

MYASTHENIA GRAVIS ASSOCIATION OF QUEENSLAND INC.

PRESIDENT'S ANNUAL REPORT – YEAR ENDING 30 JUNE 2011

Welcome and thank you for attending the 20th 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:

- Research Projects – funding for which is supplied from the generous bequest to the Association by the late Des Zeimer, of Bundaberg:

Data Collection Survey – this ground breaking project, the genesis of which was a suggestion by Dr Stephen Reddel during his presentation entitled 'MG- Update 2009' to members in June 2009, commenced in February this year, and is being conducted in conjunction with the University of Queensland and the Royal Brisbane and Women's Hospital. This purpose of this project is to collect data (medical, personal and lifestyle) on people who have myasthenia gravis, so that researchers can access the aggregate of the data to potentially research things such as causal links between MG and other immunosuppressant conditions, genetic relationships, dollar cost to the nation of MG, etc. We understand that this is the first time such data has been collected in Australia. The project is ongoing and as well as collecting data from our members, survey documents have been forwarded to medical professionals to hand to patients who have MG but are not members of the Association. MG sufferers interstate have also been supplied with survey kits by our interstate associates, MG NSW and MG Friends and Support Group WA. We wish to thank everyone who has made the effort in filling out the survey. I would like to thank Susan White and Bill Synnot for their time and effort in organising this project.

Exercise Effect on myasthenia gravis – a Pilot Study – this project, conducted by the Ageing and Balance Clinic in the Physiotherapy Department of the University of Queensland, is designed to determine the effect of exercise on persons who have MG and to determine whether exercise has a positive effect on those persons. At this stage we are in the process of recruiting the required number of participants for the study. Because of the logistics of this project, participants must have reasonable access to the St Lucia campus of UQ.

Keep watching the newsletter for news on the progress of both projects.

- 'Meet the Members' program

A program of meeting with our members outside of the Brisbane area was commenced last year and continued with during 2010/2011. For these functions, the Management Committee travel to a regional area in Queensland to meet the members in that region and to give them the opportunity to get to know the committee and to provide feedback on whether the Association is meeting their expectations in respect of support and services. In the past year 'Meet the Members' functions were held at the Sunshine Coast and Townsville. These functions have been a resounding success, have both been very well attended and have proven beneficial to both committee and members.

In the coming year, 2011/2012, 'Meet the Members' functions are scheduled for the Gold Coast (November 2011) and Mackay (March 2012). Other regions will follow in ensuing years.

- 20th Anniversary of MGAQ –

2010/2011 year saw the 20th anniversary of the Association and was celebrated by a function held in Brisbane on 19 June 2011. The Guest Speaker on the day was our Patron, Dr Cecillie Lander, who spoke about the history of the Association and gave a potted history of myasthenia gravis. A robust Question and Answer session followed her presentation.

- Production of DVD's of Guest Speaker presentations –

As is now our practice, DVD's of Guest Speaker presentations from both our Annual General Meeting and the 20th Anniversary function were produced and distributed to all Category Members. Feedback from members has been only positive. The DVD's are produced professionally and the practice will continue. Suggestions for future Guest Speaker topics are welcomed.

- Myasthenia Gravis Information Packs –

Our Information Pack, which currently consists of quite a few disparate pamphlets, has been consolidated into a single Information Booklet by Committee member, Carol Buchanan, and reviewed by our Patron, Dr Cecilie Lander. This will make it easier to look up information on MG instead of having to go through different pamphlets. Supplies of the new Information Pack will be available shortly.

- MGAQ Website Upgrade -

Our website at www.mgaq.org.au has been enhanced during the year and now provides extra features such as 'News and Events', a more secure 'Contact Us' facility, a means whereby people can subscribe to receive the 'News and Events' information automatically via email, a Resources page and an 'Association Reports' page.

Our current membership stands at 215 of which 27 are unfinancial. Of those 212 members 154 are category "A" (people who have been diagnosed with MG) 47 are Category "D" (Carers) and 14 are Category "E" (Supporters). During the year 7 of our members passed away and the Association expresses its sympathy to their families on their loss. Our Mailing list is 234 of which 31 receive the newsletter via e-mail.

We wish our fellow MG organisations in New South Wales, South Australia and West 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, the MG Foundation of America and the Myasthenia Gravis Foundation of Illinois for their generous permission in allowing us to reproduce in our newsletter, MessaGes, material which appears in their newsletters or on their websites.

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

Vice President Kris Klitgaard - for his help and guidance on many subjects and also for taking the reins whilst I have been away;

Treasurer Susan White - for an excellent job in looking after our books and also looking after our investment accounts and overseeing the Survey project,

Secretary Graeme Peters - for all the Secretarial jobs as well as editing, compiling and distributing the Newsletter;

Shirley Johnston - who looks after all the calls to the 1800 number as well as doing ring-arounds for our functions, etc.;

Committee Members Bill Synnot and Carol Buchanan - for all their hard work in regards to the projects they have been overseeing;

Gordon Jiear - for looking after the phone whilst Shirley was away and also for his assistance when we have needed it;

Our Regional Co-ordinators - for their efforts in keeping their members in touch;

The wives, husbands, partners and families of committee members - for their support and forbearance;

Queensland Health - for their very generous financial support;

Our members for having sufficient confidence and trust in the Association to renew their membership;

Everybody who donated – our sincere appreciation; and

Anyone else who has provided support and encouragement throughout the year.

The coming year will be the Association's 'coming-of-age', i.e. it's 21st birthday. Given that the Association is run entirely by volunteers, it is no mean feat to still be in existence after such a long time.

Our Secretary, Graeme Peters, has indicated that after 6 years in the position, 2011/2012 will be his last year in this position. Of late his health has been not too good and he wishes to relinquish his position as Secretary but is willing to serve on the Committee in another capacity, if required. We are therefore looking for someone to take over the Secretary's function as from the Annual General Meeting in 2012. Graeme will be on hand to provide guidance and assistance until the new Secretary has settled in. So I would ask that members give this matter some thought between now and next year's call for nominations to the Committee. Remember, the Secretary does NOT have to be a member of the Association, so possibly someone from a member's family or friends may be interested in performing the duties of the position. If you require any further information about what the position entails, please contact Graeme on (07) 32884484.

Looking forward to an even better 2011/2012 year and wishing everyone great health and happiness.

Anita Jackson (President)

TREASURER'S REPORT 2011

2010-2011 Financial Year was again very positive with subscriptions and member donations well supported. Thanks to accumulated funds (which are now significant following the generous bequest received previously) lodged on term deposit we earned a substantial amount via interest payments. Despite investing in research work our overall financial situation has remained constant with the interest payments generally supporting our work. On average, funds have been invested at 6% and are currently secured for seven months at 6.3%.

A small increase in funds received from the Queensland Health Grant ensured that all our planned community work continued.

Overall expenditure increased significantly during the past financial year.

Generally, expenses were in line with the previous year after allowing for CPI increases in prices.

Three particular areas of additional activity explained the jump in outgoings.

Firstly, we successfully produced a survey and then printed 1000 copies of which approximately 350 have been distributed and more than 100 have been returned by reply post mail. This expenditure was funded from the Research Fund.

Secondly, due to additional regional meetings during the period our travel costs increased.

Thirdly, in support of the broadening work undertaken by the committee, the website was also enhanced requiring technical support.

Given positive feedback from using professional services to record speaker events the association has continued to engage this assistance.

The carry over surplus of funds from the previous financial year was expensed as committed.

Budget items for the forthcoming year include a continuation of the regional meeting program, two recorded guest speaker events, publishing and printing a new information booklets, completion of remaining obligations with regard to the survey and to initiate the research into Exercise and MG (for these expenditures, \$16,000 (\$10,000 for the Survey, and \$6,000 for the 'Exercise effect in MG' Study) has been transferred from the Research Fund and is sitting in the Operating Fund for easier access when required). The Association remains in a strong financial position.

Susan White (Treasurer)