

MYASTHENIA GRAVIS ASSOCIATION OF QUEENSLAND INC.

PRESIDENT'S ANNUAL REPORT – YEAR ENDING 30 JUNE 2012

Welcome and thank you for attending the 21st Annual General Meeting of the Myasthenia Gravis Association of Queensland Inc.

The past year has been a very full and busy one and was another very successful year for the Association highlighted by the following:

Membership:

Our current membership stands at 252, of which 175 are Category A (MG sufferers), 58 are Category D (Carers) and 19 are Category E (Supporters). Our Mailing list is 240 of which 36 receive the newsletter via e-mail. During the year 7 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 phone number.

Quite a number of our members are currently unfinancial and we will try during the coming year to ascertain why they no longer wish to be financial and hope to encourage them to renew their membership.

Data Collection Survey:

This very successful project is continuing to flourish with 475 surveys distributed and more being requested every month. The Survey was intended to run for 2 years from start which means that people with MG can still participate until April 2013. Survey documents have been sent to medical professionals and our interstate associates in order to try to gather data on as many MG sufferers in Australia as possible. Avenues to gain further publicity about the survey are being explored with various media outlets.

Data from the surveys is being entered into a computer for analysis and the lead researcher, Dr. Stefan Blum, will present a progress report on the Project following the Annual General Meeting.

I would like to thank Susan White and Bill Synnot for their time and effort in keeping this Project moving.

Exercise Effect in Myasthenia Gravis – Pilot Study.

Participants in this study have completed the exercise regime and final assessments and the data is currently being analysed. Professor Jennifer Nitz, University of Queensland Ageing and Balance Clinic, who supervised the study will present a progress report on the study following the Annual General Meeting.

As the number of members who participated in the study was below expectations, I encourage other members who live in the UQ 'catchment area' to think seriously about participating in the study by contacting the Secretary, Graeme Peters.

Meet the Members' Program:

This very successful program continued during the past year with the committee visiting the Gold Coast and Mackay Regions. This gave the members who live in those regions the opportunity to put a face to the names of the committee members, to tell their story, meet other MG sufferers and share their experiences with MG.

Production of DVD's of Guest Speakers:

The following DVD;s were distributed during the past year to current financial members:

Presentation by Dr. Jean Foster, (a GP from WA who has MG) entitled 'Getting the most out of your GP';

Presentation by Ms. Justine Joppich (Commonwealth Department of Human Services) entitled 'Aged Pensions and other Benefits from Centrelink.'

This initiative of producing DVD's of our Guest Speaker presentations so that our members who are unable to attend in person will still get the benefit of the information disseminated on the day, has proven to be very beneficial and feedback received has been all positive.

Members who have joined since the DVD's were distributed will receive their back copies in the near future.

Myasthenia Gravis Information Booklet:

This project has come to fruition and the booklets are now available to people enquiring about MG. The new booklet replaces the plethora of individual brochures and pamphlets which comprised the 'old' Information Pack. The booklet will shortly be available for downloading from our website.

I would like to thank Carol Buchanan for her tireless efforts in organising and compiling the new booklet and from the feedback we have received since its production it has received rave reviews.

MGAQ Website:

Our website www.mgaq.org.au has been further enhanced during the year and we will be on Facebook in the coming year.

Statistical data from our Internet Service Provider (ISP) presents some interesting facts, such as the website has been visited mostly from Australia (as would be expected) but also has had visits from countries as diverse as USA, UK, Russia, Singapore, etc.

Self-Help Awareness Day:

Self-Help Queensland conducted a 'Self-Help Awareness' Day in August 2011 and our Association manned a stall on the day. Information Packs were made available to the general public. The committee was very satisfied with the public reaction to our stall.

National Alliance:

The MGAQ has recently initiated a project to approach the other MG organisations in Australia with the purpose of establishing a National Alliance, so that issues regarding MG which transcend state

boundaries, e.g. myasthenia gravis medications, IVIg supplies, research funding, information resources, etc., may be dealt with at a national level, thereby presenting a 'united face' to national government. The project is in its embryonic stage and will be progressed in the coming year.

What's Ahead in the Coming Year?

Plans for 2012/2013 year include:

Progress the National Alliance Proposal;

Continue with the Data Collection Survey and the 'Exercise Effect in MG' Pilot Study;

Produce a pamphlet which will publicise the Myasthenia Gravis Association of Queensland rather than MG (the Information Booklet is the vehicle for providing information on MG). It is intended that this pamphlet be made available to members to distribute to medical centres, hospitals, chemists and allied health professional centres in the member's area;

Establish a 'lending library' of resources available for loan to members;

Explore other ways in which social media can assist the Association in its aims;

Further efforts to increase the public awareness of myasthenia gravis; and

Anything else which provides support and succour to sufferers of myasthenia gravis and their families.

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 condition. I would also like to thank the MGA – UK, the MG Foundation of America (MGFA) and the MG Foundation of Illinois (MGFI) for their generous permission in allowing us to reproduce in our newsletter, MessaGes, articles which appeared in their newsletters.

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

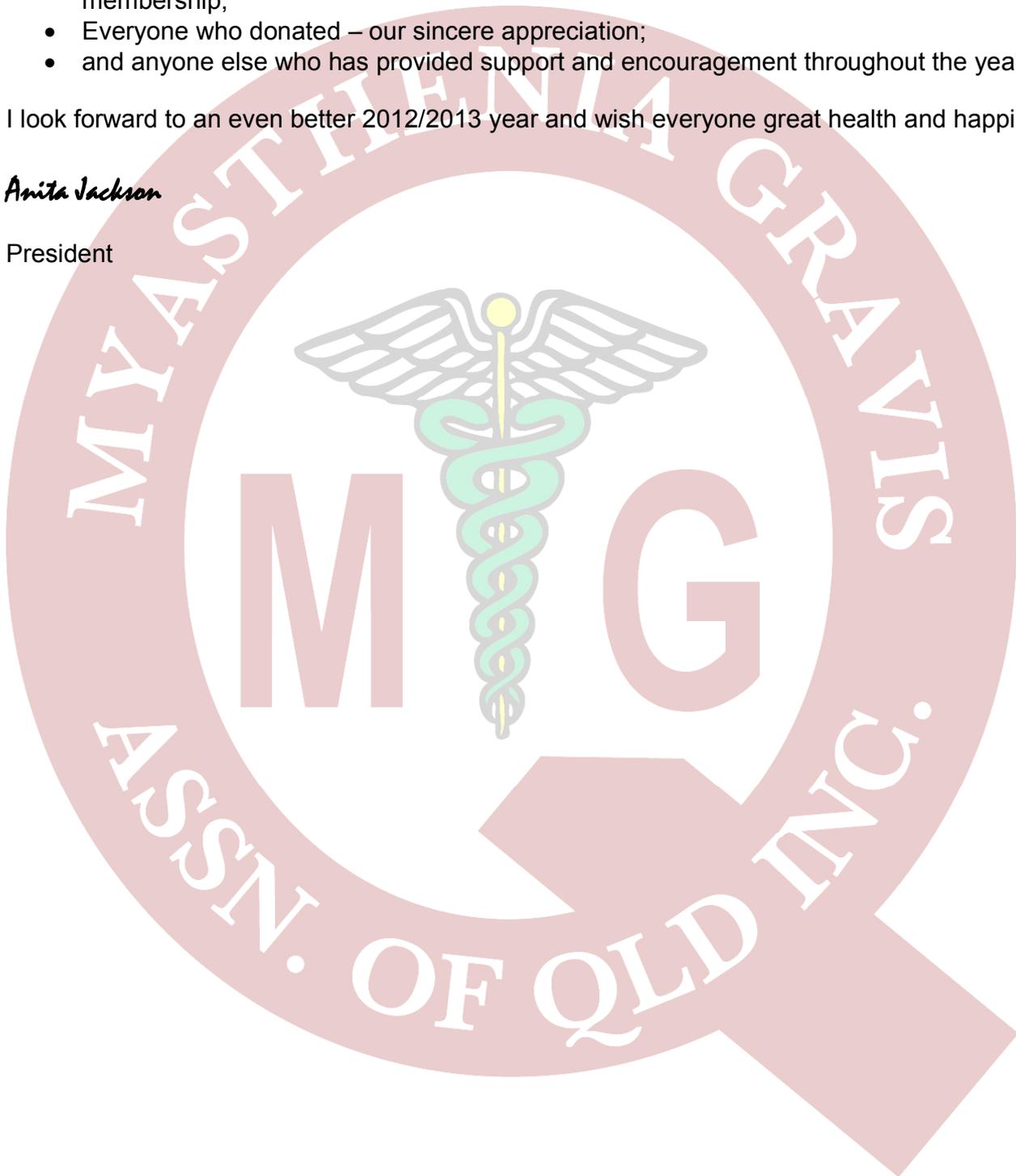
- Vice President John Noble for his help and guidance on many subjects and also for taking the reins when I have been away;
- Treasurer Susan White for an excellent job of looking after our books and also looking after our investment accounts;
- Secretary Graeme Peters for all the Secretarial jobs as well as editing and distributing the Newsletter;
- Shirley Johnston who attends to the many calls to the 1800 freecall 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 in which they have been involved;
- Our Regional Coordinators for their efforts in keeping their members in touch.
- The wives, husbands, partners and families of the committee members for their support and forbearance;
- Queensland Health for its very generous financial support;

- The University of Queensland Business School for agreeing to perform the 2011/2012 Financial Audit on a *pro bono* basis, thereby saving the Association in the order of \$1800.00 (this saving will be reflected in the 2012/2013 Financial Statement);
- 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.

I look forward to an even better 2012/2013 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 2012

The 2011-2012 Financial Year was again very positive for the Association.

Subscriptions were strong and additional donations from our members continue to be a very valuable resource.

Accumulated funds remain significant.

- The grant from Queensland Health has continued this financial year with an increase to cover rising costs. This has allowed our accumulated funds held on Term Deposit to remain largely intact. (It must be remembered and thankfully acknowledged that a generous bequest received in 2010 has been the major contributor to our strong position).
- Term deposit earnings have fallen due to reducing interest payments brought on by market factors. All moneys earned have again been re-invested.
- It should be noted that of the money allocated to research, \$5650.00 has been expensed during this financial year with a further \$10,524.00 held in the working account for payment as required.
- We remain grateful to Queensland Health as the grant continues to ensure all our planned community work becomes a reality.

Overall expenditure remained consistent with previous years (adjusted for CPI increases) and varied a little within the expensed categories according to the nature of our work.

- As previously noted, a significant payment this financial year came from our commitment to the research undertaken by the Physiotherapy Department of the University of Qld.
- All remaining assets have been fully depreciated.
- Office expenses were a little above the previous year due to printer toner cartridges being purchased in both August and June. The other additional one-off item for payment related to the acquisition of two display banners for use at functions.
- Postage cost have increased and include ongoing distribution and return of surveys.
- The new consolidated information booklets were produced and printed and this is reflected in the printing costs. Members may recall that this ONE booklet replaced the SEVERAL brochures which were previously supplied as an 'Information Pack.'
- Website costs vary each year according to major works required in the period.

The Association remains in a strong financial position. This is the final year within the current triennial agreement with Queensland Health and we await advice of ongoing support for the following financial years.

Susan White

Treasurer