



# MessaGes

Myasthenia Gravis Association of Queensland Inc

**APRIL 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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ABN 92 055 613 137

E-mail: [info@mgaq.org.au](mailto:info@mgaq.org.au)  
Internet: [www.mgaq.org.au](http://www.mgaq.org.au)

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**PATRON**  
Dr Cecilie LANDER  
Neurologist  
Founder Member, of Brisbane

## PRESIDENT'S REPORT

### *Welcome,*

A good day was had for our Picnic at North Pine Dam and the weather was perfect. We met some of our regular members and we also met some very new members. We talked about our MG journeys and how we cope from day to day. It was a very entertaining and interesting day and I know our newer members got a lot out of the day. Hoping they will join us again for our next function. It certainly was well worth the effort for the long drive and as usual I was at the wrong place.

The committee is working with the other states on a National Alliance of MG support bodies but it is still in the first stage and will take quite a bit of time before it goes ahead, if at all, as we will have to have everything documented properly and also make sure the other states are willing to participate with us.

Our Secretary, Graeme Peters, has had some health issues recently. Consequently we are looking for a Secretary and/or Editor as doing both jobs has got too much for Graeme at present. We ask that members please give some thought to helping the Association in either role. It does not take up too much of your time but it is very rewarding. Ideally, the Secretary's role is better logistically located in Brisbane, but the Editor's role can be undertaken from anywhere in Queensland as long as access to the internet is available. Interested persons may contact the Secretary on (07) 32884484 or email [graeme.peters2@bigpond.com](mailto:graeme.peters2@bigpond.com)

Take care

*Anita*

Editor's Note: The editor will be on leave from 4 May to 27 May. Consequently the May issue of MessaGes will be published towards the end of May.

Also any enquiries regarding the Association you would normally direct to the Secretary during that period, please direct to our 1800 802 568 freecall number or via email to [info@mgaq.org.au](mailto:info@mgaq.org.au)

Supported by



**Queensland** Government

## **PROJECTS UPDATE**

### **Collecting data on sufferers of myasthenia gravis –**

Fabulous news! Dr Stefan Blum is to be the guest speaker at the MGAQ June meeting. With plenty of time available for his talk, he will be able to share many more details about the potential for forthcoming work resulting from the data collection. As an amazing 200 surveys have now been entered, even more information from the data base will be available for him to share when members attend the meeting. Hopefully we can find some very challenging questions to ask regarding his research results. Please refer to page 8 of this newsletter for details on where and when this meeting is to be held. As usual the presentation will be recorded and a DVD will be issued to all currently financial Category 'A' members. If you feel you may not be able to attend in person, please forward any questions you would like to put to Dr. Blum via email to [info@mgag.org.au](mailto:info@mgag.org.au) or mailed to P.O. Box 16, Mt Gravatt, Qld 4122 by Friday 7 June 2013.

### **"SURVEY SNIPPET"**

#### **IMMUNOSUPPRESSION**

Immune therapies have been used for myasthenia since the 1960s, when Prednisone was first described. A range of other therapies have been introduced since. It appears that the majority of the survey respondents receive immunosuppressive medications. Prednisone is by far the most popular choice with around 60% using this drug, followed by Azathioprine with 30%. All other treatments register less than 10%. Prednisone seems to have such a bad reputation yet when the side effects are reported, only half the number of patients raised issues with this drug compared to the other choices - maybe because the side-effects are rather long-term than immediate?

### **'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 financial members.

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### **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/mgagqld?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

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My wife told me the car wasn't running well because she thought there was water in the carburetor.  
I asked where the car was. She said, "In the lake."

**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**

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
POPPY	3288 4484	SPRINGFIELD LAKES
MARIE	3300 0053	THE GAP
JOHN	3633 0604	ZILLMERE

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Time is what keeps everything from happening at once

**NEWS FROM MACKAY**

The Mackay group had our get-together at the Andergrove Tavern on the Sunday 17/3/2013. Eight members attended and all enjoyed the meal and the discussion which followed.

Our next function will be a luncheon to be held at Harrup Park at midday on Sunday 19 May 2013. All members, intending members and anyone else interested in MG are very welcome to come along. If you would like more information please contact Bill on (07) 49541221.

Bill Harris - Mackay Regional Coordinator

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**A CALL FOR NOMINATIONS FOR POSITIONS ON THE MANAGEMENT COMMITTEE**

Very shortly, current financial members will receive forms calling for nominations for positions on the Management Committee of the Association for the Financial year 2013/2014.

As indicated in the President’s Report in this edition of MessaGes, our Secretary, Graeme Peters, has had some health issues recently. In addition, some of our present Committee Members are now well into their senior years, and it would be disastrous for people with MG if the Association had to fold because of lack of interest.

A place on the Committee involves approximately ½ to ¾ of a day per month for meetings and some other small portion of your time (Treasurer, Secretary or the Information Officer obviously involves more time).

Please give consideration to putting your name forward for a place on the Committee, so we can look forward with confidence to the future of the Association.

If you would like to discuss this with members of the current Committee, please feel free to give them a call – their telephone numbers are on the front of the newsletter.

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**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 make 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.

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**Future Planned Activities**

- Sunday **16 June 2013** Mid-year Guest Speaker function – Brisbane - venue Southern Cross Sports Club, Logan Rd., Mt Gravatt
- Sunday **15 September 2013** Annual General Meeting – Brisbane – venue Southern Cross Sports Club, Logan Rd., Mt Gravatt
- 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.

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## **BARRY'S LINKS OF INTEREST**

The following links to items of interest regarding MG have been submitted by member Barry who browses the Internet looking for such items. The committee thanks Barry for his interest and efforts.

Myasthenia gravis Nursing Considerations & Patho Part 1

<http://www.youtube.com/watch?v=khZr99Kidus>

Myasthenia gravis Nursing Considerations & Drugs PART 2

<http://www.youtube.com/watch?v=M-Y8ATeKoNs>

Myasthenia Gravis (No I am NOT on drugs!)

<http://www.youtube.com/watch?v=Rnr4iMIqt7o>

the journey of a gentleman with MG

[http://www.beyondthelimits.net/books/Beyond\\_the\\_Limits-2005\\_MSS\\_A.pdf](http://www.beyondthelimits.net/books/Beyond_the_Limits-2005_MSS_A.pdf)

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Barrie also sent the following story of 'Stephanie'.

The original of the story can be found at <http://mgsouthtexas.org/story/stephanie/>

*'My name is Stephanie, I'm 26 years old, and I was recently diagnosed with Myasthenia Gravis.*

*I've always been a very active person, playing roller derby (which was my favorite thing to do for 3 years), fluttering around like a social butterfly, trying to be a dependable family member, and manager at work. Around October of 2008, I noticed my right hand had become weak. I also felt tired all of the time, and napping became a regular thing, which I never did before. I took a leave of absence from my roller derby league, hoping to regain some energy.*

*I love to work on and sell crafts. One day while spray painting, I realized I couldn't hold the nozzle on the spray can very well. I thought it might be from crafting, typing, and even texting way too much. I put it off, not wanting to make a trip to the doctor for something that seemed so small. In March of 2009, I felt like my vision was unstable, kind of shaky. I've always had bad vision and have to depend on contacts and glasses to even walk around my house. One night I went to wash my face before bed; I looked in the mirror and realized my right eyelid looked droopy. Maybe I needed more sleep? So I again, ignored it... until I started getting double vision.*

*I immediately set up an appointment with my Optometrist. He said my prescription had not changed, and that double vision was neurological. He recommended I see an Ophthalmologist. They used various tools to check the muscle behind my eyes, and gave me a temporary diagnosis; Myasthenia Gravis. It was the first time I'd heard of it, so obviously looked it up on the internet immediately. The description sounded spot on. I then put the connection together between my hand and my eye. I cried, especially when I saw that it was incurable. I picked myself up and went on to the Neurologist who started testing me. I got a CT scan of my chest, an MRI of my brain, an Electromyography test, and a lot of blood work done. The only thing that came back positive, were my antibodies. Myasthenia Gravis was then my official diagnosis. I was relieved to have a name for it, but at the same time, I had to make an effort to keep myself from feeling like a victim.*

*I'm very fortunate that my double vision went away, and that my other symptoms are minimal. I take Mestinon and a large dose of Vitamin D, and neither have had any negative side effects. My family and boyfriend are strong and loving, which can get a person through anything. Please don't*

*ignore your body when it's trying to tell you something. I think my double vision came specifically to push me into finding out what was wrong. It was a blessing in disguise. I promise to never ignore my body again!*

*I still work my normal 45 hours a week, and although I haven't returned to the world of roller derby, I still find time to help them in other ways that don't involve me smashing into someone full force. Besides that, I try to carry on like I did before, but I still nap often, which is kind of nice... more time for dreaming.'*

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## **POTENTIAL NEW TREATMENT FOR MYASTHENIA GRAVIS**

In the August 2010 issue of Messages, it was reported that a U.S. company, Cytokinetics, had been granted an amount of \$2.9 million to support research and development of the drug **CK-2017357**, a fast skeletal muscle troponin activator, directed to the potential treatment for myasthenia gravis.

Following is an update on clinical trials on the drug which is now known as **tirasemtiv**. More information is available at [www.cytokinetics.com](http://www.cytokinetics.com)

Tirasemtiv (formerly known as CK-2017357), a fast skeletal muscle troponin activator, which is being developed as a potential treatment for diseases and conditions associated with aging, muscle weakness and wasting or neuromuscular dysfunction. Tirasemtiv selectively activates the fast skeletal muscle troponin complex and increases its sensitivity to calcium, resulting in increased skeletal muscle force and slowing of time to muscle fatigue.

### Myasthenia Gravis Phase IIa Clinical Trial Close

In November 2012, Cytokinetics announced the successful completion of its Phase IIa "Evidence of Effect" clinical trial of tirasemtiv, a fast skeletal muscle activator, in patients with myasthenia gravis. This Phase IIa Evidence of Effect clinical trial, known as CY 4023, was a double-blind, randomized, three-period crossover, placebo-controlled, pharmacokinetic and pharmacodynamic study of tirasemtiv in patients with generalized MG. Patients enrolled in CY 4023 received single, oral, double-blind doses of placebo, 250 mg, and 500 mg of tirasemtiv in random order and approximately one week apart. The main objectives of this trial were to assess the effects of tirasemtiv on various measures of muscle strength, muscle fatigue and pulmonary function. Since CY 4023 was a hypothesis-generating trial, no single primary efficacy endpoint was pre-specified. In CY 4023, at six hours after dosing, improvements (i.e., decreases) in the Quantitative MG score (QMG) were related to the tirasemtiv dose in a statistically significant manner (-0.49 QMG points per 250 mg;  $p = 0.02$ ). The QMG is a validated index of disease severity that is often employed as a primary endpoint in clinical trials of patients with MG. In addition, decreases in certain components of the QMG and their relationships to dose were statistically significant or borderline significant. Also at six hours after dosing in CY 4023, increases in the percent predicted forced vital capacity were statistically significantly related to the dose level of tirasemtiv (2.2% per 250 mg;  $p = 0.04$ ), as were the individual comparisons of each dose level of tirasemtiv versus placebo.

Both the 250 mg and 500 mg single oral doses of tirasemtiv studied in this Phase IIa clinical trial were well-tolerated by the 32 patients enrolled in CY 4023; there were no premature terminations and no serious adverse events were reported. The most commonly reported adverse event was dizziness which increased in frequency with dose and was reported as mild in all but one case that was classified as moderate.

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Young people don't know what age is, and old people forget what youth was - *Anon*

"Never interrupt your enemy when he is making a mistake."

- *Napoleon Bonaparte (1769-1821)*

"Some cause happiness wherever they go; others, whenever they go."

- *Oscar Wilde (1854-1900)*

## Shirley's Recipe

### **ASPARAGUS AND PEA RISOTTO**

(serves 4)

#### **Ingredients:**

- |                              |                                     |
|------------------------------|-------------------------------------|
| 400g asparagus (2 bundles)   | 2 cups vegetable stock              |
| 200g frozen peas             | ¼ cup olive oil                     |
| 1 small white onion, chopped | 2 rashers rindless bacon, chopped   |
| 1 ¼ cups arborio rice        | salt flakes & freshly ground pepper |
| ½ cup dry white wine         | 30g butter                          |
| ¼ cup grated parmesan cheese | 1 ½ tablespoons chopped parsley     |

#### **Method:**

1. Cut asparagus diagonally into 2cm slices leaving tips whole. Heat stock in a saucepan on medium-high and add asparagus. Cook for 2-3 minutes until tender, then lift with a slotted spoon and set aside in a bowl. Add peas to stock, bring to a simmer, then lift and set aside with asparagus. Reduce heat to low.
2. Heat oil in a deep heavy-based saucepan and sauté onion and bacon for 5 minutes until soft. Add rice, stirring so it is glistening with oil. Season with salt and pepper, then add wine and let it bubble.
3. Add a ladleful of stock, stirring continuously. When stock has been absorbed, add another ladleful, stirring, and repeat until all stock is added and rice is tender. This should take about 20-25 minutes. If needed, add boiling water to complete cooking. The rice should be tender to the bite and the consistency like creamy porridge, or a thick soup.
4. Remove from heat and fold through peas to reheat gently. Fold through asparagus stems, butter and parmesan. Serve risotto topped with asparagus and parsley and a grinding of black pepper.

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### **HAPPY SNAPS FROM THE PICNIC AT NORTH PINE DAM**



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#### **IRISH HUMOUR**

Paddy says to Mick "I'm ready for a holiday, only this year I'm going to do it a bit different. 3 years ago I went to Spain and Mary got pregnant. 2 years ago I went to Italy and Mary got pregnant. Last year I went to Majorca and Mary got pregnant." Mick asks "So what are you going to do this year?" Paddy replies "I'll take her with me!"

Paddy says to Mick "Christmas Day is on a Friday this year." Mick says "Let's hope it's not the 13<sup>th</sup>!"

Paddy & Mick find three unexploded hand grenades, so they take them to a police station. Mick: "What if one explodes before we get there?" Paddy: "We'll lie and say we only found two."

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MID-YEAR FUNCTION

- WHEN:** Sunday 16 June 2013 commencing at 10:00am for 10:30am
- WHERE:** Southern Cross Sports Club, corner Klumpp and Logan Roads., MountGravatt (vehicular entrance is from Klumpp Rd) Lunch is available at the venue with a varied and reasonably priced menu.
- GUEST SPEAKERS:** Dr Stefan Blum – Neurologist – More information from the Data Survey, followed by a general question and answer session on MG
- WHAT DO I NEED TO BRING?** Yourself and whomever else you wish to bring along – the more the merrier
- HOW DO I GET THERE?** UBD Map 201 Reference D7.  
Ring our FREECALL 1800 802 568 and tell Shirley if you are coming, how many, and if you are staying for lunch.
- RSVP:** Please let her know by **Friday 7 June 2013.**  
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**MORE HUMOUR FROM STEPHEN WRIGHT**

When everything is coming your way, you're in the wrong lane.

Ambition is a poor excuse for not having enough sense to be lazy.

Hard work pays off in the future; laziness pays off now.

I intend to live forever... So far, so good.

If Barbie is so popular, why do you have to buy her friends?

Eagles may soar, but weasels don't get sucked into jet engines.

What happens if you get scared half to death twice?

My mechanic told me, "I couldn't repair your brakes, so I made your horn louder."

Why do psychics have to ask you for your name?

If at first you don't succeed, destroy all evidence that you tried.

A conclusion is the place where you got tired of thinking.

Experience is something you don't get until just after you need it.

The hardness of the butter is proportional to the softness of the bread.

To steal ideas from one person is plagiarism; to steal from many is research.

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