



Messages

Myasthenia Gravis Association of Queensland

JUNE 2015



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Myasthenia Gravis Association of Queensland Inc

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Neurologist
Founder Member, of Brisbane

PRESIDENT'S REPORT

Welcome,

We are nearly half way through the year so it is end-of-financial-year time and we are all questioning where has this year gone.

The inaugural Myasthenia Australia Alliance National Conference was held in Sydney on Saturday 20 June 2015 and was a resounding success. A report on the conference is on page 2 of this issue.

Nominations have closed for positions on the Management Committee for 2015/2016. It is gratifying that nominations were received for all positions. (See page 3 for full details).

The coming year presents a new challenge for the Management Committee and the MGAQ with the cessation of funding support from Queensland Health. It is very hard when we have to find suitable people to fill these positions as the committee needs to rotate through these positions as well as get more people involved in the committee. We all have to remember that most of us on the committee have MG so that we are liable to burn out and get tired and would like to take a break from these roles from time to time.

The committee has been working hard to produce a book entitled 'Journey with Myasthenia Gravis' which comprises personal stories of some MGAQ members. The book was launched at the MAA Conference. The book is another avenue of increasing awareness of Myasthenia Gravis. The book is now available for purchase and an Order Form is on page 8 of this issue.

Our next function is on Sunday July 12 2015 at the Southern Cross Sports Club in Klumpp Road Mt Gravatt. Details are on page 5.

We are still looking for contributions to the Newsletter, in particular to the Members' Forum, so please give consideration to putting pen to paper and telling your experience with MG. It matters not whether you are a sufferer, a carer, family member or friend of a sufferer. The Forum is also the place to raise an issue or question in order to get feedback from other members.

Take care,
Anita

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PROJECT UPDATE

SURVEY UPDATE

Treasurer, Susan White, recently worked with reporter Leonie Mellor from the ABC TV and Dr Stefan Blum to bring a story to the general Australian community about Myasthenia Gravis. The research paper recently released and the ongoing opportunities for further research work were a focus of the report. It is important that surveys continue to be sent out as this will allow the data base of people diagnosed with MG to continue growing. Greater numbers are required for DNA research. Funds have been secured for initial work in this area. The segment was telecast on the eve of the MAA Conference on both ABC1 and ABC News24. The segment is available for viewing at <https://www.youtube.com/watch?v=2alxuJWtfVg>

MYASTHENIA AUSTRALIA ALLIANCE

Myasthenics from all over Australia gathered on Saturday 20th June at the Brain and Mind Research Institute in Sydney for the inaugural conference of Myasthenia Alliance Australia (MAA). The room filled with sufferers, carers, and fraternity from the medical profession. All were excited to meet others facing the same challenges as them and for some putting faces to names.

The information provided by the medical guest speakers was very informative and interesting according to the feedback surveys. Our very own MGAQ President, Anita, spoke of what our Association has been able to achieve for our members. The NSW Association President, Glenda, also gave a talk on their Association.

Dr Stephen Reddel provided the closing address by summarising “What a wonderful day it had been; an absolute success”.

He reflected that such a day was not possible without the Myasthenia Gravis Associations coming forward and helping other myasthenics.

Dr Reddel first suggested to the Associations six years ago, that for them to go forward they should plan for three things:

1. A Patient survey
2. A Federal voice
3. A National Conference

These three goals have now successfully happened. This would not have been achieved without the work of committed long-term volunteers.

Dr. Reddel went on to talk about the next step for the Associations to keep moving forward. This gives plenty of opportunities for the community to get involved and together we CAN do great things. He praised the Conference as being a great success.

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NOMINATIONS FOR MANAGEMENT COMMITTEE FOR 2015/2016

The following nominations have been received, and accepted by the nominees, for positions on the MGAQ Management Committee for year 2015/2016:

President	Graeme Peters
Vice-President	John Noble
Treasurer	Iris Suen
Secretary	Carol Buchanan
Committee Members	Shirley Johnston, Anita Jackson, Susan White, Roslyn Holland, Donna Formosa

Currently there are 8 members of the MGAQ Management Committee comprising the Executive (i.e. President, Vice-president, Treasurer and Secretary) plus 4 Committee Members. As shown above, a total of 9 nominations were received for positions on the Management Committee for year 2015/2016.

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. The decision by the committee will obviate the need for an onerous and costly Postal Ballot.

This decision of the Management Committee will be put to the membership at the Annual General Meeting on Sunday 13 September 2015 for ratification.

Future Events

Sunday 12 July 2015 – Member’s meeting “Feedback on MAA Conference” – Southern Cross Sports Club, Mt Gravatt

Sunday 13 September 2015 – AGM – Southern Cross Sports Club, Mt Gravatt



MGAQ Facebook Page -- <https://www.facebook.com/mgqld?fref=ts>

If you haven’t visited the MGAQ Facebook site in a while, please take the time to go back and check it out. We have updated the page to make it more interactive with our members. It’s not perfect yet and therefore we would like your input. Please “post” a comment and start a discussion. “Like” the page and spread awareness of Myasthenia Gravis.



MEMBERS' FORUM

Rosemary writes:

It was good to see a new member Trevor wrote his story.

As you know I have found out I do not have MG but for 30 years thought I did. Two years ago I was diagnosed with Central Core Disease which comes under the Muscular Dystrophy Umbrella.

I thought I was going crazy as I couldn't understand what my body was doing and I'm in a wheelchair (motorised) now so I can get around.

I just wanted to let people know that never give up on your symptoms or what your body is telling you. Only do what you can and no more.

My illness has affected every muscle in my body especially my eyes and throat and neck and it is awful not being able to hold up one's head. Of course the legs have decided to call it a day and my arms are weak but I can one finger type. It is slow but gets the job done. I am on thickened fluids. This is something that some MG sufferers may have to go on if their throat muscles play up. It's surprising what flavours you can get.

Well I wish everyone with MG the very best.

Kind regards,

Rosemary

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.



Around Queensland

News from Cairns

The next Cairns get together is on Saturday 15th August. 11.00am to 12.30pm. We meet in the new Boardroom upstairs in the RSL Club, Cairns Esplanade.

Some of our members will stay on afterwards for lunch (own expense).

Saturday 17th October

Saturday 19th December

Donna Formosa – M 0414 397462 or H 40392148

News from Townsville

The next lunch will be on:

Saturday 18th July 12noon - The Avenues Hotel, 270 Kern Brothers Drive, Kirwan. Townsville

If you can come please RSVP

Daphne Clay

07 47 733695 Mobile- 0400 778 637 (text please)

email-daphclay@gmail.com

I am looking forward to your company. Family members are welcome. Thanks for attending our May lunch.



"JOURNEY WITH MYASTHENIA GRAVIS" -

A Book of Personal Stories, written by Sarah-Jane Fleer and produced by the Myasthenia Gravis Association of Queensland Inc.

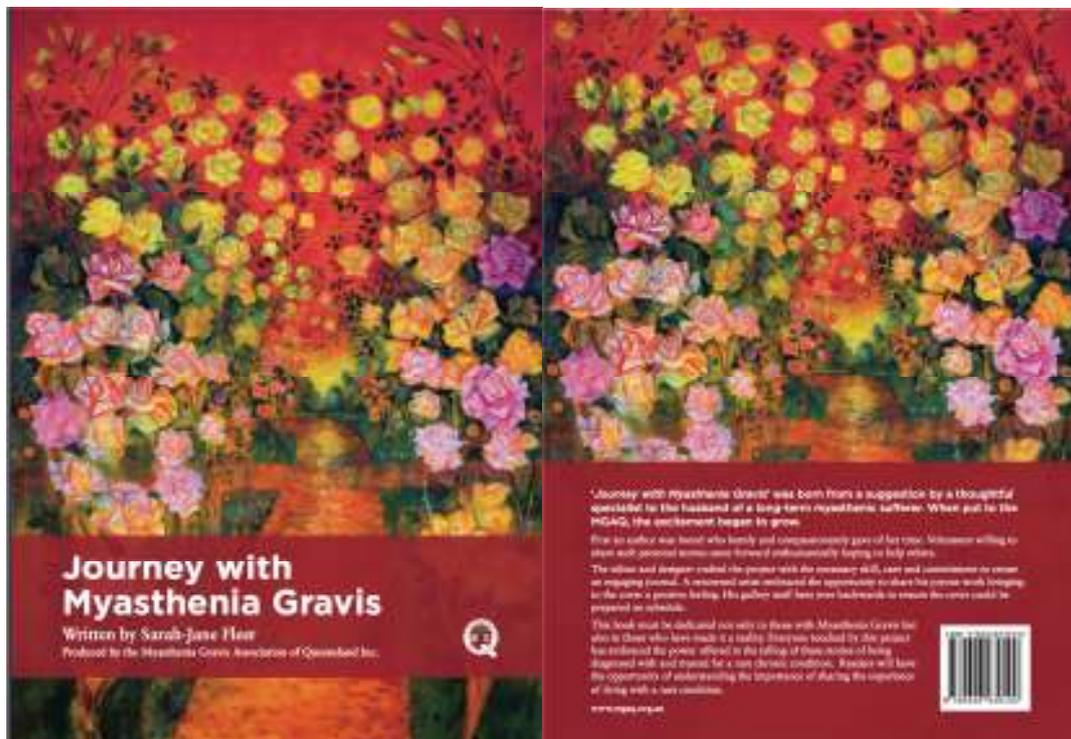
Made possible with the support of the Queensland Department of Health.

It is done! This wonderful book is now available to our members, to the general public and to medical professionals interested in understanding more about life with Myasthenia.

Again, it should be shared with our MG community, that there is indeed incredible community support for people with MG. Bringing this book to you has been truly heart-warming at every turn. Once people heard about the project and why it is important to share these stories with others, there has been such willingness to help.

The Association is truly indebted to Sarah-Jane Fleer, the author, who made this project possible. Her generous offer to commit the necessary time to this project provided the catalyst for the project to grow. Financial support from the Queensland Department of Health ensured that there were no delays in having the publication available for launch at the inaugural Myasthenia Alliance Australia Conference on June 20, 2015.

Books can be purchased from the Association using the attached order form or via the website (info@mgag.org.au). Books cost \$22.00 per copy plus \$5.00 postage and handling within Australia for one copy or \$10.00 postage and handling within Australia for two or more copies.





"Journey with MyastheniaGravis"

A Book of Personal Stories, written by Sarah-Jane Fleer and produced

by the Myasthenia Gravis Association of Queensland Inc.

Made possible with the support of the Queensland Department of Health.

"Journey with Myasthenia Gravis" was born from a suggestion by a thoughtful specialist to a husband of a long-term myasthenic sufferer. First an author was found who keenly and compassionately gave of her time. The editor and designer crafted the project with the necessary skill, care and commitment to create an engaging journal. A renowned artist embraced the opportunity to share his joyous work, bringing to the cover a positive feeling. This book must be dedicated to not only those with Myasthenia Gravis but also to those who have made it a reality. Everyone touched by this project has embraced the power offered in the telling of the stories of being diagnosed with and treated for a rare chronic condition. Readers will have the opportunity of understanding the importance of sharing the experience of living with a rare condition.

After being launched at the inaugural Myasthenia Alliance Australia conference, this wonderful book is now available to our members, to the general public and to medical professionals interested in understanding more about life with Myasthenia.

Books can be purchased from the Association using the attached order form or via the website (info@mgaq.org.au). Books cost \$22.00 incl GST plus \$5.00 postage and handling for one copy or \$10.00 postage and handling for two or more copies.

We are also giving you the option of paying direct 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 & Initials

If you use the direct debit method, it would help if you could email us at info@mgaq.org.au to advise us 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. **Also, ensure that you include your name and address so we know to where we need to post the book/s.**

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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

Please find my cheque / money order / cash for the sum of \$_____ being payment for
 _____ copies of the book "Journey with Myasthenia Gravis" plus \$_____ for postage – a total of
 \$_____

NAME _____ PHONE NO _____

ADDRESS _____

ADDRESS _____

Your receipt will be forwarded to you with the book/s you have purchased.