

MYASTHENIA GRAVIS ASSOCIATION OF QUEENSLAND INC.
PRESIDENT'S ANNUAL REPORT – YEAR ENDING 30 JUNE 2013

Welcome and thank you for attending the 22nd Annual General Meeting of the Myasthenia Gravis Association of Queensland Inc.

The past year has been another very successful year for the Association highlighted by the following:

Membership: Our current membership stands at 308 of which 120 are unfinancial, while our Mailing list is 257 of -which 56 receive the newsletter via e-mail. Of those 308 members 205 are category "A" (people who have been diagnosed with MG) 77 are Category "D" (Carers) and 26 are Category "E" (Supporters). During the year 8 of our members passed away and the Association expresses its sympathy to their families on their loss.

Our Information Officer, Shirley Johnston was kept busy answering a host of calls to our 1800 802 568 Freecall number.

Data Collection Survey:

The project is still ongoing as well as collecting data from our members, the Survey document has been forwarded to Medical professionals to hand to patients who have MG but are not members of the Association. The Survey document has also been forwarded to our interstate associates for distribution. Dr Stefan Blum is very passionate about the survey, as he expressed on the occasions he has been guest speaker.

I would like to thank Susan White and Bill Synnot for their time and effort in their ongoing meetings to keep this survey moving.

Exercise Effect in Myasthenia gravis – Pilot Study.

This project is now in the stage of collating the results. We had 2 more members who participated in the study in the last twelve months and their participation helped increase the study sample. It is expected that the Study results will be published in '*Muscle and Nerve*' in the very near future. '*Muscle and Nerve*' is an international journal devoted to neuromuscular disorders & treatment options & is considered essential reading for neuromuscular, musculoskeletal, & EDX (Electro-Diagnosis Services) physicians.

Copies of the exercise booklet, *Preventative Health – Exercise for your Bones, Strength and Balance*, on which the exercise regime used for the study was based, are available in hard copy or electronic form to current financial members on request.

'Meet the Members' program:

This very successful program continued with a very enjoyable Picnic in the Park at North Pine Dam and the weather was perfect and lots of stories about MG were told.

The next meeting under this program is scheduled for November in Toowoomba.

Guest Speakers

Guest Speakers during the year were:

9 September 2012 (AGM) – Dr Stefan Blum – Progress Report on the Data Survey on MG sufferers; and Dr Jenny Nitz – progress Report on the Exercise Effect in MG Pilot Study.

16 June 2013 – Dr Stefan Blum – Some Interesting Results of the Data Survey on MG Sufferers.

DVD's of the Guest Speakers' presentations were distributed to all Category A financial Members. This initiative of producing the DVD's of our Guest Speaker presentations is so that our members who are unable to attend in person will still get the benefit of the information.

Myasthenia Gravis Association Pamphlet:

Carol Buchanan has worked tirelessly in organising the design and production of the new pamphlet. The pamphlet's purpose is to increase public awareness of the Association, what support it provides and how to join. We have already had new members join the Association by completing the Membership Application in the Pamphlet.

MGAQ Website.

Our website at www.mgaq.org.au has been enhanced during the year and we are now on Facebook. I would like to thank Kate for administering our Facebook page and adding stories.

National Alliance:

The committee is still working on the National Alliance but with the other MG organisations in Australia not meeting as regularly as we do it is taking quite a long time; but we also do not want to rush this as we need to get it right from the start.

Lending Library:

We have a few resources available for loan to our members so please make use of this library.

Radio and Hospitals interviews:

Shirley Johnston has been busy this year with doing an interview with the ABC and also telling her story to Nurses at the QE2 Hospital. This is another avenue for spreading the word about MG.

Ongoing Funding from Queensland Health:

The latest Service Agreement with Queensland Health expired on 30 June 2013. Under this Agreement, Queensland Health provided funding, paid quarterly, to assist the Association to provide the support services that it does.

The Association was offered a six-monthly extension of the Agreement until 31 December 2013. This offer was accepted by the Management Committee and the relevant Addendum to the Agreement was signed and returned. Unfortunately, Queensland Health decided not to execute the Addendum to the Agreement, and instead offered the Association (and many other Community Self-Help organisations) a new Service Agreement for the period 1 July 2013 to 31 December 2013. This Agreement has certain Performance Reporting Requirements and Insurance Cover Requirements attached to it. The Committee considers these requirements excessive taking into consideration the volunteer nature of the Association and the fact that we do not provide any medical procedures, treatments or advice. The Committee is currently in negotiations with Queensland Health with a view to having the conditions of concern changed or removed. One outcome from the negotiations may be that the Committee decides to not accept the Service Agreement and becomes self-funding. Refer to the Treasurer's Report for further comment.

Plans for 2013/2014 year include:

- Progress with the National Alliance Proposal
- Continue with the Data Collection Survey
- Explore other ways in which social media can assist the Association in its aims
- Further efforts to increase the public awareness of myasthenia gravis
- Follow up on our unfinancial members to see if they can be encouraged to become financial
- and anything else which provides support to the sufferers of myasthenia gravis and their families.

I wish our fellow MG organisations in New South Wales and Western Australia all the best in their endeavours to provide support for sufferers of MG and increase public awareness about the disease. I would also like to thank the MGA of UK and the MG Foundation of America for their generous permission in allowing us to reproduce in our newsletter, MessaGes, articles which appear in their newsletters.

Finally I have many people to thank, and not in any order of importance they are:

- Vice President John Noble for his help and guidance on many subjects and also for taking the reins whilst I have been away. And for managing our Lending Library;
- Treasurer Susan White for an excellent job of looking after our books and our investment accounts, for her oversight of the Data Survey and for her work on the National Alliance;
- Secretary Graeme Peters for all the Secretarial jobs as well as doing the Newsletter by compiling and distributing it;
- Shirley Johnston who looks after all the calls from the 1800 number as well as doing ring-arounds for our functions and meetings etc.;
- Committee Members Bill Synnot and Carol Buchanan for all their hard work in regards to the projects they have been working on;
- Our Regional Coordinators for their efforts in keeping our regional members in touch;
- The wives, husbands, partners and families of the committee members for their support and forbearance;
- Queensland Health for their very generous financial support;
- Philipp Hartle (interactiveFocus) , our Webmaster, and Jamie Kehoe (Keydesignz) who produces our DVD's, for their contribution to the Association's objectives by providing their services at a generous discount to normal commercial rates;
- Our members for having sufficient confidence and trust in the Association to renew their membership;
- Everyone who donated – our sincere appreciation; and
- anyone else who has provided support and encouragement throughout the year.

We look forward to an even better 2013/2014 year and wish everyone great health and happiness.

Anita Jackson
President

MYASTHENIA GRAVIS ASSOCIATION of QUEENSLAND INC.

TREASURER'S ANNUAL REPORT – YEAR ENDING 30 JUNE 2013

The 2012 – 2013 Financial Year has been very sound for the Association. With greatly appreciated support from Queensland Health in the form of the continued grant (\$25,687.00) and support from the community, the Association remains in a strong financial position. Membership contributions have been generous, represented by membership payments and very thoughtful additional donations. Whilst term deposit rates have fallen, interest received on funds has strengthened the Associations position by \$4534.00.

General expenses have remained consistent with previous financial years and carry a heavy focus towards communicating with our membership. Here the Freecall telephone number is important plus postage costs, as information is made available to the members via the information booklets, the newsletter and DVD distribution.

Some expenditure has been taken from the research account to support on-going data collection from the 'Exercise Effect in MG' project at the University of Queensland Physiotherapy department. The total for this was additional work was \$2260.00.

A further commitment has been made to secure an Economic Report on the data provided by the survey. An invoice for \$15,000.00 (plus GST) was received prior to June 30 and this amount can be seen in the figures. The deducted amount will show in the Research account balance in the 2013-2014 audit as payment was not made during this financial year. It should be noted that \$10,000.00 of this commitment was supported out of the agreed contribution to the University of Qld and RBWH for the MG Survey shared project.

Serious review of the Insurances was again undertaken this year and a significant saving was achieved.

The Association must express our sincerest appreciation to the UQ Business School for performing the audit of the 2011/2012 accounts pro bono, and to BDO Australia Ltd for agreeing to audit the Associations accounts for 2012/2013. Again, the work has been offered pro bono. These pro bono services provide a significant saving to the Association. Gratefully, it can be reported that BDO Australia Ltd is prepared to offer the same support again next year, i.e. for the 2013/2014 accounts.

The Association has a commitment to return to Queensland Health the amount of \$3690.23, as this money was not expensed from the Grant during the current financial year. The surplus comes from achieved operating savings via the audit and insurance items. A significant restructure of the committee is in place and supportive office equipment will be required for the necessary transitions. It is proposed that the savings fund this restructure however this cannot be assumed as the Grant Agreement requires the Association to make a formal application to Queensland Health to allow the funds to be carried over in this way. It was unfortunate and unavoidable that the details could not have been determined prior to June 30th.

The resource lending library has expanded this year and will hopefully continue to grow. Banners have been supplied to the Regional Coordinators to help them in their work and a brochure was developed for the Association to raise awareness of the organization and to provide an additional source for membership application. These items are listed in the Office Supplies and Equipment section of the report.

As mentioned in the President's Annual Report, the future of funding from Queensland Health is uncertain and is under negotiation. An acceptable agreement has not yet been secured with Queensland Health to continue funding the Association. Consequently, at present, operating costs are being reduced and overall operational strategies are under review pending the outcome of these negotiations.

Should the outcome of these negotiations result in there being no ongoing funding from Queensland Health, the Management Committee is of the opinion that the Association is in a position to support itself into the future, having significant capital reserves, and by making some changes to operational strategies.

Susan White

Treasurer