



Messages

Myasthenia Gravis Association of Queensland Inc

SEPTEMBER 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

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COMMITTEE MEMBERS

President
Anita JACKSON
Ph. 3800 4913

Vice-president
JOHN NOBLE
Ph. 3269 5066

Secretary
Carol BUCHANAN
Ph. 4773 7122
email: info@mgaq.org.au

Treasurer
Susan WHITE
Ph: 3358 1056

Information Officer
Shirley JOHNSTON
Ph. 1800 802 568

Committee

Katren Wallis
Ph: 0418778082

Scott MacKay
Ph: 5448 1749

PATRON
Dr Cecilie LANDER
Neurologist
Founder Member, of Brisbane

PRESIDENTS REPORT

Welcome,

The Annual General Meeting on 15 September 2013 was very successful. There was a good roll up of members as well as prospective members who had only just contacted us on the 1800 number. Dr. Pandey's very informative presentation was well received, and we all gained knowledge on how to look after our mind, body and soul as we age.

I would like to take this opportunity to welcome our new committee members, Scott MacKay and Katren Wallis, and hope that they enjoy their time on the committee as they bring their valuable experience to the team. As notified in last month's newsletter, both Scott and Katren have also taken on the role of coordinators for the Sunshine Coast and the Gold Coast respectively. I would like to thank Shirley Langshaw for all the work that she has done in the Sunshine Coast region and also thank the late John Nielsen for his work for the Gold Coast region.

I would like to also thank Bill Synnot and Graeme Peters for all their hard work over the years in their respective roles in the Committee.

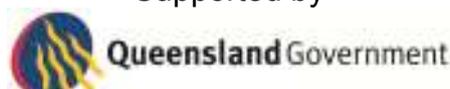
Negotiations are continuing with Queensland Health in regards to the Service Agreement offered for the period 1 July 2013 to 31 December 2013. The Association has lodged a submission with Queensland Health requesting an exemption from the Performance Reporting Requirements and a variation to the Insurances Cover specified in the Agreement. We are awaiting a response from Queensland Health to the submission.

The next 'Meet the Members' will be held in Toowoomba on 10 November 2013 at the City Golf Club. Members from Brisbane and other locations are welcome to join our members from the Toowoomba region for a good day in which members tell of their experiences with MG and also find new fellow MG travellers. (see Page 8 of this edition for full details).

Take care

Anita

Supported by



PROJECTS UPDATE

Collecting data on sufferers of myasthenia gravis –

There is no update this month, as the Coordinator for this Project is overseas. Updates will resume next month.

‘Exercise Effect in MG’ Pilot Study –

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 abovementioned 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@mqaq.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.

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NEWS FROM THE 2013 AGM

- The following were appointed to the Management Committee for 2013/2014:
 - **President** Anita Jackson **Vice President** John Noble
 - **Secretary** Carol Buchanan **Treasurer** Susan White
 - **Committee Members** Shirley Johnston, Katren Wallis, Scott MacKay;
- Kristian (Kris) Klitgaard was conferred with Honorary Life Membership in recognition of his outstanding service and dedication to the ideals and aims of the Association;
- BDO Audit Pty Ltd were appointed Auditors for 2013/2014. BDO offered to perform the audit *pro bono* as they did this year;
- There will be no increase in Subscription Rates for the coming year.

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How can a cemetery raise its burial costs and blame it on the price of living?

When someone rings the doorbell, why do dogs always assume it’s for them?

Alcohol may be man’s worst enemy, but the Bible says love your enemy - *Frank Sinatra*

If nothing in life is free, why do they make samples?

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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 COORDINATORS

| | | |
|--------|------------|--------------------|
| DONNA | 0414397462 | CAIRNS |
| CAROL | 4773 7122 | TOWNSVILLE |
| BILL | 4954 1221 | MACKAY |
| VACANT | | ROCKHAMPTON |
| SCOTT | 54481749 | SUNSHINE COAST |
| KATREN | 0418778082 | GOLD COAST |
| VACANT | | BUNDABERG/WIDE BAY |
| VACANT | | DARLING DOWNS |

CHAT LIST – QUEENSLAND REGIONAL

| | | |
|------------------|------------|-----------------|
| KELLY | 4728 4913 | AITKENVALE |
| ROSALYN | 0407697206 | ANDERGROVE |
| JOHN | 4783 1556 | AYR |
| YVONNE | 4783 4643 | AYR |
| MARK | 4067 1784 | BABINDA |
| LYNDA | 4159 2890 | BARGARA |
| JOHN | 4959 5492 | BAKERS CREEK |
| SARA | 0422109492 | BLACK RIVER |
| HENRY | 4982 6507 | BLACKWATER |
| KELLY | 4782 5542 | BRANDON |
| PAMELA | 4151 5499 | BUNDABERG |
| SYDNEY | 4051 6896 | BUNGALOW |
| ROBYN | 5520 4242 | BURLEIGH HEADS |
| MOYRA | 5576 4979 | BURLEIGH WATERS |
| PATRICIA | 5535 0274 | BURLEIGH WATERS |
| JIM | 0414241091 | BURPENGARY EAST |
| DENISE | 4788 0798 | BUSHLAND BEACH |
| DAVID | 4053 2291 | CAIRNS |
| 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 |
| KARLIENE | 0432431591 | HERVEY BAY |
| 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 |
| KEITH | 5441 7236 | COES CREEK, NAMBOUR |
| MICHAEL | 5545 2802 | NORTH TAMBORINE |
| DAVID | 5474 5534 | NOOSA |
| MARLENE | 5447 4986 | NOOSA HEADS |
| SHARON | 4151 7661 | NORTH BUNDABERG |
| MAUREEN | 0411331258 | PACIFIC PINES |
| JUNE | 0409636467 | PALM BEACH |
| SCOTT | 5448 1749 | PEREGIAN BEACH |
| TOM / SCOTIA | 4693 3730 | PITTSWORTH |
| BILL / COLLEEN | 4926 2410 | ROCKHAMPTON |
| DONALD | 5563 7207 | RUNAWAY BAY |
| HELEN | 5445 4853 | SUNSHINE COAST |
| BERNIE | JoyPaul28 * | TEWANTIN |
| CAROL | 4773 7122 | THURINGOWA CENTRAL |
| BETTY | 4635 6270 | TOOWOOMBA |
| DIANNE | 4638 8447 | 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 |
| ANDREA | 5486 7671 | WOLVI |
| JAN | 5493 4441 | WURTULLA |
| SANDY | 0458980667 | YANDINA |
| 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

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.

Where do they get the seeds to plant seedless watermelons?

The following heart-warming story was found by Barry at <http://www.irishmirror.ie/female/cork-woman-edel-buckley-tells-2161437>

Everything's coming up Roses for Edel after her illness battle

A brave Rose Of Tralee contestant has told how she can now smile again after being diagnosed with a rare condition:

Edel Buckley, 27, from Donoughmore in Cork, says she wants to help other sufferers of auto-immune disease Myasthenia Gravis after being told she had the illness just four years ago.

She said: "This year I had done a lot with the Myasthenia Gravis (MG) Association. I had done the Annual Rag Doll walk and I wanted to continue that and raise awareness of the condition because I was diagnosed with that four years ago but I am doing really well now. "

It's an auto-immune condition which causes extreme muscle weakness and it affects every muscle in the body, so your limbs, your face, your eye would be drooping." Edel first started to get symptoms around seven years ago but it took a long time for her to get diagnosed. She said: "I started noticing there was something wrong in my late teens - the first big incident was I fell down the stairs and from then on I was in and out of the doctor all the time. "I couldn't smile for years before I was diagnosed, I was falling a lot and very clumsy. "The muscles are just literally too weak, so repetitive motions (are hard) you might be able to lift your arm once but then the next time, it would be dead. "You definitely kind of think there is something wrong, I'm not the same as everyone else, my eye goes droopy, when I go out for a night out it takes me two days to recover from it. "But when there is thing forthcoming, you don't know what exactly it is and you're taking medication for iron deficiency and fatigue and resting, you just learn to live with it and then once I was diagnosed it was a massive relief, it was like my life started again once I started getting treated."

And since her diagnosis Edel has fought her way back to health and is currently in remission. She said: "I was diagnosed four years ago and I started having treatment and I'm doing really well." "Since my diagnosis and receiving treatment, I'm very active, I run with my running club at work, I do tug of war and tag rugby, I'm always out and about. I'm loving it, it's like a new lease of life." Edel says she is lucky as she doesn't need to take any medication after undergoing a serious operation to remove her thymus gland. She said: " They cut open your chest and cut through your chest bone and remove your thymus. I think that definitely benefitted me but I'm not a doctor so I can't say exactly. I just know I'm doing really well at the moment as I am not on any medication. "Other people with the condition would have to have regular treatment - one of the forms of treatments is plasma exchange, so you have to be put up on IV. So some people have to go in and out of hospital."

Edel said she entered The Rose Of Tralee to give hope to other MG sufferers. She said: "I wanted to raise awareness and to show people that there is life living with the condition, with any type of condition, that you can live life to the full."

Editor's Note: *The Rose of Tralee International Festival is one of Ireland's largest and longest running festivals, celebrating 54 years in 2013. The heart of the festival is the selection of the Rose of Tralee which brings young women of Irish descent from around the world to County Kerry, Ireland for a global celebration of Irish culture.*

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TOWNSVILLE GET-TOGETHER

The get-together for the Townsville group of the MG Association will be held at The Avenues Tavern on Saturday 23 November at 12 noon. We have a couple of newly diagnosed members so hope everyone can attend and help them by sharing experiences and ideas.

Please phone Carol on 47737122 or 041874849 by 16 November so a final booking can be made.

MEDICAL COOLING AND HEATING ELECTRICITY CONCESSION

The Queensland Government provides financial assistance to low income Queenslanders with a medical condition which requires the use of electricity for cooling or heating. This assistance is provided for a period of 2 years, at which time eligibility will require review

The concession is provided to assist individuals with the increased electricity costs incurred by frequent operation of an air-conditioning unit in order to regulate body temperature.

The concession is not limited to one person per household, but all persons must meet all of the eligibility criteria.

Eligibility for the concession:

An applicant must:

- be a Queensland resident, and
- have a qualifying medical condition requiring cooling or heating to prevent the symptoms of their condition worsening, and
- be residing at their principal place of residence and use an air-conditioning unit in that residence to meet their heating and cooling requirements.

The applicant and/or legal guardian of a minor with a qualifying medical condition must also:

- hold a current Pensioner Concession Card (issued by Centrelink or Veterans' Affairs), or a current Health Care Card (issued by Centrelink), and
- be financially responsible for the payment of the relevant component of the electricity bill.

Qualifying medical conditions include multiple sclerosis, autonomic system dysfunction, loss of skin integrity or sweating capacity, severe compromising of functioning such as mobility at extremes of environmental temperature, or hypersensitivity to extremes of environmental temperature leading to increased pain or other discomfort or an increased risk of complications.

How to Apply:

To apply for the concession, complete the application form (available for downloading from <http://www.communities.qld.gov.au/resources/communityservices/community/government-concessions/every-dollar-counts/heating-cooling-brochure.pdf>)

and arrange for your medical practitioner to complete the Medical Certification attached. Costs associated with the medical assessment must be met by the applicant (or parent or legal guardian). A parent or legal guardian can complete an application on behalf of children aged under 18 years. A legal guardian or person holding a power of attorney may also complete the application on behalf of an adult applicant. The person with the qualifying medical condition must be listed on the form as the applicant.

Quarterly payments will be made by electronic funds transfer to the applicant's nominated bank account. Payments can not be made to a credit card.

For more information contact:

Concession Services
Smart Service Queensland
PO Box 10817
Brisbane Adelaide Street Qld 4000
Telephone: 1800 460 849

Email: concessions@smartservice.qld.gov.au

Or visit: <http://www.qld.gov.au/community/cost-of-living-support/medical-cooling-heating-electricity-concession-scheme/index.html>

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Why do they advertise 'ear piercing while you wait'?

Can atheists get insurance for acts of God?

Doesn't expecting the unexpected make the unexpected become the expected?



MEET THE MEMBERS - TOOWOOMBA



WHEN: Sunday 10 November 2013 at 10:00am

WHERE: Albatross Room, City Golf Club, 254 South St., SOUTH TOOWOOMBA

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 Toowoomba area to attend. Lunch is available at reasonable prices. Morning tea is provided.

HOW DO I GET THERE? From Brisbane take the Warrego Highway to Toowoomba. Turn left onto the New England Highway. After approximately 1km turn right into South St. Golf Club is on the left. If parking is a problem, i.e. you have to park a fair way from the main entrance, there is a drop-off point at the front entrance to the Club.

RSVP: Ring our FREECALL 1800 802 568 and let us know if you are coming, how many, and if you are staying for lunch. It is important for us to know. Please let us know by **Friday, 1 November 2013**

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PRESIDENTS ANNUAL REPORT and AUDITED FINANCIAL STATEMENTS

All current financial members who were not present at the AGM will shortly receive copies of the President’s Annual Report and the full Audited Financial Statements for the year 2012/2013, which were presented to, and adopted by, the Annual General Meeting held on 15 September 2013.

If you have not received your copies by the end of October, please contact our 1800 802 568 Freecall number or email info@mgag.org.au

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Need Medical Help? Not sure about what to do or where to go?

Queensland Health operates a 24 hour, 7 day-a-week Statewide telephone service providing access to health information, triage and referral.

If you are not sure about the seriousness of your symptoms or where you should go for help, there are qualified nurses manning the phones to listen and assist. They will direct you to the most appropriate service.

The Phone number is: **13 43 25 84 (13HEALTH)**

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The Politician

The politician was at his campaign headquarters when the phone rang. He listened intently, and after a moment his face brightened. When he hung up, he immediately phoned his mother to tell her the good news.

"Mum!" he shouted, "The results are in. I won the election!"

"Honestly?" his mother replied.

The politician’s smile faded. "Damn, mum, why bring that up at a time like this?"

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