



Messages

Myasthenia Gravis Association of Queensland

APRIL 2014



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Myasthenia Gravis Association of Queensland Inc

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PRESIDENT'S REPORT

Welcome,

I am back after my holiday in New Zealand where I had a great time and saw some amazing places and also learnt about some of the customs of the Maori people.

We had a very enjoyable morning with Meet the Members in Brisbane and it was interesting to hear how we all cope with MG and also the side effects of our medication. It was good to welcome new members and I hope they enjoyed their day.

We are awaiting advice from Queensland Health of the name of the consultant appointed by Queensland Health to assist us in the development of a transition plan tailored to our organisation.

We have received some feedback from the Rare Voices conference that Susan and I attended in February and also from Orphanet which is a reference portal for information on rare diseases. One of the specialists spoke about this site and said that most Doctors used it for up to date information.

We have started making plans for our meeting on 15 June at the Southern Cross Sports Club in Mt Gravatt so mark this date on your calendars.

Take care,

Anita

Editor's note: I welcome and encourage all members to contribute to YOUR newsletter To ensure that the newsletter meets the publishing deadline I would appreciate if all items could be e-mailed to me by the first Friday of each month.

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Government

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SURVEY UPDATE

Collecting data on sufferers' of myasthenia gravis:

Dr Blum can confirm that surveys are still being received and contact with Australian sufferers continues to expand. During conversations with Rare Voices (see page 3) it became obvious that formulating registries of sufferers of Rare disease is a priority. Compiling such information is not easy and the survey work may be invaluable in this regard.

Dr Blum also confirmed that a first article for publication regarding malignant thymoma and MG was submitted a few weeks ago. As acceptance of papers usually takes a number of months there is no news as yet in this regard. The quality of life data article is also nearing final stages, and will probably be submitted to an Australian journal.

FUTURE OF QUEENSLAND HEALTH FUNDING - UPDATE

In the March edition of Messages it was noted that funding from Queensland Health will cease at 31 December 2015. However it may be earlier, depending upon Queensland Health's acceptance or rejection of MGSQ's Transition Plan for the period 1 July 2014 to 31 December 2015.

The Management Committee have identified the following matters to consider in the compilation of the Transition Plan. These matters could result in either increasing revenue or decreasing expenses, and will assist the MGAQ to continue functioning after funding from Queensland Health ends.

The committee would also welcome suggestions from our members on how the MGAQ can continue beyond the time Queensland Health funding ceases.

Matters to be considered

- * Publication of MessaGes every 2 or 3 months (MGA – UK and MGFA -US only publish their newsletters 3-monthly, as does the NSW MG Association)
- * Non-financial members to receive MessaGes by email only;
- * Production of only one (1) DVD each year containing videos of all guest speakers during the year;
- * Increasing Membership Fees;
- * Email delivery of MessaGes to all members who have access to the Internet;
- * Replacing the current Freecall 1800 phone service with a cheaper option which would require the caller to contribute to the cost of a call;
- * Re-assess insurance requirements with the aim of reducing premiums while still maintaining adequate cover;
- * Use website more to keep members up-to-date with MGAQ news;
- * Investigate sponsorship for things such as newsletter and DVD production and distribution;

- * Investigate what other funding grant sources are available and MGAQ's eligibility for them;
- * Review administrative procedures where possible, such as teleconferencing management committee meetings where feasible;

The Management asks that our members give consideration to these matters, especially with respect to the impact they may have on the continuing support expected by the membership. Please provide feedback via an email to info@mgaq.org.au or a phone call to our Freecall 1800 802 568 number.

RARE VOICES AUSTRALIA supporting RARE DISEASES.

Anita and Susan on behalf of the Association took up the invitation to attend a Brisbane based meeting hosted by Rare Voices Australia to celebrate Rare Diseases Day which was held Australia wide on February 28th 2014. Rare voices is an Australian not-for-profit organisation aimed at providing a voice for all Australians suffering from a rare disease.

Myasthenia Gravis certainly qualifies under the internationally used description of a rare disease. There are 8000 such diseases and they affect in total 6-8% of the Australian population. Currently, the Federal Health Department has issues recognising individual conditions within this group. It is hoped that by forming a collective of these diseases as is being done overseas, it will be easier to communicate with Health authorities.

The Rare Voices Australia aims to (as taken from their literature)

Collaborate and connect all Australians sharing the experience of living with a rare disease.
Advocate for a National Rare Disease Plan
Raise awareness of issues faced by the rare disease community and the impact on the community
Educate with current information and resources to promote understanding, motivation and empowerment.

Other support groups were present at the round table discussion hosted by Megan Fookes, Director of Rare Voices Australia. It amazed Anita and Susan that the discussion and commentary on key issues experienced by individuals affected and by the organisations aiming to support those affected repeatedly and exactly expressed our feelings, frustrations, sentiments and experiences. It is felt that this body has the potential to bring invaluable assistance to the committee in the work that is being undertaken to support MG sufferers.

Great interest was shown in the work undertaken by MGAQ in regard to the MG Survey and the subsequent Economic Analysis which was undertaken.

Do have a look at the website www.rarevoices.org.au. The site gives access to information about various conditions and assists in finding groups who can be a support to people. Your Association has purchased two copies of a glossy book highlighting life with rare diseases. These are available via our library service and can be recommended. It is hoped that an MG story may be told in the second edition of this publication.

Live each day as if it's your last. Someday you'll be right.
If you can smile when things go wrong, you have someone else in mind to blame.

REGIONAL COORDINATOR VACANCIES

Currently there are vacancies for the following positions of Regional Coordinator for the South (Gold) Coast, North (Sunshine) Coast, Wide Bay/Burnett and Rockhampton regions.

With the impending cessation of funding to the MGAQ from Queensland Health, the role of Regional Coordinator will take on an increased importance as the conduit between our members in the regions and the Management Committee.

The role of Regional Coordinator includes: maintaining regular contact with the members in the respective region, usually by means of regular (say 3 to 4 monthly) get-togethers; dissemination of MGAQ Information Booklets and Pamphlets throughout the region; and bringing concerns or suggestions from local members to the attention of the management Committee.

The Management Committee would like to hear from members (or carers) who are interested in taking on the role of Regional Coordinator in any of the abovementioned regions via an email to info@mgaq.org.au or a phone call to our Freecall 1800 802 568 number.

MessaGes – HAVE YOUR SAY

We invite you, our members, to let us know what you think of MessaGes.

In particular, we are interested in hearing why or why not MessaGes meets your expectations. Does it include items of interest to you? Is there something you would like to see more or less of?

Please send any constructive feedback you may wish to provide, including suggestions for improvement, to info@mgaq.org.au or call Shirley on our Freecall 1800 802 568

INCREASED POSTAGE RATES

As members are no doubt aware Australia Post recently increased its domestic postage rates.

At the same time, it introduced a scheme whereby people who hold any of the following Australian Federal Government Concession Cards may be eligible for a MyPost Concession Card which, among other things, provides access to up to 50 reduced postage stamps per year:

- Pensioner Concession Card
- Health Care Card
- Commonwealth Seniors Health Card
- Department of Veterans' Affairs Card
- Veterans' Repatriation Health Card

To get more information and/or to apply for this scheme download the Application Form at www.austpost.com.au or go to your local Post Office.

I wish I was a teddy bear. Everybody likes 'em. Nobody cares how fat they are. The older they are, the more they're worth.

CHAT LIST:

Each member of our Management Committee is happy to speak with you, while the following members, who include MG sufferers or their carers have offered to join our Chat List. If you have a need to have a yarn, particularly about how MG affects you, please ask if it is convenient to talk, and respect the privacy of those whom you call.

In the interests of one's privacy, we have not listed surnames. Do not be embarrassed by ringing a stranger and asking to speak to say, "Fred or Mary". If you wish to disclose your surname, that is your prerogative. Simply explain that you are a MYASTHENIC or a CARER.

The opinions expressed by the person you call are entirely those of that person. 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 there is also the FREECALL telephone number for Australia manned (or is it womanned?) by Shirley and is 1800 802 568. Please do not hesitate to call if you feel the need. If the 1800 802 568 is not answering, please leave a message and Shirley will get back to you as soon as practicable. Your call is valuable to us, so please do not hang up without leaving a message.

CHAT LIST – BRISBANE MEMBERS

TERRY / JUDI	3824 4158	ALEXANDRA HILLS
JESSICA	3369 8315	BARDON
JOHN	3269 5066	BRIGHTON
THOMAS	3386 1918	BEENLEIGH
CLIVE	32617564	BRACKEN RIDGE
EILEEN	3269 5660	BRIGHTON
KENNETH	0414525241	CAMIRA
GWENDA	3390 2643	CAPALABA
CAROL	33901788	CAPALABA
LORRAINE	3206 0789	CLEVELAND
PETER	3821 4725	CLEVELAND
PATRICIA	3207 0456	COOCHIEMUDLO ISLAND
PAM / RAY	3801 5347	CORNUBIA
HELEN	3203 0150	DECEPTION BAY
STEFAN	3807 0541	EAGLEBY
NORMA	3281 5079	EASTERN HEIGHTS (IPSWICH)
KIRSTIE	0408311110	EATONS HILL
CAROL	3341 0707	EIGHT MILE PLAINS
ROGER	3379 8916	GRACEVILLE
JOHN	3899 9387	HAWTHORNE
LEILANI	0448192521	INDOOROOPILLY
DANIELLE	3202 2509	IPSWICH
HELEN	3279 3060	JAMBOREE HEIGHTS
PENNY	0415613242	KANGAROO POINT
GEOFFREY	33556441	KEPERRA
CARLY (14 years old)	3354 3014	MITCHELTON
PATRICIA	38867802	NARANGBA
SUSAN	33581056	NEW FARM
KEVIN	32819225	NEWTOWN
BILL & JITLADA	33997041	NORMAN PARK
PATRICIA / LES	5464 6719	PURGA IPSWICH
SYBIL	3219 9535	ROCHEDALE
CATHERINE	041851110	SPRINGFIELD LAKES
POPPY	3288 4484	SPRINGFIELD LAKES
MARIE	3300 0053	THE GAP
JOHN	3633 0604	ZILLMERE

MEMBERS FORUM

Sarah-Jane writes,

Growing up with a parent with Myasthenia Gravis can be challenging at times. When Mum first began showing symptoms of the disorder, she declined quickly from the bubbly, energetic woman I had always known. Her eyes began to droop, she couldn't smile, eat, or even breathe properly, and she was no longer capable of many of the household tasks I had so often taken for granted, let alone the sports and family activities that she had previously loved doing.

Watching her decline like this within a matter of weeks, without any diagnosis, was probably the most difficult Myasthenia Gravis related experience that we endured as a family. It came as a relief, despite the seriousness of the condition, to finally have a diagnosis. A diagnosis meant that we could have an idea of what was in store for Mum and for us as a family. It meant that we, in some small way, had regained control of an uncontrollable situation.

Over the few years that followed, there were certainly ups and downs. Mum's health was never consistent. Some months she would seem fairly well, to the point where I would even forget that she was sick and that she wasn't capable of doing everything that she was capable of before. It was frustrating at times, because I couldn't entirely understand how she was feeling and how hard it was for her to do everyday tasks alone. She seemed healthy in comparison to before she was on medication, so it was easy to forget that she was still unwell and needed extra help.

There were also times when she was very obviously unwell. She might catch a common cold from either Dad or myself, and we would have the sniffles, but mum would struggle to stand up or breathe. Those times were especially worrying in the beginning, and they still can be.

When I was in year twelve, Dad was interstate for work, so it was just Mum and me for a while. Mum called out to me in the middle of one night, wheezing for breath, and asked me to get her emergency bag from the wardrobe and take her to the hospital. I had only just learned to drive, so I was still unsure of myself behind the wheel, but I knew I had to stay calm and try to emulate the strength that Mum had always had, particularly in the face of her illness. It was a frightening experience, especially on my own, but in hindsight I just thank God that I had reluctantly agreed to get my license a few months earlier, despite my introverted (and somewhat lazy) brain's persistent objections.

Over time, the management of the condition has become easier and there's less fear. Experience has taught Mum how to deal with her condition appropriately both when she's well and when she's not. She has reacquainted herself with the limits of her body, learned the details of the medications and procedures that work best for her, found doctors with a good understanding of the condition and how to effectively treat it, and has learned, perhaps most importantly, not to let the condition stop her. Now that she knows how to manage it, Myasthenia Gravis doesn't rule her life. She knows that she can go out and do things that she loves as long as she doesn't overextend herself, and she finds the positive in every situation.

It's been a long and rather unstable journey to this point, but it's taught our whole family to be more positive and not take good health or each other for granted. We've grown together through this experience, because even though Dad and I aren't sick, and even though we sometimes struggle to grasp the full extent of Mum's condition, we're all in it together. Every day we're still learning how best to help Mum live the fullest life she is capable of, and she teaches us so much about making the best of bad situations. I'm proud of Dad for the consistent love and support that

he has given Mum since she was diagnosed with Myasthenia Gravis, and I'm proud of Mum for never letting her illness stop her from doing anything that she wants to do.

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.

PUMPKIN FRUIT CAKE

1 cup warm mashed pumpkin	125g butter
1 cup sugar	2 tbsp. golden syrup
2 cups S.R. flour	250g packet dried fruit
2 eggs	pinch salt

Method:

1. Beat pumpkin, sugar and butter for a few minutes.
2. Add golden syrup and beat till creamy.
3. Add eggs flour and fruit.
4. Place in 22cm baking tin and cook 350c for 1½ hrs. Check after 1 hr.

TRIVIA

Barbers at one time combined shaving and hair cutting with bloodletting and pulling teeth. The white stripes on a field of red that spiral down a barber pole represent the bandages used in the bloodletting.

There are 45 miles of nerves in the skin of a human being.

Natural gas has no odour. The smell is added artificially so that leaks can be detected.

In the Netherlands, in 1634, a collector paid 1,000 pounds of cheese, four oxen, eight pigs, 12 sheep, a bed and a suit of clothes for a single bulb of the Viceroy tulip.

The human body contains enough iron to make a six-inch nail, sulphur to kill all the flees on an average dog, carbon to make 900 pencils, potassium to fire a toy cannon, fat to make 7 bars of soap, phosphorous to make 2,200 match heads and water to fill a ten-gallon tank.

The world's tallest mountains, the Himalayas, are also the fastest growing. Their growth – about half an inch a year – is caused by the pressure exerted by two of the Earth's continental plates (the Eurasian plate and the Indo-Australian plate) pushing against one another.

Although identified with Scotland, bagpipes were actually introduced into the British Isles by the Romans.

FUTURE PLANNED ACTIVITIES FOR BRISBANE**Sunday 16 June 2014**

Mid-year function – Brisbane – Southern Cross Sports Club, Mount Gravatt

MACKAY GET TOGETHER

Our lunch gathering was held on Sunday 2/3/2014 @ the Boomerang Hotel / Motel. Ten members attended and had an enjoyable lunch. One of our members Roslyn has relocated to Brisbane. All attending wished her all the best. It was decided our next lunch get together will be held at the Harrup Park Country Club on Sunday 18/5/2014. Every one received a small Easter gift.

Wishing everyone a Happy Easter 2014

Bill - Area Coordinator 0749541221

FUTURE PLANNED ACTIVITIES FOR CAIRNS

Meetings are held at the RSL Club Boardroom, Esplanade Cairns, at 11.30am unless advised otherwise. Some people stay on for lunch in the restaurant afterwards (at own expense).

We have set the dates for the meetings in 2014.

- * Saturday 21st June – Venue to be advised for “MG Awareness Month”
- * Saturday 16th August
- * Saturday 11th October
- * Saturday 6th December – Christmas function

Donna Formosa – Phone 0414 397 462 or email formosed@bigpond.net.au for more information.

CHANGE TO MANAGEMENT COMMITTEE

Following the previously advised resignation from the Management Committee of Mr Scott MacKay, the continuing members of the Management Committee have exercised their right under Clause 16 (1) of the Association's Constitution and have appointed Catherine Ormsby to fill the casual vacancy resulting from Scott's resignation. The appointment is only for the period remaining until the 2014 Annual General Meeting.

Things NOT To Do When You're Feeling Blue:

- Don't weigh yourself.
- Don't watch *Old Yeller*.
- Don't go near a chocolate shop.
- Don't open your credit card bill.
- Don't go shopping for a new bathing suit.