



MessaGes

Myasthenia Gravis Association of Queensland Inc

JULY 2008



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: mgqld@gil.com.au

Internet:

www.mg-qld.gil.com.au

COMMITTEE MEMBERS

President (Acting)

Anita JACKSON
Ph. 3800 4913

Vice-president

Anita JACKSON
Ph. 3800 4913

Secretary and Editor

Graeme Peters
Ph. 3288 4484
email: grapop@dodo.com.au

Treasurer

Kris KLITGAARD
Ph/Fax 3890 0115

Committee

Shirley JOHNSTON
(Information Officer)
Ph. 1800 802 568

John CHESTER
Ph. 3899 9387

Judie BARBOUR
Ph. 0439461288

PATRON

Dr Cecilie LANDER
Neurologist
Founder Member, of Brisbane

PRESIDENT'S REPORT

Hi Everyone,

Editor reporting again – Anita has just arrived home after her holiday so it's only fair to give her time to recover before asking her to don her thinking cap again.

We still don't have any member feedback on our new look website, so we are pleading for some.

Our games day on June 15th was very enjoyable and lively. Although the turn out was not very high, all present had a 'ball' – in fact it was one of our most successful get-togethers in the last few years. Again our thanks to Judi Allison for raffle prizes.

We are pushing for a big attendance at the AGM on August 31, so please do not forget to let Shirley know if you are going to be there – it is vital that we fill our Management Committee vacancies so that the work of the Association can continue.

Contributions to the Members Forum seemed to have dried up. There must be someone out there who has a story to tell or a question to ask.

Finally, I have received some complaints that too little humour has been present in the last few editions of MessaGes, so I have tried to address this in this issue.

See you at the Annual General Meeting.

Keep well,

Graeme

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 – BRISBANE

JOHN	3269 5066	BRIGHTON
TERRY / JUDI	3824 4158	CAPALABA
JOHN	3899 9387	BRISBANE
JESSICA	3369 8315	BARDON
HELEN	3279 3060	JAMBOREE HEIGHTS
POPPY	3288 4484	SPRINGFIELD LAKES
EILEEN	3269 5660	BRIGHTON
PAM / RAY	3801 1335	CORNUBIA
PATRICIA / LES	5464 6719	PURGA IPSWICH
WILMA / NOEL	3807 2391	MT WARREN PARK
LORRAINE	3206 0789	CLEVELAND
GWENDA	3390 2643	CAPALABA
STEFAN	3807 0541	EAGLEBY
DANIELLE	3202 2509	IPSWICH
MIKE	3288 4037	SPRINGFIELD
ROGER	3379 8916	GRACEVILLE
HELEN	3203 0150	DECEPTION BAY
KEVIN	32819225	NEWTOWN
NORMA	3281 5079	EASTERN HEIGHTS (IPSWICH)
MARIE	3300 0053	THE GAP
BILL & JITLADA	0418196707	NORMAN PARK
MELISSA	0411039060	ACACIA RIDGE

WEB-Site Update

Our redesigned website is now up and running, and is available for viewing at www.mg-qld.gil.com.au. You can now download current and previous issues of MessaGes and we now have links to other MG sites. Also you can email us direct from the website. Your feedback on the site would be appreciated via an email from the 'Contact Us' page on the website.

Please note that as from 1 August 2008, our website address will change to www.mgaq.org.au. For a period of time, the existing website address will redirect visitors to our site.

* * * *

Shirley's Recipe

PEACH CRUMBLE SLICE

Base Ingredients:

- 125g butter or margarine
- 2 eggs
- 300g light sour cream
- 1 or 2 425g cans peaches (I used just over 1/2 a large can)
- 1/2 cup sugar
- 2 cups S/R flour

Topping Ingredients:

- 1/2 cup plain flour
- 1/2 teaspoon cinnamon
- 1 cup slivered almonds
- 1/2 cup brown sugar
- 60g butter or margarine

Base Method:

1. Beat butter and sugar; add eggs one at a time, beating well after each one.
2. Fold flour into butter mixture alternating with sour cream; mix until smooth.
3. Place into greased and lined 18cm X 28cm slab tin; smooth mixture and place peaches evenly on top.
4. Sprinkle topping over peaches and bake for about 45 minutes at 180°C.
5. Cool in tin for 10 minutes before lifting out and cut into squares.

Topping Method:

1. Combine flour, brown sugar and cinnamon.
2. Rub in butter until mixture resembles breadcrumbs. Add almonds and mix well.

*****AAAAAAAAAAAAAAAAAAAAAAAA*****

MEMBERS FORUM

There were no contributions for the members Forum this month.

* * * * *

ONLY FROM KIDS

TEACHER: Maria, go to the map and find North America.
 MARIA: Here it is.
 TEACHER: Correct. Now class, who discovered America?
 CLASS: Maria.

TEACHER: Glenn, how do you spell 'crocodile'?
 GLENN: K-R-O-K-O-D-I-A-L'
 TEACHER: No, that's wrong
 GLENN: Maybe it is wrong, but you asked me how I spell it.

TEACHER: Donald, what is the chemical formula for water?
 DONALD: H I J K L M N O.
 TEACHER: What are you talking about?
 DONALD: Yesterday you said it's H to O.

The following was published in the Spring 2008 edition of MGA News, the official newsletter of MGA UK and is reproduced here with their kind permission:

LIFE WITH GRAVIS

I have mentioned before that the reason that I started the Gravis chronicles was that I had complained that the MGA News (circa 1996/7) seemed to be one long series of articles on the problem of loose bowel movements. I was told that perhaps I might like to provide an alternative, which I did and found myself committed. Now I even get an email from the Editor reminding me that the deadline for copy is approaching. Recent events have caused me to have a bit more sympathy with the bowel movement, movement. Sorry I could not resist that one.

Nine months after switching to methotrexate and bringing my fungus-infected tongue under control, I am generally on the up. The steroid dose is gradually coming down and is half what it was last year at this time. I can speak and eat normally and attempt modest outings. Mrs Gravis tells people that I am "Now well enough to be a real nuisance".

Unfortunately I have also been having an exciting time with rather regular and urgent calls of nature. This is probably due to the high level of Mestinon® that I was using; it is now down by half, indeed there are times when I miss a dose and only realise about an hour after it was due. The usual remedies prescribed for the looseness associated with Mestinon® are Atropine sulphate, Propantheline® or Hyoscine patches. I have found that Atropine and Propan-theline® tend to make me sleepy and although the patches work, I can't keep them on, there appears to be something in my sweat that dissolves the adhesive. They are supposed to be changed every 72 hours, I am lucky to achieve six hours. I discussed this with my GP who prescribed a fibre supplement. This involves a packet of powder dissolved in water twice a day. For me the effect was miraculous, within two days I was back to normal and with no side effects. It is of course only effective for loose bowels and would not help with excess saliva. As always, consult your GP or Consultant before trying this.

Like all myasthenics, I have found that Mestinon® is a vital part of my treatment. I believe that one of the most valuable activities which the MGA supports is its Branch meetings. Bringing myasthenics together does no end for their morale and confidence and helps the newly diagnosed to come to terms with their MG and live with it. Members and carers can exchange ideas on how to live round MG. There is however, one aspect of exchanges at meetings which really frightens me and has Mrs Gravis foaming at the mouth. It happens when we break up for informal chats and the 'Expert' (there is always one at a meeting) starts to lecture, pontificate and give advice on drugs and the doses to be taken. Of course they are not medically qualified and speak from their own limited experience. Neurologists experienced in managing MG will tell you that every myasthenic is different, requires the medication appropriate to their individual condition and that the only people competent to determine this and give advice are GP's and Consultants.

Mrs Gravis and I have both heard the 'Expert' advising that a hefty dose of Prednisolone would work wonders. Even I know that changes to the steroid dose should only be made under medical supervision and normally in small steps. The only helpful advice to someone who is unsure is, go back to your doctor and discuss any problem you may have.

Overdosing with Mestinon® can lead to what is called a 'cholinergic crisis', which results in a worsening of the myasthenic weakness. My Tame Boffin tells me that it almost never happens in people taking fewer than six 60 mg tablets per day. The 'expert' is often good at recommending the most alarming alternative therapies. Many are benign and can relieve things like stress, but some are downright dangerous, such as massive doses of selenium or germanium. Always ask your doctor and do what he says and tell the 'expert' to do the same.

The trapped nerve in my elbow, mentioned in the summer 2007 MGA News is about to be operated on. By the time that you read this it should all be done and dusted. I have had my pre-op assessment to which, as is my custom I took a copy of the MGA's Volume 5. The sister doing the assessment was well versed in MG, but the student nurse was keen to have a copy and I have been asked to take more copies in with me for the other students.

February 2008

Editor's note: *The MGA Volume 5 referred to in the article is entitled 'Volume 5 – Medical Information – mainly for medical professionals' and is available for download from the MGAUK website at www.mgauk.org*

KEEP YOUR BRAIN ACTIVE WITH THE TRIVIA QUIZ

Here are this month's questions for you to try. (Answers are at bottom of this page)

1. What is the capital of Canada?
2. Who composed the opera 'Carmen'?
3. Who is the Australian Federal Minister for Education?
4. How many sides does a trapezium have?
5. Which make of car took its name from the Latin for 'I roll'?
6. How many keys are there on a standard piano?
7. Who got headlines for claiming, 'We're more popular than Jesus'?
8. What is the capital of the USA state of Kentucky?
9. For which chemical element is 'R' the symbol?
10. Which country invented the hat called a fez?
11. Who lit the torch to open the Atlanta Olympic Games in 1996?
12. Where is it bad luck to say 'Macbeth'?
13. How many golf balls are there on the moon?
14. What mountains form the spine of Italy?
15. What's the name for the little plastic tags on the end of shoelaces?
16. In which Australian state is Grong Grong?
17. Who is the Premier of Tasmania?
18. What part of the body does lachrymal fluid lubricate?
19. Who was John the Baptist's mother?
20. How many toes does an ostrich have on each foot?

Answers: 1) Ottawa; 2) Bizet; 3) Julia Gillard; 4) Four; 5) Volvo; 6) 88; 7) John Lennon; 8) Frankfort; 9) None; 10) Morocco; 11) Muhammed Ali; 12) In a theatre; 13) Three; 14) Apennines; 15) Aglets; 16) NSW; 17) David Bartlett; 18) Eyes; 19) Elizabeth; 20) Two.

REMINDER - MEMBERSHIP SUBSCRIPTION RENEWAL TIME

It's that time of the year again when Membership Subscriptions for the financial year 2008/2009 are due.

.....
Tear off along this line

Herewith please find my cheque / money order / cash for the sum of \$ _____ being annual subscription \$ _____ and/or Donation \$ _____ :

NAME: _____ **Category A – Myasthenic \$15**
Category E – Supporter \$15

ADDRESS: _____

AND FOR: _____ **Category D – Carer \$5**

ADDRESS: _____

Your receipt will be forwarded to you with the next available issue of "MessaGes" following receipt of your payment. If you do not receive your receipt, please ring us on the toll free number 1800 802 568.

We thank you in anticipation of you renewing your membership.

SENIOR MOMENTS???

An elderly woman called 000 on her mobile phone to report that her car has been broken into. She is hysterical as she explains her situation to the dispatcher: 'They've stolen the stereo, the steering wheel, the brake pedal and even the accelerator!' she cried.

The dispatcher said, 'Stay calm. An officer is on the way.'

A few minutes later, the officer radios in. 'Disregard.' He says. 'She got in the back-seat by mistake.'

* * * *

Three sisters, ages 92, 94 and 96, live in a house together. One night the 96-year-old draws a bath. She puts her foot in and pauses. She yells to the other sisters, 'Was I getting in or out of the bath? The 94-year-old yells back, 'I don't know. I'll come up and see.' She starts up the stairs and pauses 'Was I going up the stairs or down?' The 92-year-old is sitting at the kitchen table having tea listening to her sisters. She shakes her head and says, 'I sure hope I never get that forgetful, knock on wood.' She then yells, 'I'll come up and help both of you as soon as I see who's at the door.'

* * * *

A little old lady was running up and down the halls in a nursing home. As she walked, she would flip up the hem of her nightgown and say 'Supersex.' She walked up to an elderly man in a wheelchair. Flipping her gown at him, she said, 'Supersex..'

He sat silently for a moment or two and finally answered, 'I'll take the soup.'

* * * *

As a senior citizen was driving down the freeway, his car phone rang. Answering, he heard his wife's voice urgently warning him, ' Herman , I just heard on the news that there's a car going the wrong way on the Pacific Highway. Please be careful!'

'Heck,' said Herman , 'It's not just one car.. It's hundreds of them!'

* * * *