



MessaGes

Myasthenia Gravis Association of Queensland Inc

MARCH 2013



Myasthenia Gravis Association of Qld Inc IN NO WAY endorses any products, medical procedures or medical practitioners mentioned. Articles are provided as a guide, and/or for information purposes only.

We take this opportunity to thank Queensland Health who by the provision of a grant, make the work of the Association and the publication of this Newsletter possible, and to those who take the effort to contribute to its success.

Myasthenia Gravis Association of Queensland Inc

P.O. Box 16
MT. GRAVATT QLD 4122
NATIONAL FREE CALL:
1800 802 568
ABN 92 055 613 137

E-mail: info@mgqa.org.au
Internet: www.mgqa.org.au

COMMITTEE MEMBERS

President
Anita JACKSON
Ph. 3800 4913

Vice-president
JOHN NOBLE
Ph. 3269 5066

Secretary and Editor
Graeme PETERS
Ph. 3288 4484
email: graeme.peters2@bigpond.com

Treasurer
Susan WHITE
Ph: 3358 1056

Information Officer
Shirley JOHNSTON
Ph. 1800 802 568

Committee

Bill SYNNOT
Ph. 0418196707

Carol BUCHANAN
Ph. 4773 7122

PATRON
Dr Cecilie LANDER
Neurologist
Founder Member, of Brisbane

PRESIDENT'S REPORT

Welcome,

Little did we know that when we celebrated New Year's Eve and wished all the best for 2013 that we would have a very wet time ahead. I think we all may have ended up with webbed feet out of this as it certainly has been a different start to the year.

The committee has been notified that Dr. Stephen Reddel, because of a family illness, is unavailable to be our Guest speaker at the June function. This is a disappointment for us but we hope that his family health issue is resolved. We are working on a replacement for Dr. Reddel and will advise when arrangements are finalised. June is MG month and it is celebrated in USA in many different ways.

We are hoping that we will get some good results from those who participated in our 'Exercise Effect in MG' project as the results are now being documented as a Masters Thesis by a Masters student at UQ.

We are still sending out Surveys to MG sufferers requesting them and are hoping that the researchers have received enough to write up meaningful results (which, I am sure, there will be). It will be interesting to see where all these results go to from here. It is something which has never been done before in Australia so it will be increasing the awareness of Myasthenia Gravis.

Take care

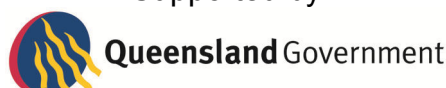
Anita

Correction: In the February 2013 issue of MessaGes, reference was made to members who may have suffered from 'cyclone Yasi'. It should, of course, read 'cyclone Oswald'. The editor apologises for the error.

Editor's Note: The editor apologises for the late production of the March issue of MessaGes, but health issues interfered with the process. It is hoped that things get back to normal for the April issue.

In the meantime, if any member, family member or family friend would be willing to take over the Editorial function, please contact the Secretary on (07) 32884484 or email Graeme.peters2@bigpond.com

Supported by



Queensland Government

PROJECTS UPDATE

Collecting data on sufferers of myasthenia gravis –

Currently, it is anticipated that the survey results will be written up during the month of April, thus allowing time for a full 200 survey results to be entered into the data base.

What an effort from everyone involved! Thank you!

As explained previously, the survey recording will not stop with this write up. There is a target to find 500 Australian sufferers for the data base.

‘Exercise Effect in MG’ Pilot Study –

EXERCISES AT HOME

The results of the Study are in the process of being fully documented and written-up formally and will then be available for the world to see.

We will advise when the MGAQ receives its copy and make it available to read to all interested members.

Doctor Jennifer Nitz, who conducted the Study at the University of Queensland’s Neurological, Ageing and Balance Clinic, has kindly provided the Association with a booklet entitled *‘Preventative Health – Exercise for your Bones, Strength and Balance.’*

The booklet details exercises which closely match those which were undertaken by participants in the above mentioned Study and are such that they can be undertaken by people in the comfort of their own home.

Each copy of the booklet comes with Cautionary Notes which should be read and understood before commencing any of the exercises.

Copies of the booklet are available, in either hard copy or electronic form (pdf), to current financial members. Those members wishing to obtain a copy should contact the Association on our Freecall number 1800 802 568 or via email at info@mgaq.org.au and state whether you prefer hard copy or email copy.

Copyright of the booklet remains the property of Dr. Nitz and the University of Queensland and should not be reproduced in any form without their express permission.

Also, if you have a try at these exercises and feel that you would like to undertake the complete set as part of the Exercise Study Project, and therefore contribute to the Study findings, please contact the Secretary on (07) 32884484 or via email at info@mgaq.org.au

* * * * *

“SURVEY SNIPPET”

Quality of Life.....

The Quality of Life segment within the survey highlighted that the most difficult issue for sufferers relates to 'Fatigue and Thinking'. How reassuring to know that others also struggle to cope with this aspect of the condition. Does one's ability to concentrate and make decisions deteriorate due to the fatigue that comes when muscles are working harder than normal to complete tasks or could there in fact be a direct influence from the condition upon the brain itself?

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 – QUEENSLAND REGIONAL MEMBERS

KELLY	4728 4913	AITKENVALE
JOHN	4783 1556	AYR
YVONNE	4783 4643	AYR
MARK	4067 1784	BABINDA
LYNDA	4159 2890	BARGARA
JOHN	4959 5492	BAKERS CREEK
SARA	0422 109492	BLACK RIVER
HENRY	4982 6507	BLACKWATER
KELLY	4782 5542	BRANDON
PAMELA	4151 5499	BUNDABERG
ROBYN	5520 4242	BURLEIGH HEADS
MOYRA	5576 4979	BURLEIGH WATERS
PATRICIA	5535 0274	BURLEIGH WATERS
DENISE	4788 0798	BUSHLAND BEACH
DAVID	4053 2291	CAIRNS
RON / HELEN	4051 3286	CAIRNS
OWEN	4742 1190	CLONCURRY
BARRY	5483 1783	CURRA
GLORIA	5534 2669	CURRUMBIN
MELISSA	4662 3337	DALBY
GARTH	4973 7983	GLADSTONE
ELIZABETH	4936 2410	GLENLEE
LILLIAN	49334281	GRACEMERE
SHIRLEY	4128 3596	HERVEY BAY
ANGELA	0427752956	HOPE ISLAND
JAMES / ROSEMARY	5530 1558	HOPE ISLAND
SERAFINA	4751 6415	JENSEN
CHRISTOPHER	0412456439	LABRADOR
JUDIE	0439 461288	MACKAY
TERRY	5494 2470	MALENY
MAUREEN	5572 7993	MERMAID BEACH
ROBERT	5492 9754	MOOLOOLAH VALLEY
KATREN	0418778082	MONTEREY KEYS
JOY	4165 4647	MUNDUBERRA
BROOKE	0404720807	NAMBOUR
ALEX (BROOKE'S CARER)	0420858386	NAMBOUR
MICHAEL	5545 2802	NORTH TAMBORINE
DAVID	5474 5534	NOOSA
MARLENE	5447 4986	NOOSA HEADS
SHARON	4151 7661	NORTH BUNDABERG
MAUREEN	0411331258	PACIFIC PINES

TOM / SCOTIA	4693 3730	PITTSWORTH
BILL / COLLEEN	4926 2410	ROCKHAMPTON
DONALD	5563 7207	RUNAWAY BAY
KARLIENE	0432431591	SUNSHINE ACRES
HELEN	5445 4853	SUNSHINE COAST
BERNIE	Joypaul28 *	TEWANTIN
BETTY	4635 6270	TOOWOOMBA
DIANNE	4638 8447	TOOWOOMBA
LARINA	4636 0046	TOOWOOMBA
HEATHER	4728 7550	TOWNSVILLE
LUCY	0418879801	TOWNSVILLE
JO	4723 8721	TOWNSVILLE
ANNE	0487305153	TRINITY BEACH
VALMA	4068 0702	TULLY
KATHLEEN	5573 0439	UPPER COOMERA
RAJKO	5556 0639	UPPER COOMERA
JAN	5493 4441	WURTULLA
PERLA	4939 2724	YEPPOON
IAN	4623 5169	YULEBAR

Please note that * indicates
that this member is available
via the VOIP Skype facility on
a computer

Myasthenia Gravis Association of Queensland is on Facebook!

MGAQ has recently joined Facebook and we now have a Facebook page. You can find us at <http://www.facebook.com/mgqld?ref=hl> or search for us when you log into Facebook.

The Management Committee has made the decision to join this online community so there is a place to share your stories, experiences, and recommendations with each other. We have already shared links to other people's experiences of living with MG and we would love to hear from you.

For those of you who are not on Facebook yet but are interested in joining us in this online community you might want to click on one of the following links: <http://www.facebook.com> or [Explaining Facebook](#). In order to join Facebook you will need to have an email address and be older than 13.

Kate Lloyd – MGAQ Social Media Administrator

* * * * *

AIDS WARNING

This warning is especially for those of you who have reached 50 years of age, or are rapidly approaching it:

SENIOR CITIZENS ARE THE NATION'S LEADING CARRIERS OF AIDS -

Hearing Aids

Band Aids

Roll Aids

Mobility Aids

Medical Aids

Government Aid, and most important

Financial Aid to their children.

And let's not forget HIV - Hair is Vanishing!!!

*** **

MEMBERS' FORUM

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.

Future Planned Activities

Sunday 16 June 2013	Mid-year Guest Speaker function – Brisbane - venue TBA
Sunday 15 September 2013	Annual General Meeting – Brisbane – venue TBA
Sunday 10 November 2013	Meet the Members Toowoomba – venue TBA
Sunday 15 December 2013	Christmas Function – Gold Coast – venue TBA

More details will be published as the events become closer.

APPOINTMENT OF AUDITOR

At the 2012 Annual General Meeting held in September 2012, a motion was passed to defer the appointment of auditors for the year 2012/2013 until the Management Committee had selected a suitable one. Therefore in accordance with the motion passed at the 2012 Annual General Meeting, the Management Committee is pleased to advise the appointment of **BDO Accounting** as auditors for the financial year 2012/2013.

NOTICE OF CAIRNS MEETING on SAT 13TH APRIL 2013

A meeting is arranged for existing members and newly diagnosed patients of Myasthenia Gravis in an informal atmosphere at the Cairns RSL Club Boardroom followed by lunch for those who wish to stay on after the meeting. Lunch will be at own expense and we would like an indication of your intention to stay for lunch so that an appropriate reservation can be made. We look forward to seeing existing members and meeting new members and their carers.

When: Saturday 13th April 2013

Where: Cairns RSL Club, Esplanade Cairns

Time: 11.30 am

RSVP: Donna Formosa, Ph:4039 2148

Email: formosed@bigpond.net.au

Member Barry came upon the following article on the website of the Myasthenia Gravis Association of Western Pennsylvania, USA :

Stress and MG

Most myasthenia gravis patients learn very quickly that emotional stress and excitement affects their MG. Stress causes many physical changes in one's body and uses up energy. The end result of tense muscles caused by stress can be similar to the effect of vigorous exercise – it may exacerbate your symptoms of weakness. Much of the literature cautions people with myasthenia to limit their stress and avoid conflicts, but you might well ask, "How?" when life is by nature stressful and full of conflict. Indeed, stress and conflict can be positive forces such as the challenges that bring about personal growth or the "good" stress that you feel when you're happily excited. Without stress and conflict, life would be boring. The answer perhaps should lie not in eliminating stress in your life, but in learning better coping skills to deal with it.

While the sources of individual stress can be varied and personal, some common sources of stress in the person with MG can be:

1. MG symptoms and the accompanying frustration and anger when your body can't do what you want to do when you want to do it.
2. Anxiety from continual worry that new symptoms may appear; anticipation of day to day fluctuations in strength, or a fear of crises. Anticipation of medication side effects such as diarrhoea or potential long term side effects of steroids can also cause anxiety.
3. Dissatisfaction with personal appearance. Drooping eye lid(s), weight gain (fluid retention), weak facial muscles (causing an inability to smile), and slurred speech can cause loss of confidence, lowered self- esteem, and avoidance of social contacts.
4. Significant changes in lifestyle, such as having to quit your job, going back to school, giving up caring for the home, yard, and children. These are the things that are part of your identity. When you lose them, you may feel depressed and cheated at times.
5. Interpersonal relationships may be strained as you (and your family) try to cope with the limitations of MG and changes in your lifestyle. The person with MG may believe their status and family role has become less important and even feel like a burden on the family.
6. The range of emotions you may feel from time to time (a few herein mentioned were frustration, anger, guilt, depression, fear and anxiety) may be difficult to handle. Emotions which run rampant or mood swings can cause family members to "walk on eggshells" around the person diagnosed with myasthenia gravis.
7. Feeling stigmatized by MG or believing that one is somehow different from others. This can lead to withdrawal from social activities and a sense of remoteness from family, friends and co-workers.
8. Lack of understanding about MG, when family members and friends find it difficult to understand why weakness can vary daily or even hourly (especially when you look well), it can leave them feeling cheated and resentful. When MG is a mystery to you, it can leave you fearful of the unknown.

Here are a few constructive steps one can take to minimize stress:

- First, realise that it's okay sometimes to feel frustrated, scared, angry, and depressed. All of us do. Accepting your illness doesn't mean you have to like it. It only means that you realise your body has some limitations, and denying it won't make it go away, so you might as well work at having the best life you possibly can. In other words, concentrate on all that you can do, all that you have, and all that you are (which certainly is a lot!) rather than concentrating on what you cannot do.
- Avoid self-pity. It builds Stress, zaps your energy, and doesn't help you. As Abraham Lincoln once said, "Most people are about as happy as they make their minds up to be."

- Take charge of your life. You control our own behaviour and attitudes, and can work on developing more positive behaviour.
- If you've always been an overachiever and you are still pushing yourself too hard, learn to slow down. You may be able to do almost everything you used to do if you balance your day with periods of activity sprinkled with little periods of rest.
- If you have always been an underachiever and an inactive person, resist using MG as an excuse for doing even less. When you use your diagnosis as an excuse too often when you don't need to you run the
 - risk of reducing your credibility with your family. Because the weakness is often invisible to others, they find MG hard to understand anyway. Try to remain active and involved with your social groups, finding activities which are within your limitations.
- Know yourself. MG affects everyone differently. While some people are severely weak and fatigue rapidly, other MG patients are working full time, jogging and playing racquetball. It is important for you to learn what your own capabilities and physical limitations are. Venture trying new activities. Pace yourself; know when to slow down or when you've had enough. Get enough rest and sleep.
- If family members don't understand MG, try to involve them in your treatment, encourage them to ask your doctor questions, take them to MG meetings so they can learn more about this muscle weakness disorder. The same applies to your friends. Many MG patients conceal the fact that they have a problem from others, and that's okay. It's not always appropriate to broadcast it, particularly when it could jeopardise a job. But if you want to explain it to some of your close friends, it may help reduce your stress. Remember: "A friend is someone who knows you well . . . and likes you anyway!"
- If you don't understand MG very well, don't be afraid to ask questions about anything and everything that
 - concerns you. Between appointments with your doctor, make a list of your questions and symptoms that you want to mention. This can help prevent the stress of "Why didn't I remember to ask about . . .?" Many anxieties and fears about MG are unfounded, and learning more about myasthenia gravis can put your worries at ease.
- Learn how to express your emotions constructively with your family members and close friends. Communicating your thoughts can aid mutual understanding and support, and bring you closer together at a time when you need it most.
- Consider others more and yourself a little less. Love more. Love can be as healing as potent medication.
- Laugh more; it relieves stress. Learn to laugh at yourself, so you don't take yourself too seriously.
- Avoid loneliness. Seek out compatible friends. Take the initiative; join clubs or take a stimulating class.
- Participate in MG activities where the support from other people with myasthenia can erase that feeling of being alone with this disorder.
- Take time each day to make the most of your personal appearance. Good grooming habits, pretty makeup, an attractive and easy hairstyle, and flattering clothing which conceals or distracts the eye

from weight gain all go a long way. For diet tips which can help minimize fluid retention, ask your nurse or dietician.

- If your health permits, get regular exercise. Exercise helps work off stress. Start out slow with an early evening walk or a game of croquet on the lawn. It's pleasant time spent with family, too.
- Develop hobbies and interests such as reading, needlepoint, exotic cooking, or painting. Immersing yourself in a hobby helps dissipate tension.
- Look into stress management classes or go to your library for books or tapes on relaxation techniques. A few techniques include meditation, yoga, or visualizing restful scenes.
- Seek professional counselling when your self-concerns or family problems threaten to overwhelm you. All of us need extra help at difficult periods in our lives.

These behavioural tips aren't magic, but with practice, they can help you to reduce stress and become happier. So make the effort – it will be well worth it.

Reviewed for publication by the Medical Advisory Board of the Myasthenia Gravis Association of Western Pennsylvania. 2009

+++++

Humour from Stephen Wright

If you're not familiar with the work of Steven Wright, he's the famous Erudite (comic) scientist who once said: "I woke up one morning, and all of my stuff had been stolen and replaced by exact duplicates." His mind sees things differently than most of us do.

Here are some of his gems:

- 1 - I'd kill for a Nobel Peace Prize.
- 2 - Borrow money from pessimists -- they don't expect it back.
- 3 - Half the people you know are below average.
- 4 - 99% of lawyers give the rest a bad name.
- 5 - 82.7% of all statistics are made up on the spot.
- 6 - A conscience is what hurts when all your other parts feel so good.
- 7 - A clear conscience is usually the sign of a bad memory.
- 8 - If you want the rainbow, you have got to put up with the rain.
- 9 - All those who believe in psycho kinesis, raise my hand.
- 10 - The early bird may get the worm, but the second mouse gets the cheese.
- 11 - I almost had a psychic girlfriend... But she left me before we met.
- 12 - OK, so what's the speed of dark?
- 13 - How do you tell when you're out of invisible ink?
- 14 - If everything seems to be going well, you have obviously overlooked something.
- 15 - Depression is merely anger without enthusiasm.