



Messages

Myasthenia Gravis Association of Queensland

July 2014



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Association of
Queensland Inc
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Founder Member, of Brisbane

PRESIDENT'S REPORT

Welcome,

Last week the committee met with our Queensland Health assigned consultants, Board Connect. Discussed at the meeting was the development of a transition plan on how the Association will continue to function without the current Queensland Health grants funding.

It was a very interesting meeting and they provided advice on what should be going into our transition plan with the hope of getting funding until December 2015.

Our June function was a great success. Our guest speaker Cindy Gallois was very down to earth and gave us plenty of ideas on how we can cope with MG. The DVDs have been posted to all our current financial members this week. I hope you enjoy this informative talk as much as we did.

Thank you to our Coordinators Donna Formosa from Cairns and Bill and Muriel Harris from Mackay for attending the meeting. It was good for our Brisbane region members to be able to put a face to their names. Thank you also to our regular members and our new members for attending. Hope to see you all again.

The next function is the AGM in September which will be held at the Southern Cross Sports Club at Mt Gravatt. Our guest speaker will be Dr Rob Henderson so this promises to be another excellent presentation.

We have received confirmation from the NSW Association that they are willing to join with us to form a National Alliance. The Association looks forward to progressing this further.

The committee is busy planning the future of the Association and how we can survive without funding from Queensland Health.

Take care,
Anita

Supported by



SURVEY UPDATE

Collecting data on sufferers' of myasthenia gravis:

Given that the survey allowed sufferers to tell what is often a very long story, many participants took the opportunity to tell a very detailed story in the hope that some obscure piece of information may be useful. The Doctors have appreciated this and recorded the brief and the lengthy answers to questions. As a result there is interest in analysing this qualitative information. How to do this would be very challenging but it is being considered.

It has been raised that these more detailed stories should be shared amongst the MG community for greater support. Professor McCombe is aware of a booklet compiled by Multiple Sclerosis patients highlighting life with MS. The selections of stories are individually told and as a result the stories show just how different each journey can be. The stories share not only the medical journey but also, in part, the emotional journey. The booklet has proved invaluable to patients. Clearly, the MG journeys also differ greatly. Professor McCombe would like to support us in compiling a range of MG stories with the subsequent production of a booklet. The MGAQ Committee would be available to assist in developing and publishing such a book and has some experience in this process. However, the committee does not have the skills or the time to actually compose the stories. Can you help us find a suitable author? Some experience in writing would be required. Please use the website www.mgaq.org.au or the free call number 1800 802 568 if you can help us get this task underway.

MEMBERSHIP RENEWAL

As the receipts need to go to Townsville for the secretary to action, there will be some delay in members receiving them.

REGIONAL COORDINATOR VACANCIES

Currently there are vacancies for the position of Regional Coordinator for North (Sunshine) Coast, Wide Bay/Burnett and Rockhampton regions.

With the impending cessation of funding to the MGAQ from Queensland Health, the role of Regional Coordinator will take on an increased importance as the conduit between our members in the regions and the Management Committee.

The role of Regional Coordinator includes: maintaining regular contact with the members in the respective region, usually by means of regular (say 3 to 4 monthly) get-togethers; dissemination of MGAQ Information Booklets and Pamphlets throughout the region; and bringing concerns or suggestions from local members to the attention of the Management Committee.

The Management Committee would like to hear from members (or carers) who are interested in taking on the role of Regional Coordinator in any of the abovementioned regions via an email to info@mgaq.org.au or a phone call to our Freecall 1800 802 568 number.

- I have learned that children and grandparents are natural allies.

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 - BRISBANE

TERRY / JUDI	3824 4158	ALEXANDRA HILLS
JESSICA	3369 8315	BARDON
JOHN	3269 5066	BRIGHTON
THOMAS	3386 1918	BEENLEIGH
CLIVE	32617564	BRACKEN RIDGE
EILEEN	3269 5660	BRIGHTON
KENNETH	0414525241	CAMIRA
GWENDA	3390 2643	CAPALABA
CAROL	33901788	CAPALABA
LORRAINE	3206 0789	CLEVELAND
PETER	3821 4725	CLEVELAND
PATRICIA	3207 0456	COOCHIEMUDLO ISLAND
PAM / RAY	3801 5347	CORNUBIA
HELEN	3203 0150	DECEPTION BAY
STEFAN	3807 0541	EAGLEBY
NORMA	3281 5079	EASTERN HEIGHTS (IPSWICH)
KIRSTIE	0408311110	EATONS HILL
CAROL	3341 0707	EIGHT MILE PLAINS
DENNIS	38559379	GAYYHORNE
ROGER	3379 8916	GRACEVILLE
JOHN	3899 9387	HAWTHORNE
LEILANI	0448192521	INDOOROOPILLY
DANIELLE	3202 2509	IPSWICH
HELEN	3279 3060	JAMBOREE HEIGHTS
PENNY	0415613242	KANGAROO POINT
GEOFFREY	33556441	KEPERRA
CARLY (14 years old)	3354 3014	MITCHELTON
PATRICIA	38867802	NARANGBA
SUSAN	33581056	NEW FARM
KEVIN	32819225	NEWTOWN
BILL & JITLADA	33997041	NORMAN PARK
PATRICIA / LES	5464 6719	PURGA IPSWICH
TRACEY-LEE	32849949	REDCLIFFE
SYBIL	3219 9535	ROCHEDALE
CATHERINE	041851110	SPRINGFIELD LAKES
POPPY	3288 4484	SPRINGFIELD LAKES
MARIE	3300 0053	THE GAP
JAMES	0433662913	WYNNUM
JOHN	3633 0604	ZILLMERE

FUTURE PLANNED ACTIVITIES

14 Sept - AGM - Southern Cross Sports Club. Guest Speaker Dr. Rob Henderson (see page 7).

14 Dec – Christmas Function Brisbane venue TBA

CAIRNS GET TOGETHER

Cairns' Group acknowledged June as Myasthenia Gravis Awareness Month with Maxine telling her MG story on ABC Radio Cairns. Two weeks later, Anne was also given the opportunity to explain her condition of MuSK on ABC Radio Cairns. We are hoping that this will raise the Awareness of MG in the Cairns region.

Our get together at the RSL Club on Saturday 22nd June was well attended by our members. Our guest speaker was Gail Rogers, Speech Language Pathologist who explained her role with helping people with chronic illness. I received some good feedback on this presentation.

Meetings are held at the RSL Club Boardroom, Esplanade Cairns at 11.00am. Some people stay on for lunch in the restaurant afterwards (own expense)

Saturday 16th August at 11.00am

Saturday 11th October at 11.00am

Saturday 6th December at 12.00 noon for our Christmas Lunch get together

Donna Formosa – Cairns Coordinator - Ph. 0414 397462 or email formosed@bigpond.net.au

NEWS FROM MACKAY

Our lunch, get together was held at the Harrup Park Country Club. Those attending enjoyed themselves. The intended guest speaker was unable to attend as a member of her family had health problems but advised she will attend our next get together. Muriel Harris stepped in and gave a talk on handy hints that will assist in daily life.

Our attendance was down, as one family suffered the loss of a family member in a traffic accident the previous week. Those attending signed a sympathy card.

It was decided our next get together will be held at:

North Mackay Bowls Club Sunday 31/ 8/2014 for lunch at midday

Bill Area Coordinator – Phone 49541221

- I've learned that the more creative you are, the more things you notice.

TOWNSVILLE GROUP

A get-together for the Townsville group is planned for **Saturday 26 July, 12 noon** at The Avenues Tavern, Kern Brothers Drive. Rosie Miacle, the nurse in charge of the Ambulatory Care Unit at the Townsville General Hospital, will be in attendance. Many locals will know Rosie and her wonderful team who administer the infusions to MG sufferers. Rosie will be available to discuss and answer general questions. She cannot, however, discuss or answer questions about specific individuals' medical concerns.

We will also discuss the list of matters outlined on page 2 of the April newsletter, which could be considered as part of our Transition Plan.

Please phone, SMS or email Carol (0418748849, c.buchanan@bigpond.com) to let me know if you can attend. Looking forward to seeing as many people as possible because, as well as being lucky to have Rosie attend, the conversation and 'stories' shared by people who attend are most worthwhile.

Correction to item in June Newsletter:

NOMINATIONS FOR MANAGEMENT COMMITTEE FOR 2014/2015

The following nominations have been received and accepted by the nominees, for positions on the MGAQ Management Committee:

President	Anita Jackson
Vice-President	John Noble
Treasurer	Susan White
Secretary	Carol Buchanan
Committee Members	Shirley Johnston

There were no nominations received for the remaining two (2) Committee Member positions and in accordance with the MGAQ Constitution, nominations for these positions will be called for from the floor at the Annual General Meeting.

D.V.D. REVIEW: CINDY GALLOIS – LIVING WITH CRONIC ILLNESS

Cindy spoke with a view to supporting the "Daily Living" information section of the MAGQ information booklet.

She emphasised how important it is to be the person one wants to be and not to be defined by the condition. She assured us all that every response is normal and part of the process and that personal variation in how we approach the situation before us is usual and correct. She reminds us that "Life is a Process of Reinvention" and that it is important to communicate well through these processes and to keep a good sense of humour, never giving up hope. She spoke about working with one's personal support team and in particular your health professionals.

- I have learned that enthusiasm is caught, not taught.

MEMBERS FORUM

Shirley writes:

Symptoms to be aware of for Myasthenia Gravis – droopy eyes (maybe only one) – muscle weakness, such as difficulty in holding arms up for any length of time and using pressure when writing – chewing – swallowing – speaking – breathing and weakness in legs.

To be fair all these symptoms were very subtle at first and came on separately. Dealing with one at a time made diagnosis very hard and took three years to diagnose. All these symptoms can come together and it does make diagnosis much easier.

My eye specialist at the time made a routine check of my eyes and said he thought I may have Myasthenia Gravis and that it was “as scarce as hen’s teeth.” I then went back to the G.P. and he referred me to a neurologist. I had a tensilon injection at the Royal Brisbane Hospital and that confirmed my condition. (1976)

Because my symptoms were fairly mild at that stage I was treated with 3x60 mgs of mestinon a day and for a period of time I could not believe how well I felt. However it did not last. I gradually crept up on medication and had a few trips to the hospital to stabilise the condition. At no stage was I happy with my neurologist, so I started “shopping around.” It was not only for a neurologist, it was for anyone who would listen to me. The time came for another eye test and the doctor asked me how my Myasthenia Gravis was and through my tears I told him it was terrible and I would try anything, even going interstate. He then said “you don’t have to do that, there is a bright young bloke just arrived from Sydney”. I then went back to the G.P. for a referral to another neurologist.

My husband Nev and I entered his surgery at 4pm and departed at 7pm. He explained all the possibilities and then said he would like me to go to Sydney and see the “guy” he trained under. That was the start of a long journey. He also told me I should have had a thymectomy three years prior and it would be advisable to have one as soon as possible.

Off to Sydney I went and saw this neurologist and arrangements were made to return in two weeks for a thymectomy. Back to “Page 8” at the Prince Alfred Hospital on the 5th August 1979 and operated on a couple of days later. After surgery I could chew, hold my arms up and speak without slurring (not all perfectly but a bit better). I was told that was because the antibodies were startled for a while and then became active again.

I had my 45th birthday in “Page 8”. My daughter Cheryl surprised me coming from a working holiday in New Zealand and we both flew home to Brisbane two weeks after the thymectomy.

After I had been home a short while all the symptoms kept coming back and my Brisbane neurologist admitted me to Princess Alexandra Hospital and I stayed there until almost Christmas, in I.C.U. or the neurological intensive care.

In the first stages of admission to P.A. hospital it was not known if I was under or over dosed with mestinon as the symptoms are the same so it was decided to give me plasmapheresis. That was an experience as I had an allergy to the first infusion.

Then I was taken off mestinon and dosed with 100mg. of prednisone and was on it for eleven years. During that time the prednisone was decreased twice and then going back to smaller doses.

The third time was a success and I have been in remission without medication for Myasthenia Gravis for almost 24 years.

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 make 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.

FUNNY QUOTES

A successful man is one who makes more money than his wife can spend. A successful woman is one who can find such a man.

Lana Turner

A word to the wise ain't necessary – it's the stupid ones that need the advice.

Bill Cosby

Wine is God's constant proof that he loves us and loves to see us happy.

Benjamin Franklin

Do not take life too seriously. You will never get out of it alive.

Elbert Hubbard

A woman's mind is cleaner than a man's. She changes it more often.

Oliver Herford

2013/2014 ANNUAL GENERAL MEETING

- WHEN:** Sunday 14th September 2014 at 10:00am for 10:15am sharp
- WHERE:** Southern Cross Sports Club, Corner Klumpp and Logan Roads, Mount Gravatt (vehicle entry to club is via Klumpp Rd.)
Lunch is available at the venue with a varied and reasonably priced menu.
Tea and coffee will be available prior to the meeting.
- GUEST SPEAKERS:** Dr. Rob Henderson – Neurologist at Royal Brisbane Hospital
- WHAT DO I NEED TO BRING?** Yourself and whomever else you wish to bring along – the more the merrier.
- HOW DO I GET THERE?** UBD Map 201 Reference D7.
Ring our FREECALL 1800 802 568 and tell Shirley if you are coming, how many, and if you are staying for lunch.
- RSVP:** Please let her know by **Friday 5th September 2014**

SUBSCRIPTION RENEWAL TIME

It's that time of the year again when Membership Subscriptions for the financial year 2014/2015 are due. Membership Fees are the same as last year.

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. If you receive the newsletter by email and are unsure whether or not you are currently financial, please ring our 1800 802 568 freecall number to enquire.

The majority of members will have 6/14 which tells you (and us) that you are financial to 30 June 2014. Others may show 6/15 or even 6/16 to indicate they have saved time and postage by paying in advance. However, there are others whose envelopes still show 6/13, 6/12, etc. and we continue to send our newsletter to these unfinancial members because we do not know what they want. **If you are unfinancial, 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".**

LIFE MEMBERS and PAID-UP LIFE MEMBERS do not pay further subscriptions.

We are also giving you the option of paying your subscription directly into our bank account. Our bank details are:

BANK: Bank of Queensland
BSB: 124 032 **ACCOUNT NUMBER:** 10263772
ACCOUNT NAME: Myasthenia Gravis Association of Qld Inc.
REFERENCE: Your Name & Initials

If you use the direct deposit method, it would help if you could email us at info@mgaq.org.au to advise that you have paid directly into our bank account and the date of the transaction. This will assist the Treasurer in reconciling with the Bank Statement.

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Tear off along this line

If you wish to pay by cheque or Money Order, please use the following form and forward to:

The Myasthenia Gravis Association of Queensland Inc.
PO Box 16
MT GRAVATT Qld 4122

Herewith please find my cheque / money order / cash for the sum of \$ _____ being annual subscription \$ _____ and/or Donation \$ _____:

NAME: _____ **Category A – Myasthenic \$15**
Category E – Supporter \$15

ADDRESS: _____

AND FOR: _____ **Category D – Carer \$5**

ADDRESS: _____

Your receipt will be forwarded to you with the next available issue of "MessaGes" following receipt of your payment. If you do not receive your receipt, please ring us on the toll free number 1800 802 568.

We thank you in anticipation of you renewing your membership.