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Myasthenia Gravis Association of Queensland Inc

FEBRUARY 2012



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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

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PATRON
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Neurologist
Founder Member, of Brisbane

PRESIDENT'S REPORT

Welcome

Hope everyone has had a good Christmas and New Year. It is certainly hard to believe that we are into February already.

What a few months we have had with extreme heat wave over most states and then a heavy rain depressions over the east coast as well as the cyclones in WA. All of us who suffer with Myasthenia Gravis will be hanging out until the cooler weather comes as the heat certainly plays havoc with us all and making us very tired and lethargic.

As previously reported the committee will be having a meeting in Mackay on 10th March 2012 at the Boomerang Motel so we are hoping that we get to meet all our Mackay members and also that you will voice what you would like to see us do for the Association in regards to keeping you in touch even though you are miles away from Brisbane. It is as very informal meeting and it is good to hear what our members have to say in regards to how they were diagnosed or what medication they are on.

As the committee has had a break for the month of January it will be good to get back to business and plan what we can achieve for the Association for the next few months especially in the progress of our projects, the data survey and the 'Exercise Effect in MG' Study in conjunction with Queensland University.

Hoping to see you in Mackay in March.

Take care

Anita

CHANGE OF EMAIL ADDRESS

Please note that the Association's email address has changed.

The new address is: info@mqaq.org.au

Supported by



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.

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 – INTERSTATE MEMBERS

BARRY / JO	02 6285 2661	CANBERRA ACT
MARILYN	02 6291 8287	CANBERRA ACT
BARBARA	02 9524 9224	CARRINGBAH SOUTH NSW
ROBERT	02 6652 6745	COFFS HARBOUR NSW
JEAN	02 4937 3110	KURRI KURRI NSW
MAX	02 6621 6386	LISMORE NSW
PENNY	02 4868 2213	MOSS VALE NSW
FRANK	02 6767 1031	TAMWORTH NSW
CANDY	02 6847 3732	WARREN NSW
ELLEN	07 5599 9511	WEST TWEED HEADS NSW
ROLAND	03 9796 6592	NARRE WARREN VIC
TAMARA	0409 186 809	HOPPERS CROSSING VIC
CORAL	03 5865 1378	KATAMATITE VIC
DENNIS	0402 285 520	PATERSONS LAKES VIC
BARBARA	03 9776 4985	SEAFORD VIC
DORA	03 5821 4191	SHEPPARTON VIC
DIANE	0421387904	CARINE WA
RONA	08 9459 7168	MADDINGTON WA
DIANE	03 6327 2563	RIVERSIDE TAS
DAPHNE	03 6428 6733	SQUEAKING POINT TAS
MARIAN	03 6257 1272	ORFORD TAS
PROSPER	08 8285 7016	ALICE SPRINGS NT

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Future Planned Activities

Saturday 10 March 2012

'Meet the Members' at Mackay

Sunday 17 June 2012

mid-year function in Brisbane - Guest Speaker being arranged

Sunday 9 September 2012

2011/2012 Annual General Meeting.

More details will be published as each event becomes closer.

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Obituary

It is with sadness that we advise of the passing of our oldest member, Beryl Deeth of Crows Nest, in her 97th year. The Association extends its condolences to Beryl's family and friends.

GOLD COAST MEET THE MEMBERS

On the 13th November 2011 Members of the MG Committee hosted a "Meet the Members" at Helensvale Bowls Club on the Gold Coast. Over 20 people attended with Carol travelling from Townsville and some members travelling from NSW. We also welcomed 2 new local members.

The meeting opened with a warm welcome from President Anita and committee members. Graeme gave a brief update on The Exercise Effect in MG Study / MG Questionnaire and also said that the committee would like to compile a data base of people with various skills who may be able to help with future projects. So if there is anyone who feels that they may be able to contribute in some way please contact Graeme for more information.

The morning was very enjoyable and interesting and everyone present had the opportunity to talk about their ongoing MG journey, ask questions, share ideas and have a good laugh in a very relaxed atmosphere. It was so worthwhile.....so make sure you make it along to the next meeting in your area and bring family or carers so they can become more informed about MG.

Thank you to all who attended and the Committee for coming to the Coast. Thanks also to John Nielsen for organizing the great venue, Helensvale Bowls Club for the beautiful morning tea and Shirley for the delicious fruit cake and door prizes.

I would also like to say thank you to all of the Committee members for their ongoing commitment and dedication to the MG Association for the benefit of the members.

Best wishes and good health to all in 2012 -- Kath Naus.....Gold Coast member

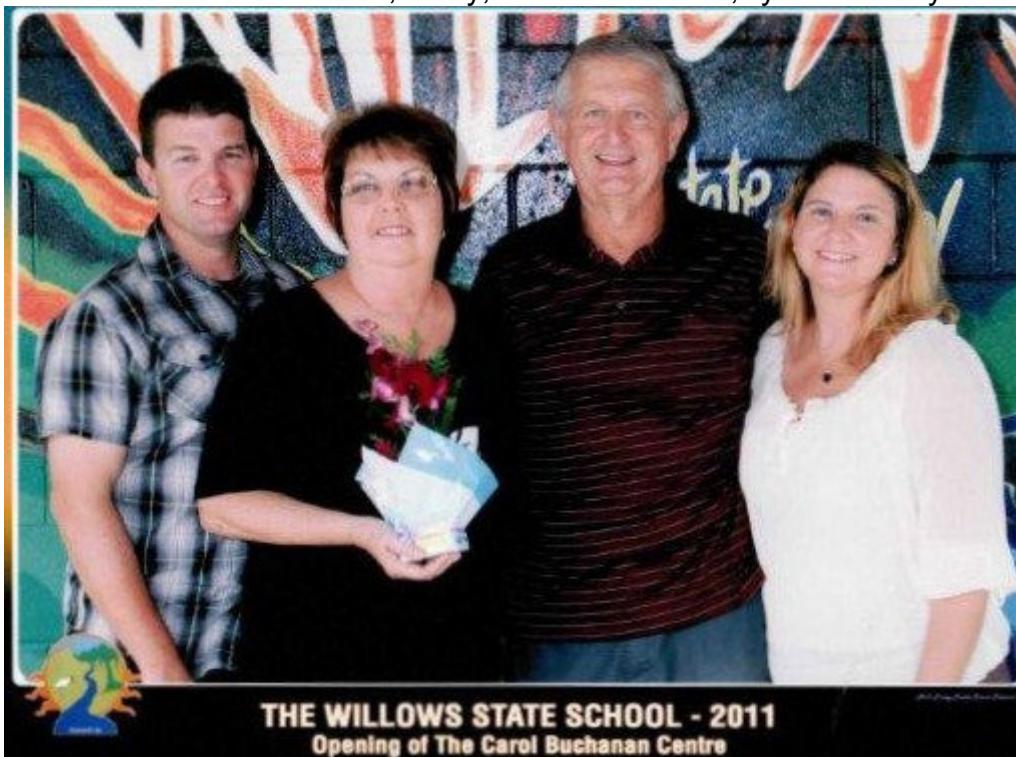
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Committee Member Carol Buchanan Honoured

Carol Buchanan, one of our management committee members, recently retired as Principal of The Willows State School in Townsville. Carol opened the school as foundation principal in 1998 with approximately 450 students and it has grown to a very large school with over 1 100 students today.

A new multi-purpose building constructed at the school was opened in November 2011 and named The Carol Buchanan Centre in recognition of Carol's contribution to the school and its community.

Carol is pictured below with her husband, Barry, and her children, Kylie and Troy:



Shirley's Recipe

RHUBARB TEA CAKE

(serves 10)

Ingredients:

125g butter, softened	1 cup brown sugar
1 egg	1 teaspoon vanilla extract
2 cups plain flour	1 teaspoon bicarbonate of soda
1 teaspoon cinnamon	1 cup sour cream
3 stalks rhubarb, finely sliced	

Topping:

$\frac{1}{4}$ cup caster sugar	$\frac{1}{4}$ cup slivered almonds
$\frac{1}{4}$ cup desiccated coconut	$\frac{1}{2}$ teaspoon cinnamon

Method:

1. Preheat oven to 180°C. Grease a 20cm spring-form tin. Line base with baking paper.
2. Beat butter and brown sugar together until pale and creamy. Add egg and vanilla and beat well. Sift flour, bicarb soda and cinnamon together. Add to butter mixture with sour cream and fold through until well combined.
3. Reserve $\frac{1}{2}$ cup of the rhubarb, add remainder to cake batter and stir well. Transfer to cake tin and smooth top.
4. To prepare topping: combine topping ingredients in a small bowl with reserved rhubarb. Scatter over cake batter, pressing rhubarb slices into surface.
Bake for 1 hour until cooked when tested. Cool for 10 minutes before removing from tin , then cool on a wire rack.

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PROJECTS UPDATE**Collecting data on sufferers of myasthenia gravis –**

Be assured that work on our survey remains a priority. After speaking with Researcher, Dr Stefan Blum, we can confirm that 90 surveys have been fully entered into the database with more still to be done. Close to 160 surveys have now been returned. If readers have been tracking our progress reports they will be aware of the constant and steady increase in numbers. Support is still strong amongst sufferers and the Committee remains committed to finding ways to reach more sufferers to complete the survey. We are aware that many contacts come directly from our members so we thank you and ask that you continue your efforts.

In reading the comments included on the survey forms, Dr Blum said how very touched he is to read the many words of thanks given to him by sufferers. He is assured of our appreciation. He also found it heartening to learn that for many families, the experience with MG has brought the family unit closer together. It can be a challenge learning to live with MG and support on all levels is so very important. A survey such as this will be important in highlighting our needs to the Government and to Health Professionals.

'Exercise Effect in MG' Study –

The study is underway and initial assessments of participants have been completed. Exercise regimes commenced Monday 13 February.

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PODIATRY and MG

By Nicholas Sprenger B.Hlth.Sc (Pod) Hons

My name is Nicholas Sprenger and I am a Podiatrist with a Brisbane and Gold Coast based podiatry group. I want to share some general information regarding how Podiatry, a branch of allied health that deals with the conservative care and management of foot and ankle conditions, can be of assistance to people living with myasthenia gravis (MG).

I am sure by now you have been to many medical specialists who have given you the breakdown on the causes, incidence, risk factors, *et al*, associated with MG. It is well understood that there are many symptoms associated with this condition, and range from the mild to severe in terms of the expression. Really from a podiatry specific stance, given the condition causes weakness of the voluntary (skeletal) muscles, our mode of application with podiatric management focuses primarily on how the foot and ankle, as well as the lower limb, moves and works collectively, because further stress from poor posture can overload things.

In a simplistic sense, muscle action should be equal and shared. However, we know through human biomechanical studies, they can be disproportional and asymmetrical in their loading habits and can result in different amounts of activity throughout the body; this thought process is also interchangeable to joint and other soft tissue structures. With reference to MG and skeletal muscle, this in turn can quickly lead to increase fatigue and feelings of lethargy and potentially a quicker cessation of a task/ activity during one's day-to-day living. MG medications prescribed can go a long way in offsetting this. However, should the load be spread more evenly as well, this can contribute further to decreasing any referral stress and strain per unit area. Obviously, maintaining a person's posture and correct alignment is the key in trying to optimise the body's efficiency in how one deals with day to day tasks and activities. Note that this is most applicable even with people living without MG. There is further application of this in the form of Pilates, Yoga and other physical therapies which look to improve how one functions and improves muscle threshold tolerance.

Over the years, I have helped manage many patients with MG. As I say to all of them, the relationship with their GP and specialist is the primary level of care. When it comes to my evaluation on things, the MG itself does not cause foot and ankle alignment issues, instead, one's foot and ankle posture is by large inherently deficient. In that sense, we are really looking at biomechanical factors associated with each individual and how it could affect an individual with MG.

Once we have an idea of a person's alignment and posture after measurements and evaluation during a consultation, because everyone is different, we then look at ways to achieve a better posture should they be deficient. Across the board, I have a fundamental rule that the treatment starts first with a good pair of shoes. Both fortunately and unfortunately, there are many varieties of brands, shoe types, colours and prices of shoes out there today. Once upon a time, the old Dunlop Volley and the Nike Air Max used to be the extent of choice. Fast forward to today and there are now custom shoe stores offering endless stock. While the consumer has never in the history of mankind been gifted by this much choice, you have to wonder, if you are not a podiatrist, what shoe is right for me? Nowadays, podiatrists know a bit more than just trimming toe-nails and are more than qualified to point you in the right direction on what choices would work best for you. It is as easy as making an appointment with your local podiatrist and taking things from there.

Once the right shoes are underfoot, we then evaluate how these are going in terms of whether the desired outcome, in holding a person's foot posture optimally, is/ was achieved. Should they be working well, we generally leave things there and talk about some other simple strategies associated with lower limb care and monitoring. In the event that one's foot or feet are not

optimum, we then look at in-shoe devices that would go about further improving the situation. With regards to in-shoe devices, we refer to these as in-shoe supports, inserts, orthoses, etc. and they come in many shapes and sizes; think of them as scaffolding in your shoes.

Previously, there was a one size fits all approach to inserts. Generally, these were a hard plastic material; this is certainly not the generic case anymore - it is actually quite an exciting time in podiatry. Given all the improvements in clinical practice methodology, equipment and technology upgrades we are now able to offer much more when treating and managing each individual. When it comes down to what an individual needs it is really down to what the clinician sees in front of them. Finding what level of support, what materials to use to achieve hold and support, covering, etc. are all changeable measurements between each individual. Therefore, what generally works for one person does not generally work for the next. In a nut shell, as stated before, the goal is to help redistribute loads more evenly and the podiatrist will judge the right amount based on what they see in front of them.

I hope that this information is in some way helpful when it comes a new understanding of how podiatry can help manage things, or if you have already been seen by a podiatrist, that you are in good hands and have been made more comfortable.

Editor's Note: If you have any questions regarding Podiatry and MG please submit them to the via email to info@mqaq.org.au or to graeme.peters2@bigpond.com with 'Podiatry and MG' as the subject and we will arrange a response from Mr Sprenger. If you do not have access to email facilities, please phone your enquiry to Shirley on our freecall 1800 802 568 number.

All questions and answers will be published in the Members' Forum

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MEET THE MEMBERS - MACKAY

WHEN: Saturday 10 March 2012 at 10:00am.

WHERE: Boomerang Hotel/Motel, 307 Nebo Rd, MACKAY

WHAT DO I NEED TO BRING? Yourself and whomever else you wish to bring along – the more the merrier. Remember you do NOT have to reside in the Mackay region to attend.

CATERING: Tea and coffee are available from 10 am. A 2-course alternate drop lunch is available for \$15 per person.

ENQUIRIES: Further information is available by ringing our Freecall number 1800 802 568 or by contacting the Mackay coordinator, Bill Harris, on (07) 4954 1221

RSVP: Ring our FREECALL 1800 802 568 and let us know if you are coming, how many, and if you are staying for lunch. For catering arrangements it is important for us to know how many will be attending.

Please let us know by **Friday 2 March 2012**.

Please note the change to arrangements for lunch on the day:

MEMBERS' FORUM

One contribution this month from Miriam in Tasmania.

Miriam writes:

"Myasthenia Gravis, what's that? never heard of it!" This or something similar, as I'm sure you've all experienced, is the response of most people on hearing what is "wrong" with me. I could explain in detail, as far as my knowledge goes, but it's easier to say my muscles don't always work properly because I have a shonky immune system, or words to that effect. They don't usually want to know any more than that anyway. All of the people who matter in my life know I can't always keep up, that they might have to pay more attention to understand my verbally expressed wisdom and be patient if I'm eating in their company.

At least my eyes stay open and point in the same direction most of the time these days, though there was a time when to see at all I held an eye open with a finger and if by chance both eyes were open at the same time, one gazed skyward whilst the other looked at something else, rather off-putting to anyone I met face to face! As advised by a young graduate at the eye clinic, patching one specs lens with clear Contact fixed that problem, letting light through and preserving peripheral vision. I soon found I could drive with that device, a great boon, as having no family around here, I'd had to rely on the kindness of friends or the Community Car, a wonderful service, though it can get a bit expensive. I live in a small coastal town 70km from the nearest proper civilisation.

September 2009:

I must say that driving on a country highway was not the best place to be suddenly endowed with spectacular double vision! After clambering up an embankment to get phone reception, always dodgy around here, my grandson and I were duly rescued by his parents and another driver for my car, as my daughter, with great consideration for other drivers, does not drive.

So off I went to an optometrist who shunted me in turn to an ophthalmologist who took little time to organise some specific tests for MG and to rule out other things. Savvy bloke! Having read others' accounts of how long it took to get a diagnosis I truly appreciate this.

"Go private," he said, "you'll see someone sooner". A neurologist, that is. By the time I saw the neuro a month later my tongue felt like a plank and my speech was interesting. But in his wisdom he pronounced that I had ocular MG and wouldn't need steroids. I was dubious at the diagnosis, having had at my fingertips my trusty laptop connected to the internet, a great resource for information. However, he was the doctor and I was there for his advice. He prescribed a minuscule dose of Mestinon of which I knew little then.

Christmas Eve 2009:

MG rampant. The neuro was not interested in helping me until my next appointment a month hence, and directed me to my GP, who was surprised to hear he was to manage MG which he'd never seen before. He organised for me to see a hospital neuro and I found myself having Christmas dinner through a tube up my nose and being monitored for breathing, what seemed like every five minutes. The neuro had delivered me personally to the ward to the astonishment of staff. I didn't know I was that sick! I might have felt I had a Besser block or two on my chest but I was still breathing – wasn't I?

A sharp learning curve had begun!

I now know about IVIg, immunosuppressants and steroids. The latter I had been taking since 2004 for polymyalgia rheumatica, and it was when PMR resolved and the dose reduced to almost

nothing that MG appeared with a vengeance. I know now that I'd had it for some years because of other mysterious symptoms unrelated to PMG, but it had been suppressed by prednisolone. However, I digress. After 9 days of TLC and effective treatment I returned home nearly as good as new and within six months had reduced the steroid and ceased Mestinon altogether. "No problem!" I thought, "Get it under control and life goes on as usual".

June 2010:

Until you get an infection. Still, with good management and increased drugs, not too bad and with the passing seasons was back to being just like a "normal" person with no Mestinon.

Easter 2011:

When one is well, one can become complacent. Travelling on a bus to a craft fair, with 49 likeminded people on a bleak Tasmanian autumn day, when some of them are spluttering their cold germs about, ain't a good idea. One of these nasties found a home somewhere in my mucous membranes and created havoc! I managed the cold but my immune system found other things to do, and an on-call GP thought a huge dose of steroid was called for – the ambos next morning were wonderful but meeting at Emergency the first neuro I had seen 18 months before, was not. Fortunately he had only been called in to sign my admission.

Breathing with a respirator in ICU is an interesting adventure. I felt safe and became very proficient with a communication board over 6 days, with my electronic devices to amuse myself as I was not sleeping like the other patients (except at night, loooove that midazolam infusion!) However, having the thing removed whilst awake isn't fun as I was not allowed to go to sleep for 1 second's work! After another week of IVIg, effective drug management and observation I went home just a little wobbly.

Still on the learning curve. Still taking Mestinon, high dose steroid and monthly IVIg to maintain equilibrium. Now considering a change of immunosuppressant, one that apparently has less than delightful other effects.

But my eyes work most of the time, breathing is fine and eating delicate morsels instead of taking great mouthfuls must be good for my digestion. It's no problem to eat chocolate! I try my best to speak clearly but sometimes get funny looks. Doesn't matter. I can't sing any more as my mouth won't keep up but other performers need an enthusiastic audience. And there are other things to do. Since my arms and hands are unaffected by MG I have taken up gardening and shall learn to play the guitar. I walk the surrounding bush and farms with the local group, and as we are mostly old folk, there are others nearly as slow as me so there's always company. I've read that tonic is not recommended so my favourite tipple is out – but hey, have discovered the martini!

Life is pretty wonderful."

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 graeme.peters2@bigpond.com.

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.

