for **"Drugs to be used with caution in Myasthenia Gravis"** has been produced.

All financial members will receive a hard copy as part of the member services from MGAQ.

Follow the link to the MAA website to download the PDF and to find more information.

www.myastheniaallianceaustralia.com.au/drugs_and_mg/

MYASTHENIA GRAVIS ASSOCIATION OF QLD INC. ANNUAL GENERAL MEETING SUNDAY, 15 SEPTEMBER, 2019

Election of Office Bearers for 2019-2020

The following were elected to the Management Committee until the 2020 AGM:

President: **Carol Buchanan**
Vice-President: **Susan White**
Secretary: **Ron Stephen**
Treasurer: **Denise Hannay**

Committee Members:
**Anita Jackson, Rosalyn Holland,
Donna Formosa, Ian Hollingworth,
Kirstine Shrubsole and Karen Downes**

AGM SUMMARY

The annual MGAQ Annual General Meeting was hosted at Hornet's Football Club on Sunday, 15 September.

A good group gathered and all agreed it was a happy day.

Carol gave a detailed President's report which people found very interesting as the work of the Association is diverse, well respected, effective and supportive. Denise went on to reflect the strong financial situation of the Association thanks

to the ongoing support from Queensland Health and also, the strong support from members.

The election of office bearers went well with three new committee members elected. We welcome Ron, Karen and Kirstine to this fun and dynamic committee.

There was still time in the day to workshop content from the recent Conference and to share some materials. Most stayed for lunch and more chatter. This format received good feedback.



MGAQ - AGM, 15 September, 2019**Welcome to our new members**

Esther D, Hurstville, NSW
Irene J, Calamvale, QLD
Annmarie P, Broadmeadows, Vic
Jill W, Bentley, WA

Sylvia B, Upper Coomera, QLD
Kirstie B, The Gap, QLD
Lenise L, Havelock North, NSW

Position Available**To support the MGAQ Organisation**

Meeting Host - Make a home available to host up to 11 attendees at monthly committee meetings. Meetings held every 2nd Saturday of the month (except January) from 8.30am-3.30pm. Requirements include 35 minute access to airport, landline facility (no significant costs), reasonable parking access. Not necessarily a Committee person. Back-up venues available if needed.

To register your interest or find out more, contact:

Freecall:

1800 802 568

Email:

info@mgaq.org.au



Coffee and
Chat

Hervey Bay
17 September



COMPETITION

“Tell us about your unexpected highlight from attending the 3rd National Myasthenia Conference!”

This competition is open to everyone who attended the conference. All attendees will be notified of this opportunity.

The prize offered by Enjo Australia, Conference Sponsor, in conjunction with the MGAQ is an Enjo Kitchen Bundle valued at \$179.00.



Please write a response to this question and submit it to info@mgaq.org.au or post to

PO Box 1287, New Farm 4005 by 10 December, 2019.

No minimum or maximum length is suggested.

A condition of entry is that your item may be used in the Members' Forum section of the MGAQ newsletter.

The winner will be selected by Lara Hudson from Enjo.

The closing date is 10 December and the prize will be posted in time to be a Christmas treat!

WHAT IS ENJO?

ENJO is a chemical free, all-natural fibre cleaning product. The fibres have been proven to remove dirt and bacteria in all settings.

ENJO was developed in Austria and is about putting healthy living first. The Company produces a range of safe and effective fibre cleaning products that need no chemicals. Asthma Australia recognise the health benefits when chemicals and allergens are removed from the home environment.

ENJO offers an easy change to the household cleaning routine for a healthier lifestyle, saving time and importantly energy.

Lara Hudson, ENJO Consultant, is available on 0419 223 455 should you wish to further understand the health and environmental benefits.

CAN YOU HELP?

Just wondering if anyone is using a motorised trike and where they got it? I am looking at getting one through NDIS for my 20 year old daughter who has LEMS.

It will be both beneficial for strength exercise and mental wellness to be able get out for a ride safely. We live in Townsville. We did meet a lovely lady (I forgot her name) at the MG Conference in Brisbane who was using one and loves it.

Any help would be greatly appreciated thank you. **If you can help, please contact 1800 802 568**





Myasthenia Gravis Association of Qld Inc.

LENDING LIBRARY

The committee has established a lending library of MG and related information resources. The collection is small, but is expanding over time.

Loans of material are available to financial members of the Association and the loan period is 1 calendar month.

Postage out is paid by MGAQ and return postage is the responsibility of the member.

To request a loan, please contact John on (07) 3293 4655 or Email: jam3740@bigpond.com

BOOKS IN LIBRARY

Attacking Myasthenia Gravis

Ronald E Henderson MD – *Easy Reading*

Living a Healthy Life with Chronic Conditions

Myasthenia Gravis & Myasthenic Disorders

Collection of Medical Papers –
Very Technical

Rare Voices the Australian Experience of Living a Rare Disease

Megan Fookes ex-Director
"Rare Voices Aust" – *Personal stories*

Journey with Myasthenia Gravis

Sarah-Jane Fleer Produced by MGAQ – *Personal stories*

Depression the Way Out

Neil Nedley MD – *Easy*

I Dropped my Chicken Soup

Rebeka Huggins Stories about Multiple Sclerosis
– *Easy*

Living Well with Autoimmune disease

Mary J Shomon – *Easy*

Myasthenia Gravis "Manual for the Nurse"

USA National MG Foundation –
Some-what Technical

Beyond Blue National Depression Initiative

Stories of Hope and Recovery
(DVD - Vol 1 / Vol 2)

DVDs IN LIBRARY

Dr Rob Henderson.

Dr Stephen Reddel.

Katrina Williams

MG. Physiotherapy and Exercise.

Mr Rick Carr

Case for a Multi-Disciplinary Neuromuscular Clinic.

Dr Jean Foster

MG. Getting the Most out of Your Doctor.

Rebecca Elkington

MG. Information on Good Nutrition.

Dr C M Lander

MGAQ 20th Anniversary Guest Speaker.

Ms Justine Joppich

Commonwealth Dept Human Services, Centrelink Benefits.

Dr Stefan Blum

Preliminary Report MG DATA Collection Survey.

Dr Jennifer Nitz

Preliminary Report MG Pilot Exercise Effect.

Dr Stephen Reddel

Presentation to MG NSW.

Dr Stefan Blum

Some Interesting Results from the MG Survey.

Dr Sharon Pandey

Health in Retirement.

Prof Cindy Gallois

Living with Chronic Illness.

Dr Rob Henderson

Thymoma other Information on MG.

Anita Jackson & Carol Buchanan

Summary of Presentation to MAA Conference in Sydney, June 2015.

Prof Pamela McCombe

"Presentation."

Nicole Millis

"Rare voices Aust" What it is and how it can help MG.

Prof Cindy Gallois

Communicating with health professionals, strangers & friends.

Judy Burrows

Importance of Getting to Know Your Pharmacist.

Zoe, Winner of the Kath Ross Memorial

Scholarship

"On Her Journey with MG"

A/Prof Stephen Reddel

The Many Myasthenias.

Katerina Williams

MG Therapeutic Exercise for Life.

Puzzlers

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

Word Search - Books of the Old Testament (2)

X	E	K	K	M	H	U	L	L	Z	V	S	I	Z	AMOS
S	K	Z	O	A	A	E	L	E	E	E	D	S	E	CHRONICLES
N	D	U	N	C	I	L	C	E	T	O	K	A	P	DANIEL
W	A	O	K	K	H	H	A	S	U	I	J	I	H	ECCLESIASTES
N	J	H	E	K	A	R	A	C	N	M	S	A	A	EZEKIEL
O	J	Z	U	R	A	I	O	G	H	P	A	H	N	HABAKKUK
M	E	N	I	M	S	B	S	N	B	I	A	S	I	HAGGAI
O	L	A	M	E	N	T	A	T	I	O	N	S	A	HOSEA
L	H	X	L	U	D	U	E	H	Q	C	I	I	H	ISAIAH
O	M	C	H	A	I	M	E	R	E	J	L	A	J	JEREMIAH
S	C	R	N	O	B	A	D	I	A	H	S	E	Z	JOEL
E	S	I	A	G	G	A	H	G	N	O	S	S	S	JONAH
C	E	B	M	I	C	A	H	C	M	T	B	O	H	KINGS
L	J	I	M	V	K	K	Z	A	H	N	U	H	W	LAMENTATIONS

Answers

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

Answers
 1. Musically Inclined;
 2. Overcome the Odds; 3. The Underdog; 4. Cut Above the Rest; 5. One Thing After Another; 6. Waving Goodbye
Word Change 26
Answers:
 stare, stale, stile, smile.

Sudoku

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

Word Change

stare

smile

Bamboozable

MUSICALLY	13579... COME	DOG THE
cut rest	another one thing	GOODBYE

NEWS FROM AROUND QUEENSLAND

News from Cairns

We will meet again on **Saturday, 21 September** and **Saturday, 7 December** at the **Cairns RSL Club, Esplanade at 11.00am**. If you are visiting Cairns, you are most welcome to join us. For more information, please contact Donna on 0414 397 462.

News from Townsville

The Townsville MGAQ group lunch will be held on **Saturday, 19 October, 12 noon** at **The Avenues Hotel**. RSVP and details - Daphne-0400 778 637, daphclay@gmail.com

At the August lunch, members and friends appreciated the conference feed back from Carol, Maree and Heather. Congratulations to the wonderful Queensland MGAQ committee helping the MAA to organise the conference. For details contact Daphne on 0400 778 637 or daphclay@gmail.com

News from Mackay

The last get together was Sunday, 18 August at Souths Suburban Bowls Club. A lovely meal and discussion was enjoyed by all present. The next get together on **Sunday, 1 December will be the Christmas break-up at 12 noon at the Rice Buffet, 22 Gregory St Mackay**. All Welcome.

For information for the Mackay region, please contact Muriel on (07) 4954 1221.

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

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

News From Brisbane

Coffee & Chats are a good opportunity to connect with people in your area. All are welcome.



- | | |
|------------|---|
| Cleveland | Sunday, 22 September at 2pm - <i>Fiction Bar, 152 Shore Street West, Raby Bay</i> |
| Nundah | Sunday, 13 October at 3pm - <i>The Royal Hotel, 1259 Sandgate Road</i> |
| Ipswich | Friday, 25 October at 10am - <i>Queens Park Café, 10A Merle Finimore Ave.</i> |
| Burpengary | Sunday, 10 November at 2pm - <i>The Coffee Club, 164-166 Station Road</i> |

For more information, Contact Anita on 0414 588 312

News from the Gold Coast

Hi Everyone

Our Gold Coast MG Group had their regular friendly coffee chat get-together, at the Kurawa Surf Club at Broadbeach.

We had a nice group of 10 people, 7 of us with MG. We had a visiting couple (Pauline and Dave) from Melbourne; here on holidays join us for morning tea. We exchanged experiences and stories and took in the beautiful ocean views.

A enjoyable morning was had by all. Time went very fast and before we knew it, two hours had passed and it was time to move on.

Nader 0415 834 401, our coordinator will be back from his overseas trip. So until then, stay safe and well.

Our next get together will be at the Southport Sharks Club on 26 October.

Regards Angela Brosnan 0427 752 956.

