



Messages

Myasthenia Gravis Association of Queensland Inc

FEBRUARY 2013



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: info@mgqa.org.au
Internet: www.mgqa.org.au

COMMITTEE MEMBERS

President
Anita JACKSON
Ph. 3800 4913

Vice-president
JOHN NOBLE
Ph. 3269 5066

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

Well what a start to 2013 we have all had. I hope that our members far and wide did not suffer any effects from Cyclone Yasi and the floods in Queensland and New South Wales as well as the Bushfires in other states. If you have and if there is anything we could help you with please call our 1800 number as there certainly was a vast array of devastation in all areas. With the extreme heat wave it was time to relax and think of our Myasthenia Gravis and how we can cope with this heat.

Our first function for the New Year is a picnic at North Pine Dam on 10th March 2013 so hoping we will meet some new members and also see some familiar faces as it is good to keep in touch with you all and listen to our own journeys with Myasthenia Gravis. See details on Page 8 of the Newsletter.

The committee has had its first meeting of the year so it was good to start our projects for the year and follow through on the ones that are still in progress. Carol Buchanan is at present away in USA doing tests at the Mayo Clinic so we hope that all is going well for her and that they find some answers to help her cope with her health issues.

I would like to send our condolences to our Secretary Graeme, his wife Poppy and their family on the loss of his Mother in Tasmania recently.

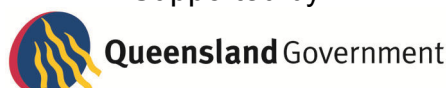
Take care

Anita

URGENT NOTICE:

Valeant Pharmaceuticals, the Australian supplier of Mestinon® has advised of a severe shortage of Mestinon® 60mg tablets. In fact, they are out of stock. It is suggested that members who are prescribed 60mg Mestinon contact their chemist to check on their stock situation. Supplies are not expected to return to normal until mid-March. Supplies of 10 mg and 180mg TimeSpan Mestinon® are not affected.

Supported by



Queensland Government

PROJECTS UPDATE

Collecting data on sufferers of myasthenia gravis –

Currently, it is anticipated that the survey results will be written up during the month of April, thus allowing time for a full 200 survey results to be entered into the data base.

What an effort from everyone involved! Thank you!

As explained previously, the survey recording will not stop with this write up. There is a target to find 500 Australian sufferers for the data base.

‘Exercise Effect in MG’ Pilot Study –

EXERCISES AT HOME

The results of the Study are in the process of being fully documented and written-up formally and will then be available for the world to see.

We will advise when the MGAQ receives its copy and make it available to read to all interested members.

Doctor Jennifer Nitz, who conducted the 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 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

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“SURVEY SNIPPET”

Bladder Busting!

Interestingly, Dr Blum has recognized that more than a third of respondents complained in regard to bladder control. Is this normal given the age demography of survey respondents or can MG play a part? In speaking with our members, many feel that bladder control definitely fluctuates along with symptoms. How will our Doctors interpret the data gathered and will it lead to further investigations?

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 – INTERSTATE MEMBERS

BARRY / JO	02 6285 2661	CANBERRA ACT
MARILYN	02 6291 3436	GOWRIE ACT
BARBARA	02 9524 9224	CARRINGBAH SOUTH NSW
ROBERT	02 6652 6745	COFFS HARBOUR NSW
JEAN	02 4937 3110	KURRI KURRI NSW
MAX	02 6621 6386	LISMORE NSW
PENNY	02 4868 2213	MOSS VALE NSW
FRANK	02 6767 1031	TAMWORTH NSW
KERRIE	0435389883	TWEED HEADS SOUTH NSW
CANDY	02 6847 3732	WARREN NSW
ELLEN	07 5599 9511	WEST TWEED HEADS NSW
ROLAND	03 9796 6592	NARRE WARREN VIC
TAMARA	0409 186 809	HOPPERS CROSSING VIC
CORAL	03 5865 1378	KATAMATITE VIC
DENNIS	0402 285 520	PATERSONS LAKES VIC
BARBARA	03 9776 4985	SEAFORD VIC
DORA	03 5821 4191	SHEPPARTON VIC
DIANE	0421387904	CARINE WA
RONA	08 9459 7168	MADDINGTON WA
DIANE	03 6327 2563	RIVERSIDE TAS
DAPHNE	03 6428 6733	SQUEAKING POINT TAS
MARIAN	03 6257 1272	ORFORD TAS
CRYSTAL	0459472165	GILLEN NT
PROSPER	08 8285 7016	ALICE SPRINGS NT

"In the End, we will remember not the words of our enemies, but the silence of our friends."
Martin Luther King Jr. (1929-1968)

Myasthenia Gravis Association of Queensland is on Facebook!

MGAQ has recently joined Facebook and we now have a Facebook page. You can find us at <http://www.facebook.com/mgqlid?ref=hl> or search for us when you log into Facebook.

The Management Committee has made the decision to join this online community so there is a place to share your stories, experiences, and recommendations with each other. We have already shared links to other people's experiences of living with MG and we would love to hear from you.

For those of you who are not on Facebook yet but are interested in joining us in this online community you might want to click on one of the following links: <http://www.facebook.com> or [Explaining Facebook](#). In order to join Facebook you will need to have an email address and be older than 13.

Kate Lloyd – MGAQ Social Media Administrator

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MEMBERS' FORUM

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.

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Future Planned Activities

Sunday 10 March 2013	Picnic in the Park – North Pine Dam - Petrie
Sunday 16 June 2013	Mid-year Guest Speaker function – Brisbane
Sunday 8 September 2013	Annual General Meeting – Carina Leagues Club
Sunday 15 December 2013	Christmas Function – Gold Coast – venue TBA

More details will be published as the events become closer.

The best thing about the future is that it comes one day at a time.
Abraham Lincoln

Moral indignation is jealousy with a halo.
H. G. Wells (1866-1946)

If you can count your money, you don't have a billion dollars."
- J. Paul Getty (1892-1976)

The following article by John MacKinnon appeared in the Edmonton Journal on 20 December 2012, and we hope it gives an encouraging message to our members that the way forward with MG is to focus on what you CAN DO, not what you CAN'T DO:

John MacKinnon Favourite: Swimmer embodies spirit of sport

Swimmer Grainne Pierse, one of five swimming sisters, overcame myasthenia gravis, a neurological condition that was remedied by invasive surgery to remove her thalamus.

EDMONTON - As a young girl, Grainne Pierse and three of her sisters followed their big sister, the Olympian and former world record holder Annamay, into the competitive swimming pool, like so many imprinted ducklings.

Competitive athletics has its ups and downs, and, of course, its challenges. But Grainne Pierse would have been excused had she abandoned sport altogether.

She overcame myasthenia gravis, a neuromuscular disease with no known cause or cure, to win a cluster of medals at the Canada West university championships in Edmonton last January.

This came just eight months after a surgeon cracked open her sternum and removed her thymus gland, part of the treatment required, along with medication, to live a normal life with that condition.

The disease ended Grainne's hopes of competing for Canada at the Olympics. It forced her to adjust her training and focus on the short sprints in butterfly, freestyle and backstroke.

It did nothing to dent her upbeat, optimistic outlook on life. As much as anyone, and more than most, Grainne Pierse embodies the spirit of sport.

Back into the swim; Grainne Pierse pushes aside serious illness to compete

John MacKinnon

Sunday, Jan. 29, 2012

It has become routine to see one or more of the five swimming Pierse sisters competing at the Kinsmen Sports Centre.

Starting nearly 20 years ago, Annamay, a 2008 Olympian, Hanna, Grainne, Fionnuala and Patricia, have all churned out the laps at the river valley facility.

That Grainne won a gold medal in the 50-metre backstroke and a bronze in the 50-metre butterfly Friday night at the Canada West swimming championships wouldn't raise eyebrows for most observers, either. The four oldest sisters all either swim for the University of British Columbia, or have done, and young Patricia is headed there, as well.

What is remarkable is that less than eight months after a surgeon broke her sternum, opened Grainne up and removed her thymus gland, the 21-year-old science student is competing at all.

Grainne suffers from the neuromuscular disease myasthenia gravis, an auto-immune disorder with no known cause or cure.

"If you like, every nerve we have has a little package of juice that it releases to make the muscle work," said Dr. Patrick Pierse, Grainne's father. "The antibodies in this disease attack that, so essentially it stops the nerve making the muscle work. And that can affect many and all muscles in the body.

"As a result, the patient just becomes weaker and weaker and doesn't know why."

The disease can be managed through medication, and a thymectomy can help alleviate symptoms, or sometimes produce complete remission. But first the condition needs to be accurately diagnosed. That can be tricky.

In the fall of 2009, all Grainne knew was she felt awful for no apparent reason.

"I started getting headaches all the time, and I was just always very tired," she said. "My left eye started drooping, I couldn't hold eye open anymore. I was too tired to even smile all and I'm a person who is always smiling."

She spent a week in hospital as a result of that episode, but tests produced no conclusive answers. A neurologist believed it was myasthenia gravis, but couldn't prove it until the symptoms returned.

Almost exactly one year later, they did.

"This time it came back a lot worse," Grainne said. "Everything went downhill. I got a little bit better for a few weeks, then I had another even worse episode at the beginning of November where I wasn't able to stand up by myself, couldn't walk at all, couldn't talk, because it was too hard to actually push words out, so my speech was slurred.

"I couldn't go to classes, couldn't do any reading because I couldn't keep my eyes open, couldn't keep my head up by myself."

Coincidentally, Grainne's condition worsened at about the same time that Annamay contracted dengue fever at the 2010 Commonwealth Games in Delhi, India.

Patrick and Johanna were understandably preoccupied with Grainne's worrisome situation, so much so they feel a tad guilty for not providing enough sympathy to Annamay and her battle with dengue fever.

"The thing is, we fell apart, and she just stayed positive," Johanna Pierse said of Grainne. "She'd say, 'It's a little setback, things will be fine.' She kept us going because she was so positive."

A treatment known as IVIG (intravenous immuno-globulins) helped get Grainne through the 2010-11 school year.

"Any time, I have a flare-up, I have to go sit in hospital for four hours and get this IV drip," Grainne said "Nobody is really sure how it works, but it's really good."

Still, the consensus was a thymectomy would further improve her condition, so a date was set for that procedure.

Within weeks, Grainne was splashing around, gently, in the Pierse’s outdoor pool. Last August, she spoke to her Edmonton Keyano Swim Club coach, Steve Price, about resuming serious training. Price had just taken the job as head man with the UBC Thunderbirds and Dolphins team in Vancouver.

When she told Price she wanted to compete this year, he was open-minded, but realistic, telling Grainne he wanted her on the team. But if it proved too taxing, he wanted her involved as a coach or a manager, perhaps.

“She’s a very bright girl, and she knows herself very well,” Price said. “We agreed we wouldn’t focus on what she couldn’t do, we’d concentrate on what she can.”

Grainne knows it is “no longer reasonable to think I’m going to be an Olympic athlete one day.” She is completing a cluster of courses that are prerequisites for entry to a veterinary college in Saskatoon.

She also knows her body will not cope with twice-daily workouts or distance work in the pool. She trains once a day, not twice like her teammates, and focuses on sprints - the 50-metre freestyle, backstroke and butterfly.

Still, in December, at her first official competition this season in Seattle, Grainne qualified for the Canadian Interuniversity Sport (CIS) Nationals in the 100-yard backstroke.

“The big surprise wasn’t that she was able to get back to the level she was at, but that she could get there so quickly,” Price said. “The surprise was she could actually surpass her previous performances.”

True to form, Grainne remains upbeat, just as she was last August when, not long out of surgery, she told her coach she was determined to get back in the pool and get back at it.

“I don’t know, that’s just kind of who I am,” Pierse said. “Things don’t ever really get me down that much. And if you get upset over something like this, then I was going to be upset for a long time. It’s something that’s there now for the rest of my life, so there’s no point getting upset over it.

“You can’t change it.”

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Editor’s Note; Thanks to member Barry Sinclair for this contribution

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Internet links to some items of interest associated with MG

(again thanks to Barry Sinclair)

Epidemiology of myasthenia gravis in Austria: rising prevalence in an ageing society.

www.ncbi.nlm.nih.gov/pubmed/23129486

MG Support group Forum:

<http://www.dailystrength.org/c/Myasthenia-Gravis/support-group>

PICNIC IN THE PARK

- WHEN:** Sunday 10 March 2013
- TIME:** 10:30am onwards
- WHERE:** North Pine Dam – Harrisons Pocket Picnic Grounds UBD Map 87 Ref L19
- WHAT DO I NEED TO BRING?** Yourself and whomever else you wish to bring along, and whatever you wish to eat and drink. (and a good mood, of course) The picnic grounds have BBQ's and hot water is available. We suggest you bring portable seating.
- HOW DO I GET THERE?** From the roundabout at the intersection of Gympie Rd, Anzac Avenue and Dayboro (UBD Map 98 Ref L3)
Turn onto Dayboro Rd/ State Route 58.
Travel along Dayboro Rd for approx. 4 km, (going through 1 roundabout) and swing left into Vores Rd.
Picnic grounds are on your left after approx. 1.5km
- RSVP** Ring our FREECALL 1800 802 568 and tell Shirley if you are coming, but please let her know by **Wednesday March 6 2013.**

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SIGNS OF THE TIME

- IN A PODIATRIST'S OFFICE - "Time wounds all heals."
- ON THE BACK OF A SEPTIC TANK TRUCK - "Caution - This Truck is full of Political Promises"
- AT A PROCTOLOGIST'S OFFICE - "To expedite your visit, please back in."
- AT AN OPTOMETRIST'S OFFICE - "If you do not see what you're looking for, you've come to the right place."
- ON A PLUMBER'S TRUCK - "We repair what your husband fixed."
- AT A TOWING COMPANY - "We don't charge an arm & a leg. We want tows"
- ON AN ELECTRICIAN'S TRUCK - "Let us remove your shorts."
- IN A NON-SMOKING AREA - "If we see smoke, we will assume you are on fire and take appropriate action."
- ON A MATERNITY ROOM DOOR - "Push. Push. Push."
- ON A TAXIDERMIST'S WINDOW - "We really know our stuff."
- ON A FENCE - "Salesmen welcome! Dog food is expensive!"
- AT A CAR DEALERSHIP - "The best way to get back on your feet is miss a car payment."
- OUTSIDE A MUFFLER SHOP - "No appointment necessary. We hear you coming."
- IN A VETERINARIAN'S WAITING ROOM - "Back in 5 minutes. Sit! Stay!"
- AT THE ELECTRICITY COMPANY - "We will be delighted if you send in your payment. If you don't, you will be."
- IN A RESTAURANT WINDOW - "Don't stand there and be hungry; come on in and be fed up."
- IN THE FRONT YARD OF A FUNERAL HOME - "Drive carefully. We'll wait."
- CHICAGO RADIATOR SHOP - "Best place in town to take a leak."