



Messages

Myasthenia Gravis Association of Queensland

September 2015



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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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Neurologist
Founder Member, of Brisbane

PRESIDENT'S REPORT

Welcome

The AGM has been held this month and our Guest Speaker Prof Pamela McCombe did a very informative talk about the history and also the different medication for Myasthenia Gravis. It was great to see so many new members and hope they gained valuable information about the disease and they will be back to visit for the next function. It is good to see our members who keep coming to each function and supporting the Association as we have become like family to you all.

I would like to thank the coordinators who have made the effort to travel to Brisbane and to attend the AGM as well as our committee meeting hoping they have enjoyed themselves. It was certainly a privilege to meet you all.

I would like to welcome back Graeme Peters to the position of President and also our new member Tracey Porter as Treasurer and also all the committee members who have taken on their positions for another term. It will be another exciting term and looking forward to working with you all.

I would like to thank Emily Sexton who is our editor of the Newsletter for the past 12 months. Emily is a University student who is presently studying Creative and Professional Writing and she has Myasthenia Gravis.

The next future function is the Christmas Party on 13 December 2015 at the Power Boat Club in Caloundra at Golden Beach for midday. Looking forward to seeing you all there as it is a very relaxing spot and the food is excellent.

Take care

Anita

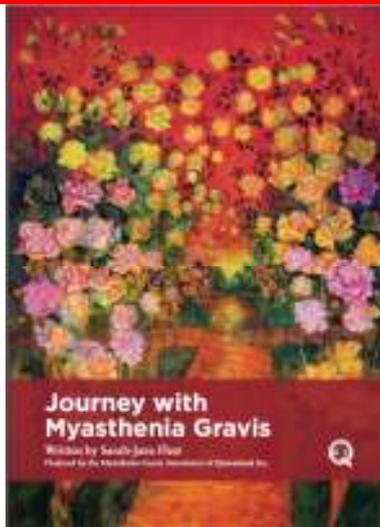
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PROJECT UPDATE**SURVEY STATUS**

Enquiries for the survey continue to come in. This means that more and more people are aware of the Association and the opportunity for support if it is required. It has been a very busy year with the Conference and other initiatives designed to raise awareness of MG. Promotion of the Survey and the work of the Association will continue over the next few months so it is hoped you will see further news items appearing. If you think your local newspaper or radio station would be interested in publishing/producing a story, this help would be appreciated. Please let us know via the Freecall number 1800 802 568 and we will follow up. Again, do remember to mention the survey to other MGers you may meet when having your treatments, visiting the doctors, gathering socially or chatting on-line.

"JOURNEY WITH MYASTHENIA GRAVIS" - A BOOK BY SARAH-JANE FLEER

The Association is close to providing an on-line purchasing option using the website and Paypal. This would allow interested people who are overseas an opportunity to purchase the book too. The stories are universal in their experiences so it would be wonderful to help so many. Of course, this will make it even easier for locals to order too. The Honourable Cameron Dick, current health minister for the Queensland Government, has been made aware that a copy of the stories is available to him via the Parliamentary library. It is available to all the State politicians. Let's ask our local members if they have taken advantage of the opportunity!

MYASTHENIA ALLIANCE AUSTRALIA

Myasthenia
Alliance Australia

The Alliance Committee is currently following up on several projects and expects to issue updated alerts closer to Christmas. The Australian Blood Bank contracts for obtaining plasma are to expire at the end of the year. News regarding the new contracts is not yet available. This situation is being

monitored. A project for the new year is to make contact with existing overseas Associations. Options for collaborative work will be discussed. It is expected that this enquiry will be well received as the Alliance website

www.myastheniaallianceaustralia.com.au is proving popular with international browsers.

MYASTHENIA ALLIANCE AUSTRALIA CONFERENCE UPDATE

The third speaker at the June conference was Dr Sean Riminton and his topic was "Safety and Risk Management with Immunotherapy". Associate Professor Sean Riminton MBChB(Dist), PhD, FRACP, FRCPA is a Clinical Immunologist at Concord and Royal Prince Alfred Hospitals in Sydney and Clinical Associate Professor with the University of Sydney. He established the

Neuroimmunology service with A/Prof Stephen Reddel at Concord Hospital with the aim of translating the advances in interventional immunology to neuroinflammatory disease.

Dr Riminton explained that antibodies are produced by the thymus gland, the spleen, the lymph system and in the bone marrow. Generally antibodies are helpful in fighting disease but sometimes antibodies are made that attack parts of the body and cause harm. In managing these rogue antibodies and the damage they do it is important to control the disease whilst creating minimal risk to the patient. Immunosuppression therapy aims to 'retune' the immune system. Modern techniques try to customise the range of medications prescribed.

He defined "Remission" as being with disease that is 'relatively unimportant' or 'quiet'. Achieving remission is distinct from being cured. When remission is achieved the aim is to use milder doses of treatment to stop actual illness. Therefore, his treatment targets are aimed at achieving MG Control, having no impact from side effects and thirdly getting Prednisone doses at 7.5mg per day or less. Eventually it is hoped that medication can be ceased.

He listed twelve things to do to help yourself:

1. Take medicines carefully as instructed.
2. Ask questions/challenge/get feedback.
3. Keep a list of current medications and doses and carry it with you at all times.
4. Be aware of possible side effects.
5. Manage possible side effects before they become unmanageable eg. osteoporosis.
6. Manage your diet, particularly if you are on steroids.
7. Be aware that steroids should not be stopped abruptly.
8. Do not smoke.
9. Be as active as you can.
10. Keep up to date with vaccines eg. 'flu.
11. If applicable, discuss your fertility with your specialist.
12. Have a thermometer and a fever plan (+38 degrees seek medical advice).

He discussed the importance of risk evaluation when prescribing treatments. A website has been developed which allows patients to assess and track their own levels of risk. It is free to use and provides a problem list and a task list. It suggests things that can make a difference and thus make your treatment of the disease better. A report will be sent via a variety of technologies. The web address is www.immunosuppressionscreen.net.

He reminded delegates that MG is a treatable disease but treatments do involve risk and should be managed across a range of professionals in a team approach. The goal is to achieve balance in life. Stress does not cause disease but it can upset the balance!

FUND RAISING!



The Association has registered with Give Now for online fund raising donations with the hope of people or businesses donating to our Appeal. Please take a look at this site and advise anyone who may be interested in donating or gifting through his or her Will to the Association.

<https://www.givenow.com.au/myastheniagravisassociationofqld>



FACEBOOK MGAQ DISCUSSION FORUM

A closed discussion forum has been setup for the MGAQ that allows for private discussion between members of the Facebook group. We encourage all our members to join in the discussion. Please visit: <https://www.facebook.com/groups/mgqld/>

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 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 possible. Your call is valuable to us, so please do not hang up without leaving a message, the phones rings for a while before the machine comes on.

MGAQ SUPPORT LINE 1800 802 568

CHAT LIST – QUEENSLAND REGIONAL COORDINATORS

DONNA	0414 397 462	CAIRNS
DEBBIE (Taroom)	4628 6103	DARLING DOWNS
BILL	4954 1221	MACKAY
JEANNE	0437 048 361	ROCKHAMPTON
COLLEEN	5493 6391	SUNSHINE COAST
DAPHNE	4773 3695	TOWNSVILLE
GARTH (Gladstone)	4973 7983	WIDE BAY/BURNETT
JANET (Hervey Bay)	0429 622 438	WIDE BAY/BURNETT

CHAT LIST – QUEENSLAND REGIONAL

DAVID	5594 0489	ARUNDEL
KELLY	4728 4913	AITKENVALE
JOHN	4783 1556	AYR
YVONNE	4783 4643	AYR
MARK	0427 717 645	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
PETER	4057 9905	CAIRNS
OWEN	4742 1190	CLONCURRY
BARRY	5483 1783	CURRA
JOHN	0419 624 767	COOMBABAH
GAIL	0407 514 241	COOROIBAH
GLORIA	5534 2669	CURRUMBIN
MELISSA	4662 3337	DALBY
MARSHA	4987 6820	EMERALD
GARTH	4973 7983	GLADSTONE
ELIZABETH	4936 2410	GLENLEE
LILLIAN	4933 4281	GRACEMERE
ANGELA	0427 752 956	HOPE ISLAND
JAMES / ROSEMARY	5530 1558	HOPE ISLAND
CHRISTOPHER	0412 456 439	LABRADOR
KAREN	0408 153 285	LOWOOD
TERRY	5494 2470	MALENY
RAYMOND	0407 724 467	MILLMERRAN
CAROLYN	5522 8987	MUDGEERABA
JOY	4165 4647	MUNDUBERRA
KEITH	5441 7236	COES CREEK, NAMBOUR
KARLIENE	0432 431 591	NANANGO
DAVID	5474 5534	NOOSA
DENISE	5545 0645	NORTH TAMBORINE
MAUREEN	0411 331 258	PACIFIC PINES
JUNE	0409 636 467	PALM BEACH
RICHARD	0418 249 640	PARFADISE POINT
SCOTT	5446 3894	COOLUM BEACH
TOM / SCOTIA	4693 3730	PITTSWORTH
BILL / COLLEEN	4926 2410	ROCKHAMPTON
JEANNE	0437 048 361	ROCKHAMPTON
DONALD	5563 7207	RUNAWAY BAY
SHIRLEY	5443 1728	SUNSHINE COAST
DEBORAH	0457 148 486	TAROOM
BERNIE	Joypaul28 *	TEWANTIN
BETTY	4635 6270	TOOWOOMBA
DIANNE	4638 8447	TOOWOOMBA
SUNSHINE	0487 365 363	TORQUAY
CAROL	47737122	TOWNSVILLE
DAPHNE	4773 3695	TOWNSVILLE
HEATHER	0538 743 234	TOWNSVILLE
LUCY	0418 879 801	TOWNSVILLE
JO	4723 8721	TOWNSVILLE
SERAFINA	4751 6415	TOWNSVILLE
RONALD	0428 826 180	TOWNSVILLE
ANNE	0487 305 153	TRINITY BEACH
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

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via the VOIP Skype facility on
a computer



Around Queensland

News from Cairns

At the get-together in August, our speaker was Judy O'Donahoo, an Accredited Pharmacist of Medication Reviews and Information. Judy's presentation and Q&A was well received by those who attended. We meet again on Saturday 17th October at the Cairns RSL Club in the Boardroom at 11:00am.

Donna Formosa
Ph: 4039 2148 or M: 0414 397 462

News from Darling Downs

Living my earliest years in Brissy and completing my Enrolled nursing, I travelled extensively and ended up doing a nursing contract in Taroom. Loved it, met my hubby and stayed. I have 2 daughters and a son. We live on a cattle property at Taroom. I have recently taken on Regional Coordinator for Darling Downs, and will embrace this with the positivity and enthusiasm I have used to cope with my diagnosis of MG after initially being diagnosed with MS incorrectly, about 11 years ago. My aim is to embark on a role to be able to support and become friends with MG sufferers in this Region. I am very excited to be able to help the Association as much as I can. Heading to the meetings next weekend in Brissy. I will update any regional news as I better understand my role.

Debbie
Ph: 4628 6103

News from Rockhampton

My name is Jeanne Harp and I have recently accepted the position of Regional Co-Ordinator for the Rockhampton area.

I am 50 years old and live with my husband Blair and our four children- two daughters and two sons- in Norman Gardens Rockhampton.

I believe I may have begun to get MG symptoms after the birth of my second child. The symptoms of voicelessness, eyelids being unable to lift, being unable to walk upstairs, being unable to hold up my arms, choking, breathlessness and muscle weakness etc persisted undiagnosed (though depression and chronic fatigue were considered) and became more severe. However it was not until two years ago when I was at the Royal Brisbane Hospital that the Endocrine surgeons when examining me for thyroid surgery also recognized the symptoms of MG and referred me to the neurologist there who diagnosed me with MG and I began Mestinon, then Prednisone, then Methotrexate.

I am a primary school teacher and am fortunate enough to teach in a school community that is supportive and flexible with MG as it fluctuates. My husband was a local State School Principal until recently but has recently taken up a Principal's position at the school where I teach to be near me and support me if I'm unwell.

As a family it has been quite the journey and though difficult and emotional at times we have grown stronger together as we managed to adapt to changes in my health.

Please feel free to call me on my mobile 0437 048 361.
Jeanne Harp

News from Townsville

Townsville MG Lunch – Saturday 17th October at the Avenues Hotel Kirwan, Townsville at 12noon.
RSVP to Daphne – 07 4773 3695 or 0400 778 637

NEW MEMBERS

We welcome the following new members:-

Lachlan – Jindalee
Ute – Diddillibah
Kim – Gladstone
Kerrie-Lee – Mooloolaba
Tracey – Northgate

MEMBERS' FORUM

Please note that names have been changed in the following member contribution.

The Trail and Trials with MG and Neurologists

By Trevor

Myasthenia Gravis, To Be or Not To Be, A questions that many MG suffers go through I suppose. I recently had the misfortune or fortune of having to change my Neurologist. I was booked in for a consultation on the Monday, don't know exactly why, I decided on Friday I should phone to confirm my appointment.

A little taken back when all I got was an answer machine, advising me to call 000 if it was an emergency, that Neurologist 1 had retired. There were a couple of words I couldn't understand and an email address. So I sent an email asking if my records were sent to my GP, I received no answer.

One would have thought a letter, email or phone call to the patient, cancelling the appointment and advising you to contact your GP for a referral would not have been too much to ask for, but nothing. I could not believe it. It more or less confirmed the not so nice things that I had been told about Neurologist 1, I suppose we live and learn.

So off to my GP for another referral. He referred me back to a Neurologist (Neurologist 2) I'd saw about 10 years ago, who diagnosed me with Peripheral Neuropathy. My GP warned me that there are times when Neurologists don't always agree with each other, that he might tell me its not Myasthenia Gravis but something else. My GP also said that it could turn out to be a good thing, as there are many symptoms I have that still have not been explained.

My GP was right on the Neurologists not agreeing. Neurologist 2 said it wasn't MG but Peripheral Neuropathy (Interesting Neurologist 1 told me that I didn't have Peripheral Neuropathy but I had Restless Leg Syndrome) Then Neurologist 2 said to phase out the Mestinon and Prednisolone and come back for a Nerve Study. The Nerve Study showed no changes in the last 10 years, so he said he wanted me to see another Neurologist (Neurologist 3) who specializes in Nerve and Muscle Diseases.

Now comes the really interesting part. Two days after I finished the medication, I got out of bed one morning, took off my CPAP Mask (Sleep Apnea) and my breathing went downhill and energy levels dropped badly in about 20 to 30 minutes. I thought this might be the Myasthenia Crisis I had read about, so I wondered if I should go in to Emergency, but as it was close to opening hours at the Neurologist 2's, I decided to wait and phone him, if it didn't get any worse.

When I got through to him I told him what was happening and that I wanted to go back on the medication until I saw Neurologist 3. He agreed, so I asked if I should go back on the medication slowly or straight back to the usual dose. At first he said the usual dose, then said no to double it and see what happens. Well at this point I thought no, I'll go back to my usual dose first and then

increase the dose.

This I believe was a good decision, as the day after starting back on the Mestinon I had a mild dose of the trot's, a side effect I never had when starting Mestinon.

There is actually a very big plus to all this.

On the double dose, I've improved out of sight. I'm the best I've been in years, back to my morning walks, added 10 laps to my swim 3 times a week. So it would now appear that I was on a far too low dose of Mestinon. It was only just keeping my head above water so to speak.

Neurologist 3 was quite good, apologized when he said he wanted to do all the Nerve Studies again, but I said that's fine. He did a far more extensive study that I had with Neurologist 1 and Neurologist 2. Towards the end of the consultation he said to stay on the Mestinon as it was obviously working, the study and tests show that I have Seronegative MG, unfortunately he said I didn't need to see both him and Neurologist 2, so just stick with Neurologist 2 and he would send him and my GP his findings.

Damn! I was just about to ask if I could stay with stay. But I thought he may already have too many patients.

Flowing on, my next visit with Neurologist 2 was interesting to say the least. There was no apology for taking me off the medication and causing a Crisis and no further discussion about the Peripheral Neuropathy he said I had.

When he had said in my first consultation we'd probably go to IVIG (I guess this is used in Peripheral Neuropathy) no more discussion of how bad Mestinon was or the IVIG, just changed me from Mestinon 2/60 ml three times a day. Two Mestinon Timespan. Said if it didn't work or I didn't like it go back on the 60 ml and come back in 12 months?! Well, at this point I was over him, I'm going to get my GP to refer me to Neurologist 3.

Even though this will mean driving from Uki NSW to Brisbane, although that shouldn't be too bad, probably being only twice a year once settled on the outcome with Neurologist 3.

The Timespan didn't work as well as the 2/60 grams 3 times a day, come night time I was really hanging out for the next dose, so I'm back on the 2/60 3 times a day and doing well.

I now have an appointment with Neurologist 3 so I am looking forward to that.

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.

Easy Date Slice

- Combine 2 cups SR flour - 1 cup brown sugar - and 125 grams slightly softened butter. This can be done in the blender.
- Press half of mixture into lamington tray lined with baking paper - Add 1 cup finely chopped dates - 1 beaten egg and 1 cup of milk to remaining flour mix.
- Spread and press on top of base. Bake in moderate oven (180 degrees) for about 25 minutes.

