



Messages

Myasthenia Gravis Association of Queensland
MAY 2015



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Myasthenia Gravis Association of Queensland Inc

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PRESIDENT'S REPORT

Welcome,

The weather has been very crazy lately with storms hail and heavy rain in numerous places so hope everyone was not affected.

The Alliance committee is busy planning for the National Conference in June and we are all very excited how this has progressed and looking forward to participating in this event.

The nomination forms have been sent to all financial members so hoping that you have thought very seriously about becoming a committee member. We are looking for someone who is willing to help us progress into the future and have access to the internet as we do a lot of our communication this way. It does not take up too much of your time but it is very rewarding knowing that you are helping the association to move forward and continue to support our members with their Myasthenia Gravis.

Susan White will not be renominating for Treasurer at the next AGM. However, as part of the renewal process within the Committee, Susan is prepared to remain on the Committee to provide support to the incoming Treasurer. She will also continue in her role as Project Officer.

There is a very interesting story in this issue from one of our members about their journey with Myasthenia Gravis. The committee members have been working hard on getting a book to be published with some of our member's stories and it is to be launched at the Conference so looking forward to this as it is another avenue of getting the word out and helping the public to hear about Myasthenia Gravis.

We have changed the date for our next function from June to the 12th of July 2015 at the Southern Cross Sports Club in Klumpp Road Mt Gravatt for 10.30am start. We will be giving feedback of the information that was discussed at the conference to those of you who could not attend.

We are still looking for information for our Newsletter so please think about putting pen to paper and telling your story or if you are a carer you could do living with and caring for someone with MG.

Take care,
Anita

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PROJECT UPDATE

MYASTHENIA ALLIANCE AUSTRALIA CONFERENCE

There has been good support for the Conference and places have filled well. It is not sold out if you are still considering attending. Please do not leave it too long however as media coverage is planned of the coming weeks with a view to promoting the conference more widely and raising further awareness of Myasthenia.

The date for the Conference is June 20th. It is to be held in Sydney at the Brain and Mind Research facility at Camperdown. Registration commences from 8.30am for the full day programme. Speakers are now being confirmed and catering details arranged. The catering will be simple with sandwiches etc so that mingling and mixing remains the priority. Shirley is making her famous fruit cake as a morning tea treat. No MG meeting would be complete without it!

Accommodation is available nearby. This is proving a popular option for MGAQ members in planning for the Conference. If you choose to stay nearby, we will go to dinner together on the Friday evening. Give Shirley a call on **1800 802 568 FREE** if you are interesting in joining in. Everyone welcome.

"JOURNEY WITH MYASTHENIA GRAVIS" - A Book of Personal Stories

The pressure is on as the Editor, Designer and Association aim to have all the details completed for this book. The work needs to go to the printer now if it is to be launched at the Conference. Pressing the 'send' button on the computer will be an experience filled with mixed emotions - excitement and nerves!

In working towards this end product, it must be shared with our MG community, the incredible support that is out there for you. It has been truly heartwarming at every turn. Once people hear about the project and why it is important to share these stories with others, support has just poured forth. The initial enthusiasm and willingness of the storytellers and Sarah-Jane Flear, the author, made this project possible. As it progresses, Rachel Grant, the editor and our designer, Conan Griffiths, have put in extra effort. A piece of artwork from a renowned artist, Victor Rubin, has been made available for the front cover. The artist "is privileged and happy" to support this work. The professional photographer, Kyle Barnes, was happy to accept a bottle of wine from the Convent Gallery, Daylesford where the painting was displayed for his efforts in bringing the cover to us. These are some examples of the willingness that prevails in bringing these stories to you.

SURVEY UPDATE

The Association is currently working with reporter Leonie Mellor from the ABC and Dr 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 will be 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.

Future Events

- **Saturday 20th June** – Myasthenia Alliance National Conference, Sydney
- **Sunday 12th July** – Member's meeting, "Feedback on Conference" Southern Cross Sports Club, Mt Gravatt (**note change of date**)

Volunteer Position - Regional Co-Ordinator Required in Rockhampton, Gold Coast, and Darling Downs

The Management Committee are seeking an interested member from Rockhampton, Gold Coast and Darling Downs to become a local contact for the members who live in these areas. If you are able to help out the Association in this capacity we would love to hear from you. Please call Shirley on Freecall 1800 802 568.

Please help MGAQ continue to support you!

Sponsorship News!

How fantastic! The Association has received its first donation under the Sponsorship request article which appeared in the recent March newsletter.

The donor is related to a sufferer and knows the benefits brought by the Association in terms of support and in promoting research into this condition.

The donor commented "it is refreshing to know that all the funds are used for the cause and not to support wages".

The Association wishes to express their sincere thanks for this contribution.



GIVE NOW DONATIONS

The Association has registered with Give Now for online fund raising donations with the hope of people or businesses donating to our Appeal. The committee was informed of this website after some discussions with Board Connect who Queensland Health has put us in touch with so that we can actively continue to be a support group for all people with Myasthenia Gravis.

Please take a look at this site and advise anyone who may be interested in donating to the Association.

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

MEMBERS FORUM

NEW MEMBERS

We welcome the following new members:-

John and Ruth, Coonbah QLD

David, Arundel QLD

Alison, Hastings, VIC

Robyn and Jeffery, Kedron QLD

Deborah, Taroom QLD

Julius, Bellevue Hill NSW



Around Queensland

News from the Sunshine Coast

Colleen writes,

"I am happy to be the Co-ordinator for the new Sunshine Coast Group. I am a retiree and was diagnosed with MG 30 years ago. I elected to have a Thymectomy 15 years ago and this has been very successful for me. Feel free to contact me to register your interest in the Group or just have a chat."

Colleen McLean - 5493 6391
colleen4551@gmail.com

News from Cairns

The next Cairns get together is on Saturday 27th June. 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 15th August
Saturday 17th October
Saturday 19th December

Donna Formosa – M 0414 397462 or H 40392148

News from Mackay

Mackay members enjoyed a mother's day lunch get-together at North Mackay Bowls Club on Sunday 10th May. We had a very good attendance and it was a great opportunity for our members to catch up with each other. The venues and dates for the rest of the year were also decided.

Sunday 30 August 2015 – Western Suburbs Football Club, Walkerston
Sunday 29 November 2015 – Boomerang Hotel/Motel, Nebo Rd, Mackay

Bill Harris - 49541221

News from Townsville

Daphne writes,

"I am the co-ordinator for the Townsville MG group.

I was diagnosed with Ocular myasthenia in early 2013.

Carol Buchanan introduced me to the group and I thank her for that and all the work that she has contributed to the organisation.

I am retired and i am kept busy with grandchildren, music and catching up with friends. i am the kindy grandma at a local C&K kindergarten.

My husband and i have been travelling this year. We have been to Perth and are going to Darwin soon."

Our May MG group lunch was attended by 13 people and our next lunch is on 18th July.

Daphne Clay – 47733695

Trevor writes,

Hello to all, my name is Trevor and I live in Uki near Woolumbin (Mt Warning) NSW.

Time for a new member to get involved, Catherine's writing has triggered me into action. Congratulations Catherine on the weight loss. Please forgive spelling and related writing problems. Along with other issues, I'm mildly dyslexic, spell check is a boost to the ego.

I relate to the over weight problem very well. For me it's always been a problem, but now on Prednisolone and Endep, the weight is climbing again. The addiction to coffee and pastries doesn't help; luckily it is my only addiction (except for motorbike magazines). There was a time when my exercise program was sufficient to balance things out, but the myasthenia gravis (MG) has put a stop to that.

I still have a pretty good routine that I keep up, but am unable to push hard enough to get the weight down. We can probably all relate to the difficulty getting into regular exercise. For me as I was a bad asthmatic as a child, I never played sports, but as I got older the asthma subsided somewhat so I was able to get into a bit of surfing, swimming and horse riding.

Back in 2000 I was put on a disability pension because of spinal degeneration and the pain involved. Fortunately, I quickly realised an exercise program was paramount if I was to remain flexible and keep the pain down. So with the help of a physiotherapist, we worked out a program. I also did a pain management course at Lismore Hospital.

I sometimes wonder, because I was into the routine, if it helped keep the strength up and maybe delayed the diagnosis of MG.

I was diagnosed about 3 years ago. I believe it started in my hands. It was very slow to develop. The energy levels would drop, then stagnate for a while then drop again. I was on a downward spiral that didn't look like levelling out, when I was finally diagnosed, taking nearly 20 years. I am very keen to see the results of the Exercise Survey.

The way I found to get exercise started and keep it up was to start my exercise before I got out of bed. I do some leg stretching lying on my back, then into the routine as I get up. Starting with very easy and low impact exercises and slowly increasing the amount. My morning program is very small, just enough to wake me up and hopefully not pull anything when needing to bend over to pick things up. I also find, even in winter, a morning shower after the exercise is a great lift to how one feels for the rest of the day.

Then last thing in the afternoon I do a longer exercise session. I am also lucky that there is a local heated swimming pool so I can swim all year round. I believe swimming is my saviour, both with the

MG and the back problems. I used to do a long morning walk, but the MG has now curtailed that somewhat. The morning walk is now very short and some mornings very hard, but I am able to tell myself that "the Dog needs it". I seem to be able to push the swimming more than the walking, probably as water takes a lot of the load off.

I used to have horses, but with the MG it was very difficult for me to trim feet etc. So as they were old and one was mildly crippled, and getting worse, I decided that when it came time for the older horse (31yrs old) to be put down, I would put them both down rather than see the stress over the loss of a long term paddock mate. A very hard day indeed, when it came time to do it. I had had the old girl for 25 years.

Now I find it a little harder to get up early as I don't have the responsibilities. So as some people say, having a pet or animals can help with a lot of human issues and encourage you to do a lot more to help keep the depression at bay.

At the moment, I only have the one dog, but I need to let him out early as I keep him in at night to protect the local wildlife; fortunately he is a clever fella and will wake me if he needs to go rather than disgrace himself. So once I've had to get up, I may as well stay up as it is usually happens a little after dawn, which used to be my preferred time to rise.

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.

MGAQ Facebook Page

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.



IT'S MEMBERSHIP SUBSCRIPTION RENEWAL TIME

It's that time of the year again when Membership Subscriptions for the financial year 2015/2016 are due. Membership Fees are the same as last year.

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 6/15 which tells you (and us) that you are financial to 30 June 2015. Others may show 6/16 or even 6/17 to indicate they have saved time and postage by paying in advance. However, there are others whose envelopes still show 6/13, 6/12, etc. and we continue to send our newsletter to these unfinancial members because we do not know what they want. **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 & 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.

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 \$15**
(or) **Category E – Supporter \$15**

ADDRESS _____

And for _____ **Category D – Carer \$5**

ADDRESS _____

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.