



MessaGes

Myasthenia Gravis Association of Queensland Inc

MARCH 2011



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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.

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PRESIDENT'S REPORT

Welcome

I hope everyone has survived the past month and getting used to the extreme heat that we are having.

As previously reported the committee will be having a 'Meet the Members' in Townsville on 12th March 2011 at the Cowboys League Club and we are hoping that we get to meet all our Townsville members and also that they will voice what you would like to see us do for the Association in regards to keeping them in touch even though they are miles away from Brisbane. I would like to thank Carol Buchanan for all her hard work in organising the event. A report on the meeting will be published in the April issue of MessaGes.

I am also taking the opportunity to visit Magnetic Island to see how much it has changed since living there 30 years ago.

Both of our Research Projects have now received approval from the relevant Ethics Committees so we are now in a position to proceed with them. More information is on Pages 6 and 7 of this issue, and we hope to get the support of our members to make them successful. Remember, the results from both projects may not find a cure but they will help to better understand MG and how we have to cope with our everyday living.

I am looking forward to visiting Perth next month for a holiday and will get to meet some of the members from the WA Association. This will be very exciting as it is so much better when you have put a face to the names.

We are still looking for Coordinators in each of the following regions - Toowoomba, Bundaberg and Rockhampton. Please contact Shirley on 1800 802 568, or email Graeme, if you are interested in becoming a coordinator. You might be surprised what you actually get out of this for a little bit of your time.

Take care

Anita

Editor's note: The President's Report was prepared prior to the Townsville meeting.

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 – QUEENSLAND REGIONAL COORDINATORS

HANNA	4054 4538	FAR NORTH QLD
CAROL	4773 7122	TOWNSVILLE
BILL	4954 1221	MACKAY
VACANT		ROCKHAMPTON
SHIRLEY	5443 1728	MAROOCHYDORE SUNSHINE COAST
JOHN / MARILYN	5532 4547	GOLD COAST
VACANT		BUNDABERG/WIDE BAY
VACANT		DARLING DOWNS

CHAT LIST – QUEENSLAND REGIONAL MEMBERS

JUDIE	0439 461288	AIRLIE BEACH
KELLY	4728 4913	AITKENVALE
JOHN	4783 1556	AYR
YVONNE	4783 4643	AYR
MARK	4067 1784	BABINDA
SARA	0422 109492	BLACK RIVER
HENRY	4982 6507	BLACKWATER
LYNDA	4159 2890	BARGARA
PAMELA	4151 5499	BUNDABERG
ROBYN	5520 4242	BURLEIGH HEADS
MOYRA	5576 4979	BURLEIGH WATERS
PATRICIA	5535 0274	BURLEIGH WATERS
DENISE	4788 0798	BUSHLAND BEACH
AILSA	4055 1303	CAIRNS
DAVID	4053 2291	CAIRNS
RON / HELEN	4051 3286	CAIRNS
OWEN	4742 1190	CLONCURRY
CAROLYN	5472 0386	COOROY
BARRY	5483 1783	CURRA
GLORIA	5534 2669	CURRUMBIN
MELISSA	4662 3337	DALBY
ELIZABETH	4936 2410	GLENLEE
LILLIAN	49334281	GRACEMERE
SHIRLEY	4128 3596	HERVEY BAY
ANGELA	0427752956	HOPE ISLAND
JAMES / ROSEMARY	5530 1558	HOPE ISLAND
GEOFFREY	5341 8747	LITTLE MOUNTAIN
TERRY	5494 2470	MALENY
RAY / MARY	5443 8667	MAROOCHYDORE
MAUREEN	5572 7993	MERMAID BEACH
ROBERT	5492 9754	MOOLOOLAH VALLEY
JOY	4165 4647	MUNDUBERRA
MICHAEL	5545 2802	NORTH TAMBORINE
DAVID	5474 5534	NOOSA
MARLENE	5447 4986	NOOSA HEADS

MEMBERS' FORUM

Thank you to Rosemary for the following contribution. We hope it encourages other members to write and tell of their experience with MG:

'I read with interest the article on a possible cluster at MUSC. I suffer with Myasthenia and have recently learned that Myasthenia has been in my family going back to the early 1800's at least. Of course it wasn't known back then what ailed my grandmother or two of her daughters, and their daughters until recently. When I was a child I always remember my grandmother having trouble getting out of her chair and doing things. As a child, my parents sent me and my twin sister to her place every Saturday to clean (starting when we were 4 years old).

I am nearly 58 years of age and the Myasthenia is affecting me greatly, but thinking back over the years, when I was 15 years of age, I was 174cm tall, weighed about 35 kilos and my sports teacher thought I'd be a great 100 metre runner and swimmer. Imagine to my surprise when I tried to run I could only go a few strides and collapsed with weakness. The same with swimming. Of course my teacher didn't understand it and thought I was "lazy" a label that stuck for a few years. I had nicknames like "slow coach and Speedie."

On leaving school, my first job was as a sales assistant in a clothing store. I lasted 6 weeks as I couldn't stand all day. Eventually I got an office job which I kept for years until I had my son and spent 12 years at home. After that I got a Public Service job and was eventually retired Totally and Permanently Incapacitated after 14 years service.

So I was able to lead a semi-normal life but now after being diagnosed 11 years ago, life has become difficult. My Myasthenia affects my legs and arms and getting out of a chair for example is an absolute chore. I'm lucky that I get Home care assistance and other assistance. I don't know what I'd do without it.

Interestingly I have three sisters, a twin and two younger sisters. I also have Systemic Lupus diagnosed 30 years ago. None of my sisters have Myasthenia but one has Lupus.

Occasionally I have trouble swallowing but if I eat moist foods then I'm okay.

I've written this in the hope that others who read the newsletter won't be afraid to write about their experiences. I think it helps if we share how MG affects us. For years I went undiagnosed and couldn't understand why I was so weak all the time. It's only when my legs gave way at work one day and I couldn't get up even with assistance and my boss got me to a doctor who referred me to a neurologist straight away that I found I had MG and had probably had it for years. I have a cousin who has looked into the family tree looking for medical ailments to pass her retiring years and she discovered the MG link to my grandmother and two other cousins and their daughters. I would be interested to know how MG affects others so I can get a better understanding of it. So far I don't think it affects my eyes all that much but I do get blurred vision occasionally.

I hope my story helps others and encourages them to write of their experiences.

Thanks

Rosemary'

Please send in contributions to our 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.

PROJECTS UPDATE

Collecting data on sufferers of myasthenia gravis –

SET TO PROCEED WITH THE SURVEY

Ethical approval has been achieved! We have the go ahead. The committee hopes that you too are feeling excited about this opportunity. It is a chance for you to tell your story in all its aspects.

By compiling this survey and working with the Doctors we hope to bring medical benefits through a range of research projects which may evaluate current treatments, look for triggers or consider the influence of related conditions. Increased awareness of this condition will help sufferers and may even result in earlier diagnosis for some. Highlighting the cost, both emotionally and financially, of this condition to the community and to health officials can only help us all.

We are at present investigating printing options and hope to have a copy of the survey to ALL our Category A Members soon. Your support for this project is critical to its success. We are here to assist you in completing the survey. You may take your time, ask for help with difficult questions or put 'Not Applicable' if you cannot or do not wish to answer any of the questions. Every piece of information that can be supplied will be useful.

Funding for research into 'Exercise and MG' –

Good news here also. This project has been approved by the University of Queensland Ethics Committee and we are currently in discussion with the Neurological, Ageing & Balance Clinic in the UQ Division of Physiotherapy regarding the full details of the next steps.

Participation in the Pilot Study (of 12 people) will only be offered to current Financial Category 'A' members who live in the Brisbane area because of logistical and transport issues. However, depending on the results of the study, we hope to extend the study further. All participants will be required to obtain from their treating Specialist or GP a written statement that their medication is stabilised and that their physical condition does not preclude them from participating. Participants will also be required to sign a Consent Form and must be 18 years of age or more.

More information will be made available in next month's issue of 'MessaGes'.

In the meantime, the following information on the study will give those interested in participating more time to think about it:

1. Purpose of the study

The primary **aim** of our study is to measure the effect of a balance strategy training exercise program in reducing the fatigue and functional weakness effect on balance, strength, endurance and fitness deficits seen in people with Myasthenia Gravis (MG). The secondary aim is to show exercise is not detrimental to the condition.

2. Participant recruitment

You will be invited to participate in this study through a letter from the Association.

Details of what you will do during participation

If you agree to, and are selected to participate in this study, you will first attend an assessment session where you will be required to undertake various physical tests of walking, balance skills and strength. Questionnaires on how MG affects you and fatigue will also be completed. All assessment sessions should take approximately 1 hour to complete including opportunities to rest. You will then be allocated to one of two groups. Immediate exercise commencement or delayed exercise commencement. For the delayed exercise commencement group 4 weeks will elapse before a second assessment session and then commencement of exercise sessions. The training exercise will occur for 8 weeks, twice per week in a supervised setting for 1 hour each session. The exercises will be tailored to meet your own needs as ascertained in the initial assessment. A trained physiotherapist will oversee all exercise programs and progressions. At the end of the 8 weeks you will undertake an assessment session, followed by 4 weeks of exercising at home without supervision and then a final assessment session. A home exercise program will be supplied. All of the assessment will take place at the University of Queensland Neurological, Ageing and Balance Research Laboratory and all training sessions will occur at the University of Queensland physiotherapy exercise clinic in Brisbane.

Any information obtained during this study will be kept in secured files at The University of Queensland and accessible only to the research staff. With your consent, we plan to publish the results from this study in scientific journals. In any publication, any information pertaining to you individually will be presented in such a way that you will NOT be identifiable.

At the completion of the study, you will receive both a verbal and written report on your performance as well as a written summary of the results of the whole project.

If you do decide to participate in this study, you are free to withdraw from the study at any stage without providing a reason and this will not affect your care situations in any way.

3. *Benefits and Risks*

There is the slight risk that you may overbalance during the balance training or experience some fatigue but this risk is minimal. A physiotherapist trained in this area will be overseeing the exercise sessions at all times. You will be allowed rest breaks as frequently as you need. If you feel unwell at any time throughout the training you should let the treating physiotherapist know immediately so the appropriate action can be taken; this is likely to be termination of the session for that day. If anything were to happen, there will be medical assistance readily available if needed. You may benefit from the training as seen by improvement in your walking, balance, fatigue and participation in daily activity ability but there is no guarantee for this.

This study has been cleared by one of the Human Ethics Committees of the University of Queensland in accordance with the National Health and Medical Research Council's guidelines

You will be given a copy of a Participant Information Sheet (from which this information is taken) to keep.

