



Messages



Myasthenia Gravis Association of Queensland Inc

DECEMBER 2010

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

COMMITTEE MEMBERS

President
Anita JACKSON
Ph. 3800 4913

Vice-president
Kris KLITGAARD
Ph. 3890 0115

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

The committee had a very successful Meet the Members day at Pacific Paradise Bowls Club on the Sunshine Coast last month. A big thank you to Shirley Langshaw for organising the venue as it was very nice and the staff were excellent. It was good to see old members who have moved to the Sunshine Coast but it was really special to meet our new members. The new members were very excited that the Association exists and that we are there to help them in any way we can. I think a lot of new friendships have been formed from this meeting with our Sunshine Coast members.

We are now looking forward to our Christmas Party at the South Coast so hoping to see all our members at the Coast.

The committee is also planning a trip to Townsville in March 2011 for another 'Meet the Members' event so that we can meet you all our members in the Townsville region and we are looking forward to a successful meeting. Full details will be published in our February newsletter.

I would like to take this opportunity to wish everyone a very Merry Christmas and the very best for 2011. Hoping to see you all sometime in the next year as we are trying to organise some very good speakers.

Take care

Anita

PS: We are still searching for Coordinators for each of the Toowoomba (Darling Downs), Bundaberg (Wide Bay) and Rockhampton regions. Please contact Shirley on 1800 802 568 if you are interested in becoming one.

Supported by



Queensland Government
Queensland Health



*The President and
Management Committee
would like to wish
our members, supporters,
their families and friends
a Joyous and Safe Festive
Season
and a
Happy and Healthy 2011*

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
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
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
SHARON	4151 7661	NORTH BUNDABERG
TOM / SCOTIA	4693 3730	PITTSWORTH

BILL / COLLEEN	4926 2410	ROCKHAMPTON
DONALD	5563 7207	RUNAWAY BAY
HELEN	5445 4853	SUNSHINE COAST
HEATHER	4728 7550	TOWNSVILLE
JO	4723 8721	TOWNSVILLE
VALMA	4068 0702	TULLY
KATHLEEN	416178458	UPPER COOMERA
RAJKO	5556 0639	UPPER COOMERA
JAN	5493 4441	WURTULLA
PERLA	4939 2724	YEPPOON
IAN	4623 5169	YULEBAR

Update on **PROJECTS**

A. Collecting data on sufferers of myasthenia gravis –

The Association is currently negotiating an agreement with researchers which will allow us to distribute, process and store the returned surveys. Our goal is to maximize the benefits which may be taken from the data. This very satisfying outcome to many hours of work makes a welcome finish to the year.

B. Establishment of an Australia-wide MG ‘umbrella’ organisation –

Dormant for the time being.

C. Funding for research into ‘Exercise and MG’ –

The management has approved this project. More details will be available in the New Year.

D. Enhancements to our website –

Updates to our website have been agreed and should be in place early in the New Year.

Future Planned Activities

Sunday 12 December 2010	Christmas Function –Sharks Australian Football Club Southport
Saturday 12 March 2011	Management Committee Meeting at Townsville Followed by ‘Meet the Members’
Sunday 19 June 2011	20 th Anniversary Function

More details will be published as each event becomes closer.

The Management Committee meets on the second Saturday of each month (except January) and all members are invited to attend. If you wish to attend any of these meetings, please contact Shirley on the 1800 number to find out the time and place of the relevant meeting.

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MEMBERS’ FORUM

We are still eagerly awaiting members’ stories that were told at the Cairns meeting.

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.

Shirley's Recipe

CHRISTMAS CHERRY & WHITE CHOCOLATE SLICE

(from Wendy's Free Recipes Online)

Ingredients:

- 125g unsalted butter
- 1 cup plain flour
- 2 eggs
- 120g white cooking chocolate broken up (use the best available)
- ½ cup white cooking choc bits
- ¾ cup caster sugar
- ¼ teaspoon baking powder
- 1¾ cups red and green glace cherries

Method:

1. Preheat oven to 180°C or 160°C for fan forced oven.
2. Grease a 20 x 30cm slice tin. Line base and sides with baking paper.
3. Put butter and white chocolate in a small saucepan over a pan of simmering water. Do not allow any water or steam to enter the choc mix as it will ruin it. Stir until smooth and creamy. Remove from heat.
4. Put sugar and eggs in a large mixing bowl and beat until well combined.
5. Stir in the chocolate mixture then sift the flour and baking powder into it.
6. Gently fold in half of the cherries with the white choc bits.
7. Pour into slice tin and lightly scatter with remaining cherries.
8. Bake for approx 25 - 30 minutes or until lightly golden. When a skewer comes out clean, remove from oven and let stand for 8 - 10 minutes before turning out on a cutting board.
9. Cut into small squares and lightly dust with a little icing sugar if desired.

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News from Mackay

A short note to advise you that the local members are having lunch @ Harrup Park on the 5/12/2010 @ midday.

Have been in contact with the local members regularly. @ the present -

- All appear to be well;
- At the lunch will try to arrange get togethers for the first 6 months of 2011
- Conditions in our area are very wet; Mackay has had the wettest November on record.

Muriel & I wish all the committee members & members of MG Assn a safe & healthy Festive Season.

Bill Harris,
Mackay Coordinator

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OBITUARY

It is with deep sadness that we advise of the passing of Ray Middap of Maroochydore. Ray and his wife, Mary, were foundation members of the Association and gave great support to its aims. Both Ray and Mary attended our social outings whenever health permitted and were a very popular couple with other members. Ray was always good for joke. He will be sorely missed.

We extend our most sincere sympathy to Mary and her family.

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MEDICAL COOLING AND HEATING ELECTRICITY CONCESSION

The Queensland Government provides financial assistance to low income Queenslanders with a medical condition which requires the use of electricity for cooling or heating. This assistance is provided for a period of 2 years, at which time eligibility will require review

The concession is provided to assist individuals with the increased electricity costs incurred by frequent operation of an air-conditioning unit in order to regulate body temperature.

The concession is not limited to one person per household, but all persons must meet all of the eligibility criteria.

Eligibility for the concession:

An applicant must:

- be a Queensland resident, and
- have a qualifying medical condition requiring cooling or heating to prevent the symptoms of their condition worsening, and
- be residing at their principal place of residence and use an air-conditioning unit in that residence to meet their heating and cooling requirements.

The applicant and/or legal guardian of a minor with a qualifying medical condition must also:

- hold a current Pensioner Concession Card (issued by Centrelink or Veterans' Affairs), or a current Health Care Card (issued by Centrelink), and
- be financially responsible for the payment of the relevant component of the electricity bill.

Qualifying medical conditions include multiple sclerosis, autonomic system dysfunction, loss of skin integrity or sweating capacity, severe compromising of functioning such as mobility at extremes of environmental temperature, or hypersensitivity to extremes of environmental temperature leading to increased pain or other discomfort or an increased risk of complications.

How to Apply:

To apply for the concession, complete the attached application form and arrange for your medical practitioner to complete the Medical Certification attached. Costs associated with the medical assessment must be met by the applicant (or parent or legal guardian). A parent or legal guardian can complete an application on behalf of children aged under 18 years. A legal guardian or person holding a power of attorney may also complete the application on behalf of an adult applicant. The person with the qualifying medical condition must be listed on the form as the applicant.

Quarterly payments will be made by electronic funds transfer to the applicant's nominated bank account. Payments can not be made to a credit card. Applicants who apply before 30 June 2011 and have a pre-existing medical condition will be eligible to receive back-pay up to the commencement of the concession on 1 July 2010. It is intended that this will allow applicants to have the medical certification signed by their specialist during their regular appointment schedule.

For more information contact:

Concession Services
Smart Service Queensland
PO Box 10817
Brisbane Adelaide Street Qld 4000
Telephone: 1800 460 849

Email: concessions@smartservice.qld.gov.au
Or visit: www.communities.qld.gov.au/community/concessions

An application form for the scheme follows.

Application form



Please detach and return to:
Concession Services, Smart Service Queensland
PO Box 10817, Brisbane Adelaide Street 4000

Failure to complete all sections of the form may delay the processing of your application.
Please read Privacy Notice before completing the form.

Personal details (mandatory)

Applicant details: *Please print*

Title Mr Mrs Ms Miss

Given name(s): _____

Surname: _____

Residential address: _____

Postcode: _____

Email address: _____

Telephone number: _____

If applicant is under 18 years insert parent or guardian details:

Given name: _____

Surname: _____

Alternative contact (should be someone who is at a different address from the applicant):

Given name: _____

Surname: _____

Telephone number: _____

(mandatory)

Please tick if you have an air conditioning unit where you are residing. Yes No
(If no, you are not eligible for the concession)

Section A (mandatory)

I hold one of the following current and valid card/benefit types:

(Commonwealth Seniors Health Cards and Veterans Gold Cards are not acceptable)

Pensioner Concession Card *(issued by Centrelink)*

Card no. -

Pensioner Concession Card *(issued by Veterans' Affairs)*

File no. -

Health Care Card

Card no. -

A legal guardian of a child with a medical condition may use their card details.

Section B (mandatory)

Please provide your bank details for electronic transfer of the concession. If you are unsure of your bank account details, please contact your bank.

Account holder's name: _____

Bank and branch: _____

BSB no: -

Account no:

Please ask your financial institution to stamp here or attach a copy of the portion of your bank statement that shows the BSB and bank account details to this form.

BANK STAMP

Declaration – This section must be signed or your application can not be progressed.

I declare that I have not lodged another application for this concession under a different name.

I will notify Concession Services immediately of any change in my circumstances that may affect my eligibility for or payment of the concession.

I consent to the Queensland Government verifying with Centrelink and/or Department of Veterans' Affairs to determine and confirm my continued eligibility for concession payments.

I consent to the Queensland Government asking my nominated financial institution to confirm my bank account details to ensure payments are made to the correct account.

I consent to the release of my medical records to the Queensland Government relevant to this application if required as part of its responsibility in administering this concession.

I declare that all the information I have given is true and correct and I understand that any fraudulent information provided in the application to obtain the concession may lead to prosecution.

I declare, as the signatory below, that I am the applicant, a person exercising the applicant's power of attorney or legal guardian of the applicant. (Please circle appropriate term below.)

Name (please print): _____ Date: _____

Sign here

Applicant/power of attorney/legal guardian *(Please circle)*



Medical Cooling and Heating Electricity Concession Scheme

Medical Certification (mandatory)

Patient:

I consent to the release of my medical records relevant to this application to the Department of Communities if required as part of its responsibility in administering this concession.

Title Surname Given Name(s)

Sign here Date

Applicant/power of attorney/legal guardian (Please circle)

For General Practitioner/Specialist's Use

Multiple Sclerosis

(certification may be signed by General Practitioner who has treated the patient for at least three months/ Neurologist. If certified by a General Practitioner, prior diagnosis by a Neurologist must be sighted)

Patients who have been diagnosed with Multiple Sclerosis by a Neurologist will not require review.

Specialist/GP Surname

Specialist/GP Given Name(s)

Provider number

Name of patient

Address of patient

Name of the hospital/clinic/practice where the patient was reviewed

Other qualifying condition

(certification must be signed by a relevant Specialist, e.g. Neurologist; General Physician; Dermatologist)

Condition

The patient's loss of thermoregulation is permanent

Patient's eligibility should be reviewed in 2 years

Specialist Surname

Specialist Given Name(s)

Provider number

Name of patient

Address of patient

Name of the hospital/clinic/practice where the patient was reviewed

Medical declaration for conditions other than Multiple Sclerosis

The patient meets at least one primary and one secondary qualifying condition (tick the relevant boxes below):

Primary Qualifying Conditions (tick at least one condition)

Please tick

1. Autonomic system dysfunction (medical conditions in which the autonomic system has been damaged e.g. severe spinal cord injury, stroke, brain injury and neurodegenerative disorders)
2. Loss of skin integrity or loss of sweating capacity (e.g. significant burns greater than 20%, severe inflammatory skin conditions and some rare forms of disordered sweating)
3. Objective reduction of physiological functioning at extremes of environmental temperatures
4. Hypersensitivity to extremes of environmental temperature leading to increased pain or other discomfort or an increased risk of complications (e.g. complex regional pain syndrome and advanced peripheral vascular disease)

Secondary Qualifying criteria (tick at least one condition)

- A. Severe immobility (e.g. such as occurs with quadraplegia)
- B. Demonstrated significant loss of autonomic regulation of sweating, heart rate or blood pressure (due to affect of extremes of temperature)
- C. Demonstrated loss of physiological function or significant aggravation of clinical condition at extremes of environmental temperature.

I certify that the qualifying conditions have been met by _____ and attest to the patient's

medical condition. I certify that the patient was diagnosed with the medical condition on _____

Signature: _____ Date: _____ Phone: _____

(of Medical Practitioner)