



Messages

Myasthenia Gravis Association of Queensland

August 2015



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Association of
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Neurologist
Founder Member, of Brisbane

PRESIDENT'S REPORT

Welcome

The committee is currently working through the Members Survey results and compiling your answers to see what needs to be actioned in the future. We take your responses seriously and will try and implement them as much as possible. We know that you took the time to fill this out so we do not want you to think that we have not taken any action from your responses.

The committee has accepted the resignation of Iris Suen from the committee and also her nomination for the Treasurer's role due to ill health. We wish her all the best and hope that she will be well enough to still come to our functions.

This means that we will be calling for nominations from the floor at the AGM for a Treasurer. Please think about this role as the Association cannot continue without a Treasurer. Susan White is happy to guide you through all the aspects of the job.

We have been advised the Prof Pamela McCombe will be our guest speaker at the AGM held on Sunday 13th September at Southern Cross Sports Club Klumpp Road Mt Gravatt.

Our book of stories 'Journey with Myasthenia Gravis' has now been distributed to the National Library Canberra, State Library Queensland and Parliamentary Library Queensland.

Feedback from the conference has meant that we have sent out approx 20 surveys in the past month as it was so well received in Sydney. This is great news as the information collated will provide a database for the DNA research.

We are slowly getting a few stories trickling through for us to print so keep up the good work everyone as they tell a different story every time.

Take care
Anita

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Government**

PROJECT UPDATE

SURVEY STATUS

During the past three months, there have been over thirty new surveys distributed to people wishing to participate in the data collection process. This result can be directly attributed to all the promotional activity associated with the MAA Inaugural Conference for Myasthenia. Given that the Doctors who spoke at the conference strongly assured us that this work should not cease, it is a very pleasing result indeed. Do remember to mention it to other MGers you may meet when having your treatments, visiting the doctors, gathering socially or chatting on-line so that we continue to reach more Myasthenics.

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

How exciting to report that with sales underway only since July 1st, the Association has already distributed 127 copies of this valuable resource. It is wonderful to see the wide range of addresses included on the order forms. There has even been enquiry from the USA. The Association is in the process of investigating an on-line purchase option via the website using Paypal. This would allow interested people who are overseas an opportunity to purchase the book too. As the stories are universal in their experiences it would be wonderful to help so many. Copies of this resource are now located at the National Library in Canberra, the State Library in Queensland and the Parliamentary Library in Queensland. We are keen to inform the current health minister, the Honourable Cameron Dick, that this copy is available to him.

MYASTHENIA ALLIANCE AUSTRALIA



Myasthenia
Alliance Australia

Whilst the Conference is over and such a big initiative has been completed, it does not mean that the Alliance Committee has shut down. A debriefing meeting has been held with notes made on how to improve the outcome next time! A letter of sincere appreciation has been sent to the Directors of the Brain and Mind Institute, University of Sydney, in appreciation of their

generous offer to host the event. Several attendees at the Conference expressed an interest in forming casual meeting groups within the states of Victoria and South Australia with a view to providing support. The Alliance Committee hopes that these events do occur and aims to support this initiative. The recently constructed Alliance website www.myastheniaallianceaustralia.com.au is proving popular with registrations to the site growing steadily. News of the Conference brought over 2,000 visits to the site from overseas browsers. This is actually a great result as strong Associations/Federations exist in the USA, Britain and elsewhere and it may be possible to share ideas and information in the future.

MAA Conference Feedback (No. 2)

One very evident happening right from the beginning of the day was the strong feeling of camaraderie in the room. People from all states got to know each other very quickly, new friendships were made and contact information exchanged. There was also a commitment by some people to set up get-togethers in their area. Hopefully, this is beginning to happen as the comment from many people was that, for the first time, they were able to talk with others who really

understood their condition.

Following Dr Reddel, the second speaker was Dr Paul Janz, a cardiothoracic transplant heart surgeon with St Vincent's Hospital Sydney who has been involved with ground breaking cardiac and thymus surgery using the Da Vinci machine. This machine has been at St Vincent's Hospital for the past ten years and is available for both public and private patients. He stressed that thymic tissue can be found throughout the chest cavity and that it is important to remove it as a whole by tracking up to the horns behind the thyroid gland and down towards the diaphragm. This is where the robot comes into its own. When Dr Paul Janz goes to the USA for training updates he takes his team of anaesthetists with him. It was fascinating to watch the video presentation of an operation on the thymus with Dr Janz commenting throughout the procedure as to what he was doing and where he was going with the robotic arm.

FUND RAISING!



The Association has registered with Give Now for online fund raising donations with the hope of people or businesses donating to our Appeal. Please take a look at this site and advise anyone who may be interested in donating or gifting through his or her Will to the Association.

<https://www.givenow.com.au/myastheniagravisassociationofqld>

CHAT LIST

Each member of our Management Committee is happy to speak with you, while the following members, who include MG sufferers or their carers have offered to join our Chat List. If you have a need to have a yarn, particularly about how MG affects you, please ask if it is convenient to talk, and respect the privacy of those whom you call.

In the interests of one's privacy, we have not listed surnames. Do not be embarrassed by ringing a stranger and asking to speak to say, "Fred or Mary". If you wish to disclose your surname, that is your prerogative. Simply explain that you are a MYASTHENIC or a CARER.

The opinions expressed by the person you call are entirely those of that person. 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 there is also the FREECALL telephone number for Australia manned (or is it womanned?) by Shirley and is 1800 802 568. Please do not hesitate to call if you feel the need. If the 1800 802 568 is not answering, please leave a message and Shirley will get back to you as soon as practicable. Your call is valuable to us, so please do not hang up without leaving a message.

MGAQ SUPPORT LINE 1800 802 568

CHAT LIST – INTERSTATE MEMBERS

BARRY / JO MARILYN	0262 852 661 0262 913 436	CANBERRA ACT GOWRIE ACT
BARBARA ROBERT MAX PENNY	0295 249 224 0266 526 745 0266 216 386 0248 682 213	CARRINGBAH SOUTH NSW COFFS HARBOUR NSW LISMORE NSW MOSS VALE NSW

FRANK	0267 671 031	TAMWORTH NSW
KERRIE	0435 389 883	TWEED HEADS SOUTH NSW
MAUREEN	0244 763 734	NAROOMA NSW
CANDY	0268 473 732	WARREN NSW
ELLEN	0755 999 511	WEST TWEED HEADS NSW
DIANNE	0245 743 787	WINDSOR DOWNS NSW
ROLAND	0397 966 592	NARRE WARREN VIC
TAMARA	0409 186 809	HOPPERS CROSSING VIC
CORAL	0358 651 378	KATAMATITE VIC
DENNIS	0402 285 520	PATERSONS LAKES VIC
BARBARA	0397 764 985	SEAFORD VIC
DORA	0358 214 191	SHEPPARTON VIC
EDMUND	0395 098 920	CAULFIELD NORTH VIC
DIANE	0421 387 904	CARINE WA
RONA	0894 597 168	MADDINGTON WA
DIANE	0363 272 563	RIVERSIDE TAS
DAPHNE	0364 286 733	SQUEAKING POINT TAS
MARIAN	0362 571 272	ORFORD TAS
CRYSTAL	0459 472 165	ALICE SPRINGS NT
PROSPER	0882 857 016	ALICE SPRINGS NT



Around Queensland

News from Mackay

Mackay members will meet again on Sunday 30 August at the Western Suburbs Football Club, in Walkerston.

All are welcome to attend this lunch.

Bill Harris — Ph 07 4954 1221

News from Townsville

The Townsville MG group lunch will be held on Saturday 17th October 2015 at The Avenues hotel, 12noon. RSVP to Daphne Clay.

0747733695

0400778637 (text)

Email: daphclay@gmail.com

News from Cairns

We welcome new members Peter and Liz who came along to our Cairns get together. At this meeting, those that attended the recent inaugural conference of Myasthenia Alliance Australia shared what they had learnt. This was followed by a lot of information sharing within the group.

Dates for your diary:- Saturday 17th October and Saturday 19th December, Cairns RSL Club Boardroom at 11.00am.

News from the Sunshine Coast

The Sunshine Coast group met for the first time in a few years and a good time was had by all who attended. We will meet every 2 months from now on. Our next get together will be on Sunday 11th October for a BYO BBQ. Please contact me for details.

Colleen McLean
Phone 5493 6391
0409 491 789
colleen4551@gmail.com

NEW MEMBERS

We welcome the following new members:-

- Bhuvana - Woolongabba
- Raymond - Millmerran
- Christine - Millmerran
- Richard - Paradise Point
- Emily - Burpengary
- Jeanne - Rockhampton
- Blair - Rockhampton

IMPOSSIBLE QUICHE!

- 4 eggs
- 1/2 cup self raising flour
- 1 tablespoon butter
- 1 1/2 cups milk
- 3-4 bacon rashers
- 1 chopped onion
- 1 cup grated cheese
- ground pepper to taste

1. Beat eggs then add all other ingredients in order given and stir.
2. Put into high sided quiche dish.
3. Bake in moderate oven 35-40 minutes or until golden brown.



facebook

FACEBOOK MGAQ DISCUSSION FORUM

A closed discussion forum has been setup for the MGAQ which allows for private discussion between members. We encourage all our members to join in the discussion. Please visit:

<https://www.facebook.com/groups/mgqld/>

Down Memory Lane



The Treasury building (Now the Casino) in Brisbane city 1895!

The Redcliffe Jetty was



a popular holidaying destination.



Aerial shot of Brisbane in 1935. Notice that City Hall dominates the skyline?

Got any memories you'd like to share?

Please send them to Emily.sexton@live.com.au to be included in the Newsletter.

MEMBERS' FORUM

There are no contributions this month.

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 make 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.

AGENDA FOR THE ANNUAL GENERAL MEETING OF THE MYASTHENIA GRAVIS ASSOCIATION OF QLD INC. TO BE HELD ON SUNDAY 13 SEPTEMBER 2015 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 14 SEPTEMBER 2014
5. BUSINESS ARISING FROM THE MINUTES
6. PRESIDENT'S ANNUAL REPORT
7. TREASURER'S REPORT
8. **NOTICE OF MOTION** That the AGM ratify the following decision of the management committee:

The MGAQ Constitution does not prescribe a maximum number of persons on the Management Committee. Consequently, the current Management Committee has exercised its discretion under Clause 17 (1) (b) of the Constitution and decided that the maximum of persons on the Management Committee shall be 9 and, as a result, there will be 9 vacancies for Management Committee for 2015/2016.
9. **ELECTION OF MANAGEMENT COMMITTEE FOR 2015/16.**

NOMINATIONS:

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

As the nomination for Treasurer has been withdrawn, nominations will be called from the floor at the AGM.
10. **APPOINTMENT OF AUDITOR**

Notice of Motion – That this meeting agrees to the appointment of BDO Australia Ltd. as Auditors for the year 2015/16.
11. **BANK AUTHORITY**
12. **GENERAL BUSINESS**
13. **GUEST SPEAKER – Professor Pamela McCombe**
14. **CLOSE**

NOTE: The AGM will be followed by a short general meeting to set membership fees and discuss actions from the association's transition plan beyond the end of 2015.

2014/2015 ANNUAL GENERAL MEETING

- WHEN:** Sunday 13th September 2015 at 10:00am for 10:15am sharp
- WHERE:** Southern Cross Sports Club, Corner Klumpp and Logan Roads, Mount 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 SPEAKERS:** Professor Pamela McCombe
- 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 802 568 and tell Shirley if you are coming, how many, and if you are staying for lunch. Please let her know by **Friday 4th September 2015**

GUEST SPEAKER BIOGRAPHY

Dr Pamela McCombe trained as a neurologist in Sydney, at Prince Henry and Prince of Wales Hospitals. She obtained a PhD from the University of Sydney. She obtained experience in Neurophysiology in Cleveland and then returned to UQ as a post-doctoral fellow. She worked for some years as a research fellow in Neuroimmunology and was an NHMRC SRF. Later she resumed clinical practice as a neurologist, and continued her research as an NHMRC Practitioner Fellow. She is currently Professor and Head of the Royal Brisbane Clinical school in the School of Medicine and Co-head of the Brain and Mental Health Theme at the UQ Centre for Clinical Research.

LATE NEWS

The MGAQ 2015 Christmas Function will be held on Sunday 13 December at the Caloundra Power Boat Club. Full details will be published in later newsletters but mark it in diary now so you don't miss it.

STOP PRESS!

Do you have a family member who is good with numbers and would like to help the Association. The MGAQ are urgently seeking a nomination from a member for the Treasurer position. If you can help, please call Shirley on 1800802568.