



Messages

Myasthenia Gravis Association of Queensland Inc

DECEMBER 2014



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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PRESIDENT'S REPORT

Welcome,

It is hard to believe that Christmas is just around the corner but the weather is certainly telling us that summer is here. I hope you are all coping well with your MG in this heat.

Our Christmas party at the Sandgate RSL was a great success and it was good that we were all together in the one room. Many members travelled from the Gold Coast and I would like to thank them for making the extra effort. The weather was perfect and the festive food was very enjoyable. We all enjoyed the company of our members and their families and catching up on our MG life stories and also welcome to the new members who came.

The National alliance now has a logo developed and the web address is www.myastheniaallianceaustralia.com.au As mentioned last month that we are planning for the National Conference which will be held in Sydney on Saturday 20th June 2015. Guest presenters are currently being approached.

The committee does not meet in January but we will still be working on the projects that are still in the work in progress stage.

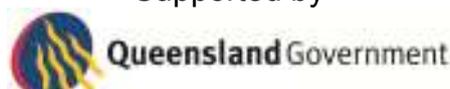
Our first function of next year will be on 15th March 2015 in the Brisbane Region for a picnic so please mark it on your new calendars and hope to see you there.

I would like to send to all our members the very best wishes for Christmas and have a safe and happy holiday and all the best for 2015.

Take care,

Anita

Supported by



PROJECTS UPDATE

SURVEY UPDATE

A brief update this month as the submission process continues. Two papers have been submitted. The Doctors have been asked to combine them into one and work is in progress for this to occur. Conversation continues about collecting DNA studies and how best the subsequent research can be undertaken. A similar project has now commenced in the USA and it may be possible and best practice to join with this work.

MYASTHENIA NATIONAL ALLIANCE

The Queensland Alliance subcommittee, working in partnership with NSW, have been very busy working towards achieving the planned projects of the Alliance as discussed in the previous newsletter.

A logo has been developed and we expect to have a website ready for viewing by 20th December. The web address will be www.myastheniaallianceaustralia.com.au. Guests to this site will be able to register allowing them to receive news of events which may occur in response to National issues. This will save interested persons remembering to visit the site regularly for current items. News will only be posted as relevant events occur.

Planning for the National Conference is progressing well. Guest presenters are currently being approached. The central Sydney venue has been secured for Saturday 20th June. Places will be limited so please consider your interest. Registration will be offered early in the new year.

IN APPRECIATION

In order to create a National Alliance your Association has relied upon two generous offers of support.

The first came from Mr Ron Eames, a senior partner with Law Firm, Holding Redlich of Brisbane. Ron worked through the options available to the Associations in forming an Alliance and then prepared the documentation as required. Ron gave freely of his time for face-to-face meetings and telephone support. Without Ron's assurances the Alliance would have seemed all too hard. He is a very busy and very senior lawyer. This has been an extremely generous gift, followed through over many years, and must be sincerely appreciated.

The second offer of support has come from a donor who wishes to remain anonymous. Very early on in the process, this sponsor pledged \$5,000.00 to be spent on establishing the Alliance. This promise removed from the table any issue of how to finance the venture during the start up period. Without this support, which was forthcoming immediately documents were signed, the discussion would have stalled. It is this donation that has funded the logo, the website and teleconferencing as required. Such philanthropic support is crucial to the ongoing success of MGAQ. Thank you.

The Queensland Association is extremely grateful to have supporters who so firmly believe that we are making a difference with the work that we do. Important and practical benefits to Myasthenia sufferers results from these gifts.

RESEARCH PAPER

Please visit www.mgaq.org.au to read the published paper which resulted from research undertaken by the University of Queensland Physiotherapy Department. Funding was provided by

the MGAQ. Volunteers came from our membership. This paper is titled "EFFECTS OF BALANCE STRATEGY TRAINING IN MYASTHENIA GRAVIS: A CASE STUDY SERIES".

Congratulations to the university on successfully publishing this work and sincere thanks to the volunteers who participated. Generous funding via a bequest supported this project.

Another great outcome!

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 – QUEENSLAND REGIONAL COORDINATORS

DONNA	0414 397 462	CAIRNS
CAROL	4773 7122	TOWNSVILLE
BILL	4954 1221	MACKAY
VACANT		ROCKHAMPTON
SCOTT	5448 1749	SUNSHINE COAST
DENISE	5545 0645	GOLD COAST
JANET	0429 622 438	BUNDABERG/WIDE BAY
VACANT		DARLING DOWNS

CHAT LIST – QUEENSLAND REGIONAL

KELLY	4728 4913	AITKENVALE
ROSALYN	0407 697 206	ANDERGROVE
DENISE	0431 571 399	AVOCA
JOHN	4783 1556	AYR
YVONNE	4783 4643	AYR
MARK	4067 1784	BABINDA
LYNDA	4159 2890	BARGARA
JOHN	4959 5492	BAKERS CREEK
NOEL	5495 2938	BELLMERE
SARA	0422 109 492	BLACK RIVER
HENRY	4982 6507	BLACKWATER
KELLY	4782 5542	BRANDON
PAMELA	4151 5499	BUNDABERG
SYDNEY	4051 6896	BUNGALOW
ROBYN	5520 4242	BURLEIGH HEADS
MOYRA	5576 4979	BURLEIGH WATERS
PATRICIA	5535 0274	BURLEIGH WATERS
JIM	0414 241 091	BURPENGARY EAST

DAVID	4053 2291	CAIRNS
HELEN	4051 3286	CAIRNS
OWEN	4742 1190	CLONCURRY
GAIL	0407 514 241	COOROIBAH
BARRY	5483 1783	CURRA
GLORIA	5534 2669	CURRUMBIN
MELISSA	4662 3337	DALBY
MARSHA	4987 6820	EMERALD
GARTH	4973 7983	GLADSTONE
ELIZABETH	4936 2410	GLENLEE
LILLIAN	4933 4281	GRACEMERE
KARLIENE	0432 431 591	HERVEY BAY
SHIRLEY	4128 3596	HERVEY BAY
ANGELA	0427 752 956	HOPE ISLAND
JAMES / ROSEMARY	5530 1558	HOPE ISLAND
SERAFINA	4751 6415	JENSEN
CHRISTOPHER	0412 456 439	LABRADOR
KAREN	0408 153 285	LOWOOD
TERRY	5494 2470	MALENY
MAUREEN	5572 7993	MERMAID BEACH
ROBERT	5492 9754	MOOLOOLAH VALLEY
KATREN	0418 778 082	MONTEREY KEYS
CAROLYN	5522 8987	MUDGEERABA
JOY	4165 4647	MUNDUBERRA
KEITH	5441 7236	COES CREEK, NAMBOUR
MICHAEL	5545 2802	NORTH TAMBORINE
DAVID	5474 5534	NOOSA
MARLENE	5447 4986	NOOSA HEADS
SHARON	4151 7661	NORTH BUNDABERG
DENISE	5545 0645	NORTH TAMBORINE
MAUREEN	0411 331 258	PACIFIC PINES
JUNE	0409 636 467	PALM BEACH
SCOTT	5448 1749	PEREGIAN BEACH
TOM / SCOTIA	4693 3730	PITTSWORTH
DAPHNE	4773 3695	RASMUSSEN
BILL / COLLEEN	4926 2410	ROCKHAMPTON
DONALD	5563 7207	RUNAWAY BAY
HELEN	5544 31728	SUNSHINE COAST
SHIRLEY	5445 4853	SUNSHINE COAST
BERNIE	Joypaul28 *	TEWANTIN
BETTY	4635 6270	TOOWOOMBA
DIANNE	4638 8447	TOOWOOMBA
CAROL	47737122	TOWNSVILLE
HEATHER	0438 743 234	TOWNSVILLE
HEATHER	4728 7550	TOWNSVILLE
LUCY	0418 879 801	TOWNSVILLE
JO	4723 8721	TOWNSVILLE
ANNE	0487 305 153	TRINITY BEACH
KATHLEEN	5573 0439	UPPER COOMERA
RAJKO	5556 0639	UPPER COOMERA
ANDREA	5486 7671	WOLVI
JAN	5493 4441	WURTULLA
SANDY	0458 980 667	YANDINA
PERLA	4939 2724	YEPPOON
SHIRLEY	4778 7117	YABULU
IAN	4623 5169	YULEBAR

Please note that * indicates
that this member is available
via the VOIP Skype facility on
a computer

FUTURE PLANNED ACTIVITY

15th March 2015 – Picnic in the Brisbane Region

TOWNSVILLE GET TOGETHER

The Townsville MG group had a well-attended get-together this month and shared good company and great conversation. Due to family circumstances, the next meeting of the Townsville will now be on Saturday 21 February instead of Saturday 31 January.

Carol Buchanan – Townsville Coordinator Ph. 47737122

MEMBERS' FORUM

Welcome to New Members

The MGAQ welcomes Carmel and Dennis from Warwick, Marshall from Emerald, Leanne from Wavell Heights and Farinaz from New Farm as new members to our association. We look forward to developing a worthwhile relationship with you all.

Emily writes,

Hello to everyone who is reading this!

I was diagnosed when I was seventeen after only a few months of symptoms, I was very lucky in this regard as I've heard that it can be years until a final diagnosis comes along. I had a droopy eye, arm and leg weakness, slurred speech and difficulty swallowing. Basically I had all the symptoms except breathing difficulties (thank goodness) and as you can imagine, the last few years at High School weren't all that pleasant.

At this stage I didn't know that the Myasthenia Gravis Association of Queensland even existed, or for that matter that any Australian group. So I decided to start my own group on Facebook. I'm not sure what I hoped to achieve. Only, I guess, to reach out to someone else with the same condition and understanding, to not be alone with this rare disease.

At first my group 'Myasthenia Gravis Australia' had only me and a handful of my close friends from High School but then slowly, over time, it grew. Today my group has 162 members and it's expanding, ranging from all ages, gender, those with MG and those who know someone with it. I've even been able to network with groups and people from across the globe. 'Myasthenia Gravis Australia' is a group to share, discuss and support each other in our daily struggles and I am quite proud of it and my new friends.

I want to say that I am so honoured to be given the chance to be the Editor and I can only hope to maintain the amazing work that Catherine has done.

Merry Christmas everyone!

What does being a member of Myasthenia Gravis Association of Qld mean to me?

We all know that people belong to MGAQ for different reasons. Below are some thoughts from our members in Cairns and we thank them all for their input.

Maxine from Cairns writes,

I was diagnosed with MG in 1959 at 15 years of age and had a thymectomy in 1960. Both my parents and I were unaware of any support groups back then and I had no contact or knowledge of other MG sufferers for more than 30 years. I am a foundation member of the Cairns branch of MGAQ of Qld started by the late Hanna Russell in 1995, and becoming a member gave me great comfort in knowing I was not alone. Being able to share experiences and milestones is of untold

help, especially for newly diagnosed patients and their carers. My husband and children also have a greater awareness now because of the literature that is produced.

Janice from Cairns writes,

I can keep in contact with other MG sufferers.

Keep updated with all information on MG from other specialists etc.

I know that there is always someone available to help at any time.

Allan from Cairns writes – A Carer's point of view

Initially the great benefit is the personal support provided. This depends very much on the personalities rather than formality and structure of MG. Whilst a certain level of formality is required to meet probity requirements (using public money) it is important that meetings are supportive and don't get bogged down in process.

The early benefit is a realisation that "you are not alone" even though MG is quite rare. Also you realise that there can be good quality of life with/after MG. Gatherings at MG naturally need to be realistic but at the same time stress the optimism that is possible. Probably this is the most important stage.

The next stage is understanding MG and this comes from understanding the experiences of others as well as from the professionals. MG still is not well understood at the professional level. We have noticed the change in professional understanding over the past approx. 20 years. We made some observations regarding things that affected the impact of MG (diet, mental stress) that were not supported in the professional literature but which now have professional acceptance. The combined experience of MG sufferers (and their support) can be gathered through MG meetings and then inform the professional knowledge. Individual information can become reliable knowledge – MG now contributes to a formal data base.

The third stage is to provide experiences to the group that is not possible for individuals. Eg the recent talks from specialists. These will add further to the combined understanding of MG.

Donna from Cairns writes,

What you get out of being a member depends on you as the individual. For me, it is important to participate in the Association. This could be by attending social gatherings and talks, or by paying the annual subscription as this all helps the Association pass on the most up to date information about MG. Support groups are a great way of connecting and forming friendships with people who truly understand what you are going through as a Carer or a sufferer.

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 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.

Editor's Note:

I would like to invite all the carers or sufferers of M.G. to tell their story. Speaking to many of you there are people who would benefit from hearing how others cope with the ups and downs of everyday life. Contributions to the newsletter can be sent to me at emily.sexton@live.com.au

CHRISTMAS TRIVIA

1. All the gifts in the Twelve Days of Christmas would equal 364 gifts.
2. In A.D. 350, Pope Julius I, bishop of Rome, proclaimed December 25 the official celebration date for the birthday of Christ.
3. Puritan Oliver Cromwell outlawed Christmas celebrations and carols in England from 1649-1660. The only celebrations allowed were sermons and prayers.
4. Commissioned by Sir Henry Cole (1808-1883), British illustrator John Callcott Horsley (1817-1903) invented the first Christmas card in 1843.

CHRISTMAS AND SUMMER RECIPES

Heavenly Filled Strawberries

**TOTAL TIME:** Prep/Total Time: 20 min.**MAKES:** 36 servings**Ingredients**

- 3 dozen large fresh strawberries
- 2 packages (one 8 ounces, one 3 ounces) cream cheese, softened
- 1/2 cup confectioners' sugar
- 1/4 teaspoon almond extract
- Grated chocolate

Directions

1. Remove stems from strawberries; cut a deep "X" in the tip of each berry. Gently spread berries open.
2. In a small bowl, beat the cream cheese, confectioners' sugar and extract until light and fluffy. Pipe or spoon about 2 teaspoons into each berry; sprinkle with chocolate. Chill until serving. **Yield:** 3 dozen.

Nutritional Facts

1 filled strawberry (calculated without chocolate) equals 41 calories, 3 g fat (2 g saturated fat), 10 mg cholesterol, 26 mg sodium, 3 g carbohydrate, trace fiber, 1 g protein.

Fresh Fruit Popsicles

**Ingredients**

- 1 peach, cut into 1/2-inch slices (1/2 cup)
- 2 kiwis, peeled and sliced into 1/4-inch rounds
- 3/4 cup strawberries, finely chopped
- 1/2 cup blueberries
- 1/2 cup raspberries
- 1 1/2 to 2 cups of fruit punch or 100 percent white-grape juice

Directions

1. Combine fruit in mixing bowl and arrange the mixture into eight 3-ounce popsicle molds.
2. Pour enough juice into each mold to just cover fruit.
3. Insert popsicle sticks and freeze until solid (about six hours).

Servings: 8

MERRY CHRISTMAS



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*The President and
Management Committee
of the Myasthenia Gravis
Association of QLD Inc.
wish our members and
their families the very best
of wishes for the festive
season and a safe and
prosperous 2015.*

*They would also like to
thank you for your support
over the past year and look
forward to a bigger and
better 2015.*

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