



# Messages

Myasthenia Gravis Association of Queensland Inc

**DECEMBER 2012**



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.

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Founder Member, of Brisbane

## **PRESIDENT'S REPORT**

### *Welcome*

We had a very informative meeting with Dr. Joanne Pink from the Red Cross Blood Service where many questions were asked about IVIg and the members concerns were answered. I would like to thank Dr. Pink for giving up her Sunday for our members and explaining it to us so that we could all understand even though some of us do not have this treatment. A special thank you goes out to member Gail Hornby who did a lot of research and followed through so that we were able to organise this meeting. The full report of the meeting is on page 5 of this issue.

The Christmas party at the Power Boat Club in Caloundra was a great success. Many members travelled from the Gold Coast and I would like to thank them for making the extra effort. The weather was perfect for sitting and looking out over the Pumicestone Passage and watching the wild life and the boats pass by. We all enjoyed the company of our members and their families and catching up on our MG life stories and of course the food was excellent.

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

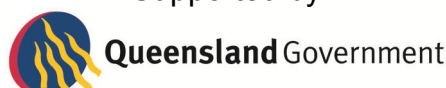
Our first function of next year will be the picnic at North Pine Dam in March 2013 so please mark it on your new calendars and hope to see you there.

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 2013.

Take care

*Anita*

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## **PROJECTS UPDATE**

### **Collecting data on sufferers of myasthenia gravis –**

As highlighted in the last Project Update, the response to our survey has been overwhelming and the Medical Fraternity are keen to explore some of the statistics further so to assist we say again that we want more sufferers (especially younger ones) to complete the questionnaires. If you can spread the word please do.

We are also quite excited by the idea of publishing a small book to tell of sufferers experiences with the condition and would love to hear from anybody interesting in helping with this project. This would be more about the qualitative findings of the survey whilst the Doctors investigate the hard statistics.

As everyone agreed, there were many interesting points in Doctor Blum's presentation and these will be explored further in the "Survey Snippets" item below.

### **'Exercise Effect in MG' Pilot Study –**

#### **EXERCISES AT HOME**

Doctor Jennifer Nitz, who conducted the 'Exercise Effect in Myasthenia Gravis' Pilot Study at the University of Queensland's Neurological, Ageing and Balance Clinic, has kindly provided the Association with a booklet entitled '*Preventative Health – Exercise for your Bones, Strength and Balance.*'

The booklet details exercises which closely match those which were undertaken by participants in the abovementioned Study and are such that they can be undertaken by people in the comfort of their own home.

Each copy of the booklet comes with Cautionary Notes which should be read and understood before commencing any of the exercises.

Copies of the booklet are available, in either hard copy or electronic form (pdf), to current financial members. Those members wishing to obtain a copy should contact the Association on our Freecall number 1800 802 568 or via email at [info@mgaq.org.au](mailto:info@mgaq.org.au) and state whether you prefer hard copy or email copy.

Copyright of the booklet remains the property of Dr. Nitz and the University of Queensland and should not be reproduced in any form without their express permission.

Also, if you have a try at these exercises and feel that you would like to undertake the complete set as part of the Exercise Study Project, and therefore contribute to the Study findings, please contact the Secretary on (07) 32884484 or via email at [info@mgaq.org.au](mailto:info@mgaq.org.au)

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### **"SURVEY SNIPPET"**

#### ***Auto-immune connection.***

The survey showed that 54% of MG sufferers have at least one other auto-immune condition and 39% of sufferers have other family members with an auto-immune condition.

Examples of the respondent's conditions included Psoriasis, Rheumatoid Arthritis, Thyroid Disease, Vitiligo, ITP, Type 1 Diabetes Mellitus, Coeliac or Crohn's Disease and Pernicious Anaemia.

These high figures were clearly of interest to the doctors and may help explain some of the variations we all experience.

Are you interested in telling of your experience with multiple auto-immune conditions? We would love to hear from you in the Members' Forum.

**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**

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**

KELLY	4728 4913	AITKENVALE
JOHN	4783 1556	AYR
YVONNE	4783 4643	AYR
MARK	4067 1784	BABINDA
LYNDA	4159 2890	BARGARA
JOHN	4959 5492	BAKERS CREEK
SARA	0422 109492	BLACK RIVER
HENRY	4982 6507	BLACKWATER
KELLY	4782 5542	BRANDON
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
BARRY	5483 1783	CURRA
GLORIA	5534 2669	CURRUMBIN
MELISSA	4662 3337	DALBY
GARTH	4973 7983	GLADSTONE
ELIZABETH	4936 2410	GLENLEE
LILLIAN	49334281	GRACEMERE
SHIRLEY	4128 3596	HERVEY BAY
ANGELA	0427752956	HOPE ISLAND
JAMES / ROSEMARY	5530 1558	HOPE ISLAND
SERAFINA	4751 6415	JENSEN
CHRISTOPHER	0412456439	LABRADOR
JUDIE	0439 461288	MACKAY
TERRY	5494 2470	MALENY
MAUREEN	5572 7993	MERMAID BEACH



## **MEETING WITH DR PINK SUNDAY 11 NOVEMBER 2012**

Over 20 people attended a meeting with Dr Joanne Pink to discuss the use of IVIg in the treatment of Myasthenia Gravis and the range of immunoglobulin products used.

IVIg is a protein produced by the cells of the immune system in response to something that the body sees as being foreign, such as bacteria or viruses. The immunoglobulin helps fight off the infection. Intravenous immunoglobulin is a pool of different immunoglobulins. It is made from plasma – the yellow portion of blood. The plasma is sent to CSL Biotherapies in Melbourne, the only company in Australia that makes immunoglobulin. They pool the plasma into 10 000 litre batches and use a process called fractionation which allows different parts of the plasma to be separated out. The process also has viral inactivation steps which kill off or remove viruses. CSL can extract about 5gm of Intragam P from a litre of plasma. Plasma from about 20 whole blood donations or 7 plasmapheresis donations are required to produce an average therapeutic dose of Intragam P of 27 gm.

Since the 1980's the demand for IVIg has greatly increased both internationally and in Australia, most recently about 10% per year. Approximately 7% of the total IVIg is used to treat patients with MG. MG is classified within the top 10 according to the Criteria (see below). In the late 1990's, worldwide shortages prompted action by the Australian Government to ensure that IVIg is available for those patients most in need. Since that time, strategies to ensure supply have included:

- Ensuring that IVIg is used appropriately – developed a criteria book “Criteria for the Clinical Use of Intravenous Immunoglobulin in Australia” first published in 2007 with the second edition in July 2012;
- Increasing the manufacture of IVIg in Australia;
- Importing IVIg from overseas. Australia has been importing product for about a decade and the percentage of imported product is gradually increasing – now about 2/3 Intragam P and 1/3 imported. The government is aware of the need to have a contingency plan of imported product in the event there is some domestic ‘disaster’ (eg the CSL manufacturing plant malfunctions or some new infection gets into the Australian population).

### **1. Assessing the Effectiveness of IVIg Use**

IVIg should be used for three to six months before determining whether or not the patient is responding. If there is not any benefit after this time, IVIg therapy should be abandoned.

Regular review by a neurologist is required and this is determined by the clinical status of the patient. Initial review should be three to six monthly. For stable patients on maintenance treatment, review by a neurologist is required at least yearly.

Clinical documentation of the effectiveness of IVIg is necessary for the continuation of IVIg therapy. Effectiveness can be demonstrated by the improvement in fatigability and weakness.

Dose for maintenance is usually 0.4 – 1gm per kg of the patient's weight administered each 4-6 weeks. The aim should be to use the lowest dose possible that achieves the appropriate clinical outcome for each patient. In some cases, a smaller dosage may be of greater efficacy. When first introduced, before surgery or during a myasthenic crisis the dose is increased to 1-2gm per kg in 2 to 5 divided doses.

### **2. Imported IVIg Products and Domestic Products**

All plasma products, whether locally manufactured or imported from overseas need to be assessed and approved by the Therapeutic Goods Administration (TGA) before they can be used in Australia. The TGA regulates the safety, quality and efficacy of all IVIg products as well as conducting comprehensive ongoing monitoring of these products. The TGA requires the sponsor company to submit updated post-marketing safety data at regular intervals for the first three years after registration. After this period, the sponsor is required to keep the TGA informed of any significant safety issues that arise with the product. The TGA also collects information from health care professionals on adverse reactions occurring in Australia through the Adverse Drug Reactions Advisor Committee reporting scheme.

There are some differences between imported and domestic IVIg, but they relate to differences in the formulation of the product eg. the type of sugar solution that is used (sucrose or maltose), the concentration of the product (5,6 or 10%) and the administration rates.

### **3. How It Is Determined If a Patient Is Allocated the Imported IVIg**

When the Blood Service receives an order for IVIg, the following occurs:

- The Blood Service confirms that the patient is eligible to receive IVIg in accordance with the Criteria Book – clinical condition and the dose;
- The Blood Service uses the state allocation plan to determine whether Intragam P or an imported product is to be supplied:
  - This allocation is based on an agreement between the Blood Service, NBA and the relevant health department, developed in consultation with the IVIg user groups.
  - Trying to keep consistency between states and territories - but this is difficult because there are different numbers of patients in each patient category.
  - The allocation plan divides patients into three large groups:
    - i. Short-term indications – first group to go onto imported.
    - ii. Immune-replacement patients – these patients have a deficiency of immunoglobulin and, because of this, their immune system is weak and they are at a higher risk of catching infections from others in the community. There is a theoretical benefit that these patients will be better protected if they receive IVIg that is sourced locally because it will carry the immune protection against infections in the local community. They are the last group to receive imported IVIg.
    - iii. Immune-modulation patients– IVIg dampens down an overactive immune system. The IVIg somehow alters the way the immune system functions and IVIg has been found useful in a large number of neurological conditions such as MG. Increasing numbers of these patients are now receiving imported IVIg. From this financial year all new patients in this group are receiving imported product and a significant number of patients who were previously on Intragam P were swapped across to the imported product.
- If the request is allocated to domestic IVIg, the order is filled with Intragam P.
- If the request is allocated to imported IVIg, then it will be for the requesting clinician to choose which imported IVIg product is to be used. The Blood Service will provide the clinician with information about the available products including relevant precautions, but will not provide any advice or recommendation on the choice of a particular imported product.
- The percentage of imported IVIg has been progressively increasing which means that an increasing number of patients need to be swapped to imported product. The Blood Service looks at how much product each patient group use, how much product needs to be swapped, how many doctors are involved in managing the group of patients and try to swap the smallest number of patient groups. MG is

one of the larger users of IVIg thus, because of the large number of patients in this group, it was one of the groups to be swapped.

**4. Future Governance Arrangements**

The government is progressing a review of the adequacy of the current IVIg authorisation and clinical governance arrangements. The purpose of this review is to ensure:

- That IVIg use reflects best clinical practice and is cost effective;
- Ensure IVIg is consistently supplied in accordance with the Criteria;
- Improve the capture of information about treatment outcomes to inform future planning.

It is expected that some recommendations will be available by the end of this year. The review advisory committee includes representatives from government, clinical experts, the Blood Service and patient representatives.

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**DVD's FROM ANNUAL GENERAL MEETING**

We have had feedback from members regarding the quality of the graphics on the DVD from the AGM.

If members would like a printed copy of the graphics for either or both of the presentations, please contact our 1800 802 568 freecall number and they will be mailed after the Christmas/New Year period.

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**TOWNSVILLE GET-TOGETHER**

At the recent get-together of the Townsville group, members and their families were very interested in the results of the survey that Stefan shared with the association at the Annual General Meeting. Quite a deal of discussion occurred about some of the trends already identified in the data.

There was also interest in the Exercise and MG study results. Some sufferers expressed their appreciation for the list of exercises that had been recommended and used during the study.

As well as the interesting discussion that was generated from the above, people enjoyed pleasant company, sharing stories and helpful advice for coping, particularly with the hot weather upon us.

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**MACKAY CHRISTMAS GET-TOGETHER**

The Mackay Myasthenia gravis group held its Christmas Get-Together at the Boomerang Hotel/Motel on 2 December 2012. Everyone had an enjoyable time.

Ten people attended plus invited guest Dr Andre Horak, Eye Surgeon and Physician. Dr Horak gave a Powerpoint presentation on how MG affects the eyes and other muscles and answered questions. This was greatly appreciated by those attending as they now have a better understanding of MG. We thank Dr Horak for attending our function and for his presentation.

A special thanks to the Manager and staff of the Boomerang for setting up the venue and for the meal which was excellent.

Our next get-together will be in the new year on a date to be advised.

Bill and Muriel wish everyone a Merry Christmas 2012 and a Happy New Year 2013.

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# MERRY CHRISTMAS



*The President and  
Management Committee*

*of the Myasthenia Gravis  
Association of Queensland Inc*

*wish our members and their  
families*

*the very best of wishes for the  
Festive Season*

*and a safe and prosperous 2013.*

*They would also like to thank you*

*for your support over the past  
year*

*and look forward to a bigger and  
better 2013.*

