



# Messages

Myasthenia Gravis Association of Queensland Inc

**JUNE 2009**



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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Neurologist  
Founder Member, of Brisbane

## **PRESIDENT'S REPORT**

How sad Frank Ross' passing and then Kath followed after a long battle with Motor Neurone disease. They were such a vibrant couple and we will miss them dearly. I met them at the first meeting to form a support group for MG sufferers in 1991. Neville met them at a following meeting and we became firm friends. Kath organized a small group with Gerald and Pearl to meet at Early Street Village and the rest is history. Nev and I had a lot of trips with Kath and Frank and it was always a laugh a minute. Our Patron, Dr Cecilie Lander, has very fond memories of Kath and the inaugural meeting.

It is very important to keep the Association moving forward as a lot has been achieved since that inaugural meeting 18 years ago, and we must ensure that Kath's work was not in vain.

Thank you for the great response to Dr Reddel's visit to Brisbane. We had a record attendance for an MGAQ function with people coming from Cairns, Townsville, Rockhampton, Dalby, Sunshine Coast, Gold Coast and from Brisbane and surrounds. Well done. I am sure that all who attended went away with more knowledge of MG and the state of research into the disease. The Management Committee decided, on behalf of our members, to make a donation towards further research.

That's all for now,

*Shirley*

Two things to ponder:

Anger is a condition in which the tongue works faster than the mind.

And

Whether one is 20, 40 or 60,  
Whether one has succeeded, failed or just muddled along;  
Whether yesterday was full of sun or storm or one of those dull days  
with no weather at all,  
Life begins each morning.

Supported by



**Queensland Government**  
Queensland Health

**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 – QUEENSLAND REGIONAL COORDINATORS**

HANNA	4054 4538	FAR NORTH QLD
CAROL	4773 1213	TOWNSVILLE
GWEN	4954 5353	MACKAY
JOAN / HAROLD	4928 1438	ROCKHAMPTON
SHIRLEY	5443 1728	MAROOCHYDORE SUNSHINE COAST
JOHN / MARILYN	5532 4547	GOLD COAST
SHARON	4151 7661	BUNDABERG/WIDE BAY
VACANT		DARLING DOWNS

**CHAT LIST – QUEENSLAND REGIONAL MEMBERS**

JOHN	4783 1556	AYR
YVONNE	4783 4643	AYR
MARK	4067 1784	BABINDA
HENRY	4982 6507	BLACKWATER
DAVID	4053 2291	CAIRNS
RON / HELEN	4051 3286	CAIRNS
SHIRLEY	4128 3596	HERVEY BAY
SHARON	4151 7661	NORTH BUNDABERG
BARBARA	4124 2312	POINT VERNON
RAY / MARY	5443 8667	MAROOCHYDORE
DAVID	5474 5534	NOOSA
MARLENE	5447 4986	NOOSA HEADS
JOY	4165 4647	MUNDUBERRA
BILL / COLLEEN	4926 2410	ROCKHAMPTON
TOM / SCOTIA	4693 3730	PITTSWORTH
HEATHER	4728 7550	TOWNSVILLE
JO	4723 8721	TOWNSVILLE
KELLY	4728 4913	AITKENVALE
VALMA	4068 0702	TULLY
PERLA	4939 2724	YEPPOON
IAN	4623 5169	YULEBAR
CAROLYN	5472 0386	COOROY
ROBYN	5520 4242	BURLEIGH HEADS
MAUREEN	5572 7993	MERMAID BEACH
HELEN	5445 4853	SUNSHINE COAST
OWEN	4742 1190	CLONCURRY
PATRICIA	5535 0274	BURLEIGH WATERS
AILSA	4055 1303	CAIRNS
JUDIE	0439 461288	AIRLIE BEACH
BARRY	5483 1783	CURRA
JAMES / ROSEMARY	5530 1558	HOPE ISLAND
DONALD	5563 7207	RUNAWAY BAY
RAJKO	5580 6404	OXENFORD
ELIZABETH	4936 2410	GLENLEE





## Shirley's Recipes

### ZUCCHINI AND SWEET POTATO FRITTERS

**Ingredients:**

- |                       |                                  |
|-----------------------|----------------------------------|
| 400g green zucchinis  | 300g sweet potato, peeled        |
| ½ leek, finely sliced | 2tbs chopped mint                |
| Pinch nutmeg          | 2 eggs, lightly whisked          |
| ⅔ cup plain flour     | ½ cup grated parmesan            |
| ½ cup vegetable oil   | purchased tzatziki dip, to serve |

**Method:**

1. Coarsely grate the zucchini and sweet potato and squeeze out any excess moisture.
2. Place in a bowl with leek, mint and nutmeg. Season with salt and pepper.
3. Add eggs, flour and parmesan and mix well together.
4. Heat oil in a medium frying pan over medium-high heat. Using a ¼ cup measure, drop batter into oil and flatten slightly. Fry for about 2 minutes each side until golden. Remove to a plate lined with paper towel and keep warm. Continue with remaining mixture.
5. Serve fritters with tzatziki.

**NOTE:** Serves 8

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### Clever Old Man

One evening the old farmer decided to go down to the pond as he hadn't been there for a while and look it over. He grabbed a five gallon bucket to bring back some fruit. As he neared the pond, he heard voices shouting and laughing with glee. As he came closer he saw it was a bunch of young women skinny dipping in his pond. He made the women aware of his presence and they all went to the deep end. One of the women shouted to him, "We're not coming out until you leave!" The old man frowned, "I didn't come down here to watch you ladies swim naked or make you get out of the pond naked." Holding the bucket up he said, "I'm here to feed the alligator." Moral of the story: Old men can still think fast.

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### Lost Wives

Two men, one old and one young, are pushing their carts around Bunnings when they collide. The old man says to the young man, "Sorry about that. I'm looking for my wife, and I guess I wasn't paying attention to where I was going." The young man says, "That's OK. It's a coincidence. I'm looking for my wife, too. I can't find her and I'm getting desperate." The old man says, "Well, maybe we can help each other. What does your wife look like?" The young man says, "Well, she is 27 yrs. old, with red hair, blue eyes, long legs, big boobs, and she's wearing tight white shorts. What does your wife look like?" The old man says, "Doesn't matter son.... let's look for yours first."

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### Selection

Young Johnnie was attending the horse sales with his dad. He watched as his dad went around several horses and ran his hands over the horses' chests, rumps and legs. After a few minutes, Johnnie asked, "Dad, why do you do all that?" "Well, when I'm buying horses son, I have to make sure they are healthy and in good shape." Johnnie then looks very worried and quietly said, "Dad, I think the milkman wants to buy mum."

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**LIFE WITH GRAVIS** (published in the Spring 2009 edition of **MGANEWS** (UK))

The Gravis kitchen has been a hive of activity, not always to Mrs Gravis' delight. In the summer 2008 edition of MGA News I rashly said, "Given my experiences in coping with eating and swallowing problems, my speech and language therapist suggested that I write them up into a booklet. I will give it a go and would appreciate any ideas that readers may have." So far no one has sent in any ideas, so I have decided to include a recipe with each LWG. This has entailed trying them out and hence the kitchen activity. Mrs Gravis complains that I create too much chaos and washing up. I have been encouraged to continue by the response to my tips which I have passed on to the members of our local branch who have eating and swallowing problems.

My first experience of what could be done to make eating puréed food enjoyable was when I emerged from hospital following a myasthenic crisis. I came home on Christmas Eve. Things looked bleak on the festive food front, but I hadn't reckoned with Mrs Gravis' culinary inventiveness; she had been carefully watching what kind of food the hospital had been giving me. It was announced that I would have a complete Christmas dinner. Being a country lad, this has always been roast pheasant, sage and onion stuffing, potatoes and assorted vegetables. Dinner time came and I was summoned to the table; to my delight there was a plate with several piles of everything puréed to a texture that I could swallow. It looked like an artist's palette and painted a wonderful picture. The important thing was that each item had been individually blended, it was not that awful khaki goo that springs to mind when puréed food is mentioned. As I became stronger I began to attempt small dishes myself; it is these which I will start with and promise to come back to Christmas dinner in another edition, perhaps in the autumn, to be in time for Christmas.

Strange as it may seem, it is easier to swallow thickened fluids than thin ones such as water. The aim is to produce a smooth creamy texture. The first task is to blitz the solid food to as near a smooth past as possible. To do this I use a 'Kenwood White Mini Chopper', the same one that Delia used in her last TV series on cheating, but any similar make will do the job. It may be necessary to add a suitable fluid to assist the blitzing; you will certainly need something to bring the purée to the required consistency. For example, I use low fat mayonnaise when preparing tinned salmon. Plain yoghurt also makes a good base. This time I thought that I would give you my recipe for one of my luxury favourites, Prawn Avocado. Take a ripe avocado, halve it and remove the stone. Scoop out the flesh from both halves, keep the skins; you will need them later. Put the avocado flesh into the chopper with a tablespoonful of plain yoghurt and reduce to a smooth paste. Return half the paste to each skin and put on one side. Next put two handfuls of cooked prawns into the chopper and add a tablespoonful of seafood sauce. You can adjust the amount of sauce to taste and to enable the purée to reach the desired consistency. Again plain yogurt can be substituted if preferred. Arrange the puréed prawns on top of the avocado; if it's thick enough it will form an attractive dome. The pink and the green make it look appetising and that's half the battle. Some folk add a squeeze of lemon juice, but beware; acidic things like lemon juice can stimulate swallowing, which can be a problem if the associated muscles have been weakened by MG.

Finally, do consult your Speech Therapist before attempting these recipes. If you have chewing and swallowing difficulties and don't see a Speech Therapist, then ask for a referral. I learned so much from mine, particularly how to eat and drink without it going down my windpipe. This can lead to serious respiratory infections, an additional problem to be avoided at all costs. I have often pointed out that although MG follows a general pattern, each myasthenic is different. What works for one can be harmful to another, but with the care of a good Neurologist experienced in managing MG, even the most awkward patient like me can be stabilised. In my case it has been methotrexate which seems to be doing the trick. Not only has it inhibited the MG to a point where I am free of myasthenic weakness, but I can tolerate it. Whereas until last summer I could only be a minor irritant, I can now really be a pain, a sentiment wholly endorsed by Mrs Gravis. I am aware that some readers have been upset by my recounting my experiences of an MG crisis, indeed writing one article from a bed in intensive care, but I hope that my steady progress will make fellow myasthenics realise that MG is not the end of the world.

**February 2009**

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ATTORNEY: How was your first marriage terminated?

WITNESS: By death.

ATTORNEY: And by whose death was it terminated?

WITNESS: Now whose death do you suppose terminated it?

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**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. In which year did Sir Edmund Hilary conquer Mt Everest?
2. In which African country did the Mau Mau uprising take place?
3. What did Sir Alexander Fleming discover?
4. Who composed the opera 'Tosca'?
5. Which common eight-lettered word has 5 consecutive vowels?
6. What are the main components of brass?
7. What is the chemical symbol for Platinum?
8. Which famous international player won the Australian Golf Open seven times between 1958 and 1974?
9. Which mountain range runs through Liechtenstein?
10. Who is Adam holding his hand out to on the Sistine Chapel ceiling?
11. Which musical includes the song 'Memory'?
12. Who did Pakistan defeat in the final of the cricket World Cup in 1992 at the MCG?
13. The Grand Canyon is in which US state?
14. In which public space would you find a statue of Eros?
15. What was the largest concentration camp in WW2?
16. What beverage did Louis Pasteur first pasteurise in 1864?
17. Who was Wimbledon's first unseeded men's champion?
18. Which European language is Semitic?
19. What does a Russian mean when he says 'Spasibo'?
20. What title is bestowed upon the ruler of Venice?

**Answers:** 1) 1953; 2) Kenya; 3) Penicillin; 4) Puccini; 5) Queueing; 6) Copper & Zinc; 7) Pt; 8) Gary Player; 9) Alps; 10) God; 11) Cats; 12) England; 13) Arizona; 14) Piccadilly Circus; 15) Auschwitz; 16) Wine; 17) Boris Becker; 18) Maltese; 19) Thank You; 20) Doge.

REMINDER - IT'S MEMBERSHIP SUBSCRIPTION RENEWAL TIME

It's that time of the year again when Membership Subscriptions for the financial year 2008/2010 are due.

The envelope in which this notice was enclosed will advise you when your membership expires. If you look along the top line you should see "YOUR NAME" followed by some figures in smaller print than your address.

The majority of members will have 6/09 which tells you (and us) that you are financial to 30 June 2009. Others may show 6/10 or even 6/11 to indicate they have saved time and postage by paying in advance. However, there are others whose envelopes still show 6/08, 6/07, etc and we continue to send our newsletter to these non-financial members because we do not know what they want. If you are non-financial, please take a minute to ring on the FREE call number, 1800 802 568 and advise whether or not you wish to retain your membership and receive "MessaGes".

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Please help to make our Treasurer happy - she loves writing receipts.

Tear off along this line

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We thank you in anticipation of you renewing your membership.

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Heart Murmur

An eighty-year-old man was having an annual physical. As the doctor was listening to his heart with the stethoscope, he began muttering, "Oh oh!" The man asked the doctor, "What's the problem?" "Well," said the doc, "you have a serious heart murmur. Do you smoke?" "No," replied the man. "Do you drink in excess?" "No." replied the man. "Do you have a sex life?" "Yes, I do!" "Well," said the doc, "I'm afraid with this heart murmur, you'll have to give up half your sex life." Looking perplexed, the old man said, "Which half - the looking or the thinking?"

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