



Messages

Myasthenia Gravis Association of Queensland Inc

OCTOBER 2011



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: mgag@gil.com.au
Internet: www.mgag.org.au

COMMITTEE MEMBERS

President
Anita JACKSON
Ph. 3800 4913

Vice-president
JOHN NOBLE
Ph. 3269 5066

Secretary and Editor
Graeme PETERS
Ph. 3288 4484
email: graeme.peters2@bigpond.com

Treasurer
Susan WHITE
Ph: 3358 1056

Information Officer
Shirley JOHNSTON
Ph. 1800 802 568

Committee

Bill SYNNOT
Ph. 0418196707

Carol BUCHANAN
Ph. 4773 7122

PATRON
Dr Cecilie LANDER
Neurologist
Founder Member, of Brisbane

PRESIDENT'S REPORT

Welcome

It is our 21st year of the Association and the Committee now have to reflect on what we have achieved and what we need to do for the next 12 months to make the Association work best for our members. We are open to any suggestions from our members so please give Shirley a call on the 1800 802 568 as she would love to hear from you. It is really amazing that the Association has stayed together this long. It is from dedication from our loyal members and we would like other members to become involved in the Association. It is not hard work and it is very rewarding to know that you have helped a new member feel less vulnerable about Myasthenia Gravis or we have spread the word to the public.

I attended the Self Help Awareness Day in Brisbane in September and it was interesting to see the public walk past our stand and try and say the words Myasthenia Gravis and of course I got a lot of requests about what is it and how does it affect our bodies. I made it a point to ask them to say the words Myasthenia Gravis and that meant they had learnt new words and maybe it might crop up in their conversations with other people somewhere down the track.

On 13th November 2011 we are travelling to Club Helensvale on the Gold Coast for a 'Meet the Members' meeting and are looking forward to meeting our members who reside in the Coast region and anyone else who would like to travel to the Gold Coast.

It is hard to believe that we are 2 months away from our Christmas celebrations at Carina Leagues Club on Sunday 11 December 2011 at 12pm so please mark it in your diaries as they will be filling up with other Christmas parties.

Take care

Anita

**The Past –
We must respect it;
We must not forget it;
We must learn from it; but
We must not live in it.**

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

TERRY / JUDI	3824 4158	ALEXANDRA HILLS
JESSICA	3369 8315	BARDON
JOHN	3269 5066	BRIGHTON
THOMAS	3386 1918	BEENLEIGH
EILEEN	3269 5660	BRIGHTON
GWENDA	3390 2643	CAPALABA
CAROL	33901788	CAPALABA
GORDON	3398 7891	CARINA
LORRAINE	3206 0789	CLEVELAND
PAM / RAY	3801 1335	CORNUBIA
HELEN	3203 0150	DECEPTION BAY
STEFAN	3807 0541	EAGLEBY
NORMA	3281 5079	EASTERN HEIGHTS (IPSWICH)
KIRSTIE	0408311110	EATONS HILL
MELISSA	0411039060	FOREST LAKE
ROGER	3379 8916	GRACEVILLE
JOHN	3899 9387	HAWTHORNE
LEILANI	0448192521	INDOOROOPILLY
DANIELLE	3202 2509	IPSWICH
HELEN	3279 3060	JAMBOREE HEIGHTS
PENNY	0415613242	KANGAROO POINT
CARLY (14 years old)	3354 3014	MITCHELTON
PATRICIA	38867802	NARANGBA
SUSAN	33581056	NEW FARM
KEVIN	32819225	NEWTOWN
BILL & JITLADA	33997041	NORMAN PARK
IAN	3266 2449	NUNDAH
PATRICIA / LES	5464 6719	PURGA IPSWICH
SYBIL	3219 9535	ROCHEDALE
MIKE	3288 4037	SPRINGFIELD
POPPY	3288 4484	SPRINGFIELD LAKES
MARIE	3300 0053	THE GAP
JOHN	3633 0604	ZILLMERE

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Future Planned Activities

Sunday 13 November 2011
 Sunday 11 December 2011
 Saturday 10 March 2012

'Meet the Members' at Club Helensvale, Gold Coast
 Christmas function – Carina Leagues Club
 'Meet the Members' at Mackay

More details will be published as each event becomes closer.

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RETIRING COMMITTEE MEMBER – KRIS KLITGAARD

The 2011 Annual General Meeting held on Sunday 11 September 2011 saw the retirement from the Management Committee of Kris Klitgaard. However Kris' service to the Association was not given the due recognition it deserved on the day.

Kris joined the association in November 1998 and was appointed to the Management Committee at the 2000 Annual General meeting. Kris was appointed to the Treasurer's position in January 2001 and performed those duties until the AGM in 2008 when he relinquished the Treasurer's position and became a Committee Member. In 2010, Kris became Vice-President, a position he held until his retirement this year.

Kris was a scrupulous Treasurer always ensuring that any Association monies expended were to the benefit of its members and kept waste to a minimum. Kris also assumed responsibility for the printing and distribution of the monthly newsletter until the present Editor took on the function in 2006.

Following the appointment of the present Secretary, Kris volunteered to take on the task of attending to the Association's P.O. Box at Mt Gravatt as the Secretary lives at Springfield Lakes, a considerable distance away. This function included perusing the correspondence and forwarding it to the relevant office bearer. Kris continued with this task until his retirement. Kris also took on the task of making venue investigations and reservations in the Carina/Carindale area for the various functions held in that area.

In recent years Kris was considered the 'father-figure' on the Committee and provided advice and guidance for others on the committee, especially Susan, who replaced Kris as Treasurer, and the Secretary. Kris' duties were always undertaken in an unassuming and diligent manner – he is not one to hog the limelight.

As can be seen from the above, Kris has given 11 years of voluntary committed, unstinting and devoted service to the members of the Association and the President, Committee, on behalf of the members, acknowledge and thank him sincerely for his contribution to the success of the organisation over the years, and wish to apologise for the oversight at the AGM.

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MEMBERS' FORUM**

There are no contributions this month.

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 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.

Self-Help Course for Chronic Illnesses

(by Bill Synnot, Committee Member MGAQ)

Background

At a MG committee meeting (2010), an A4, black and white photocopy of a flier was handed around as part of inward correspondence. It advertised a course on self-help for chronic conditions. The flier was rather unattractive and bland. By chance I read the flier and thought that this course could be of interest as it addressed a side of chronic illness that the medical profession appears to ignore, ie the emotional/social impact on sufferers, carers, family, friends, etc of chronic health challenges, such as MG.

The flier stated the course teaches life skills needed for daily management of chronic conditions and encourages an attitude of embracing life's opportunities. It has been designed to enhance regular treatment and disease-specific education, while not undermining existing programs or treatments.

In early 2010, my wife (MG sufferer) had to stop working owing to the impact of MG. This had posed severe emotional strain on the family as work had been a very important social activity for my wife. In late 2010, we as a family (including our 2 teenage sons) consulted a physiologist as our interactions had become judgmental, ie the blame game dominated. This appointment proved unhelpful, partly because we had an unfair expectation that the physiologist would resolve our challenges.

In early 2011, my wife and I attended the course promoted by the flier: "Chronic Conditions Self-Management Course". It involved one morning session, once a week for 6 weeks, and each session was highly participative. After the 6 week course, there are 2 follow-up sessions around 3 and 6 months later to re-enforce the learnings. This course is conducted by Spiritus (part of Anglicare Australia) and is based on work developed by Stanford University (USA).

Our Course Experience

The benefits of the course were enormous, for both my wife and me, and consequently I would strongly recommend it for all MG sufferers, their carers and immediate family members who interact with the sufferer. I would have liked our 2 sons (one 20 and the other 16 years old) to attend but this is not allowed owing to their age.

Also, I was invited to attend a 4-day, train-the-trainer course. Attending this training re-enforced my views of it, ie I cannot speak highly enough of the benefits of the course in developing life-skills and techniques so that you improve the handling of health challenges and, as a result, you take more control of your life. It fosters a sense of reclaiming control of your destiny/future.

It is of interest that we were rather reluctant to mention the course to one of the medical specialists who has treated my wife since 2008. We regard him as very objective, analytical in his approach to MG and felt that he may regard this like a dubious, alternative therapy. To my amazement, he was very supportive. He stated that handling the emotional/social side of chronic health challenges is one of the most difficult parts and praised us for being willing to attend. In fact, I wish he had mentioned this option when we first started visiting him. If this had been the case, we would have attended the course much earlier and saved ourselves much angst, emotional stress, etc.

With people living longer and the resultant increasing aging population, dealing with chronic illnesses via self-management is a growth industry. If more people can improve their skills in handling these health challenges, then sufferers, carers, families and communities will benefit. The current, expanding community cost of chronic illness (mostly money, people's time, emotional stress, etc) could therefore be reduced. In fact, chronic illness would become less of a burden on the community, families, etc if sufferers are better able to handle their chronic health challenges themselves.

Course Content

The first session is an introductory one that outlines what will happen in the following 6 weeks. The course shows how to effectively control your health challenges by putting yourself in charge. It empowers people to manage their health, builds self-confidence and self-esteem by providing valuable and sustainable life-skills and techniques.

Some of the content and skills studied include how to

- work with and maximize the effectiveness of your medical/health care professionals
- work with the health care system
- set goals and achieve them using action plans
- optimally manage your time
- conduct brainstorming effectively
- handle feedback positively
- problem-solve effectively
- prioritise so that you maximise use of your time, resources and energy
- handle your diet and nutrition
- handle your health, medications and treatments including evaluation of new treatments
- learn relaxation techniques like mediation, physical activities, etc
- use a buddy system/peer group pressure effectively
- become self-motivated and focus on wellbeing rather than illness
- use your mind to manage symptoms like tense muscles, pain, stress/anxiety, difficult emotions, disease, depression, frustration, isolation, fatigue etc
- improve communication (includes listening skills) with family and friends, especially those who could lack empathy/understanding of your situation
- chose an exercise and fitness regime that best suits your situation so that you maintain and improve strength, flexibility and endurance
- breathe correctly
- understand distractions techniques, etc

General Comments

The course provides plenty of useful background information; the key reference being "Living a Healthy Life with Chronic Conditions" from the Stanford University. The main method of learning used is "demonstration and practice" that utilizes visual (seeing), auditory (hearing) and kinesthetic (doing) techniques.

PROJECTS UPDATE

Collecting data on sufferers of myasthenia gravis –

Progress regarding the survey remains very positive. This month the Myasthenia Gravis Association of NSW gave us a plug with their members via their newsletter and as a result additional surveys are being sent out almost daily. We thank them for their support and interest in the work that is being done.

Dr Jean Foster from WA was guest speaker at our AGM held in September and she too has assured us of the support coming from WA members. More surveys have been distributed to WA also. The collection of boxes in Susan’s store room is gradually reducing which is gratifying.

Remember to continue your efforts in mentioning the survey to anyone who will listen. One never knows what may result!

‘Exercise Effect in MG’ Study –

The UQ Physiotherapy Department’s Ageing and Balance Clinic has provided some variations to the Study program which we will now put to prospective participants in the Brisbane area in the hope that we will now acquire the required numbers for the Study.

Enhancements to our website –

Please let us know of any suggestions you may have to improve our website.

MEET THE MEMBERS - GOLD COAST

- WHEN:** Sunday 13 November 2011 at 10:00am.
- WHERE:** Club Helensvale, Discovery Drive, Helensvale
- 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 on the Gold Coast to attend.
- HOW DO I GET THERE?** Club Helensvale is located at **20-28 Discovery Drive, Helensvale**, just 200m from the train station or Westfield Shopping Centre. Driving, take Exit 62 off the Pacific Highway, turn into Discovery Drive off the Gold Coast Highway (Brisbane Road).

(UBD Gold Coast Map 17 Reference I 11.)
- 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 4 November 2011**

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