



Messages



Myasthenia Gravis Association of Queensland Inc

FEBRUARY 2011

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

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PRESIDENT'S REPORT

Welcome

Welcome to 2011.

The Management Committee sends our thoughts to all our members and their extended families who may have been affected by the floods throughout Australia and also to our North Queensland members who witnessed the force of Cyclone Yasi and to our members in WA who are experiencing bush fires. The weather has been very damaging so far this year so let's hope we have seen the last of it.

Our Christmas party was a huge success at Sharks Football Club at Southport and it was good to see our members from the Gold Coast.

We are looking forward to our visit to Townsville at the Cowboys League Club on Saturday 12 March 2011. Hoping to meet our Townsville region members, both old and new, and hope that they will come away with a lot of information about MG and also new friendships.

Even though we did not publish a Newsletter in January the Committee has still been committed to following up on our projects for the coming year. I would like to thank Susan White and Bill Synnot for all their hard work in keeping the Data Collection Project moving along smoothly.

In April 2011 I am going on holidays to Perth WA and hoping to meet up with some of our counterparts in WA. We have been advised that Dr Jean Foster will be the Guest Speaker for our AGM this year so please mark this date in your Diaries as it will be a very informative talk.

Take care

Anita

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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 – INTERSTATE MEMBERS

BARRY / JO	02 6285 2661	CANBERRA ACT
MARILYN	02 6291 8287	CANBERRA 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
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
RONA	08 9459 7168	MADDINGTON WA
DIANE	03 6327 2563	RIVERSIDE TAS
DAPHNE	03 6428 6733	SQUEAKING POINT TAS
PROSPER	08 8285 7016	ALICE SPRINGS NT

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MEMBERS' FORUM

Could we please have some stories of members' experiences with MG.

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.

Update on **PROJECTS**

A. Collecting data on sufferers of myasthenia gravis –

Great news! A research submission is currently with the Human Ethics Review Committee at the Royal Brisbane and Women's Hospital to approve the collection, collation, analysis and storage of data obtained from the survey developed by the MG Association of Qld Inc. We expect approval in the near future after which ALL members who are sufferers (Category 'A' members) will receive a package in the mail.

The package will include

- The survey in a bound booklet.
- A letter from your committee.
- An information sheet clarifying issues arising from participating in the survey.
- A consent form for you to sign.
- A one page verification form to take to your treating medical professional.
- A reply paid envelope in which to return the survey, the consent form and the medical professional's information.

Also included will be a few flyers we hope you will pass on to health professionals, friends, family or anybody who may help us make contact with other sufferers. For the greater success of this survey we need to reach as many people affected with this condition as possible (even if they are in remission or feel that their symptoms are minor). Encouraging your treating medical professional to help us to reach others is also vital.

C. Funding for research into 'Exercise and MG' –

A Pilot Study Proposal has been submitted to the University of Qld Ethics Committee for approval. When approval is received, All Category 'A' Members in the Brisbane area will be invited to participate in the study. Depending on the results of the Pilot Study, it is hoped to extend the Project to other areas in Queensland. More information will be provided later.

D. Enhancements to our website –

Updates to our website are currently being tested and are expected to be in place soon.

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GUEST SPEAKERS FOR 2011

The Committee has been successful in obtaining the services of Dr Cecilie Lander as Guest Speaker at our 20th Anniversary function to be held on Sunday 19 June at Carina Leagues Club, Creek Rd, Carina.

Dr Lander is the long-standing Patron of our Association and is a distinguished practicing neurologist. She will speak on MG and an overview of autoimmune disease in the nervous system.

Further to this, Dr Jean Foster from Western Australia has accepted our invitation to be Guest Speaker at this year's Annual General Meeting to be held at Club Pacific, Carindale, on Sunday 11 September 2011.

Dr Foster is a General Practitioner and a Category 'A' member of the Association who suffers from MG. Her presentation will address 'How to make the most of your GP' and 'How to live with chronic illness'.

Both speakers will bring a wealth of knowledge and experience to their respective presentations and the Committee is confident that our members will find both presentations informative and absorbing.

More details of both functions will be published closer to the dates but we ask that you note the dates in your diary and help to make both days successful.

The following article appeared in *The Post & Courier* (Charleston, South Carolina USA) on 16 August 2010 and may be of interest to our members:

Was disease at MUSC a cluster? State researchers try to connect the dots among former hospital workers

By TONY BARTELME
The (Charleston) Post and Courier

In September 2005, a letter landed on the desk of Dr. Jerry Gibson, the state's top disease detective.

It came from a person who once worked on the sixth floor of the Medical University of South Carolina's Children's Hospital. In the letter, the person said that three colleagues who worked within steps of each other developed a rare disease called myasthenia gravis. Myasthenia gravis means "grave muscle disease" in Latin. Though it's rarely fatal, sufferers may lose muscle control in their arms and legs and may have trouble swallowing and talking. Scientists believe it's caused by an abnormal immune response but don't know what triggers it. There is no cure.

Gibson was intrigued. As the state's chief epidemiologist, he runs a department that tries to prevent as many diseases and health problems as his budget will allow. And scientists have long relied on the study of clusters to identify a mysterious disease's cause and stop its spread. Gibson convened a committee to investigate the letter writer's allegations.

What did and didn't happen next is a story of detective work, mystery and frustration. On a deeper level, it's about a world that scientists sometimes don't understand well enough to determine cause and effect, and where the outcome isn't always clear.

'Very uncommon'

The red brick Children's Hospital sits on the southern edge of MUSC's campus and is the state's largest pediatric health center. It was built in 1987 and has rooms for patients, offices and labs. To do tests and clean utensils in the lab, employees and students routinely use a laundry list of chemicals, including chloroform, formaldehyde and other known carcinogens, documents obtained by *The Post and Courier* show.

In the late 1990s, some of the labs' hoods — air handlers that vent chemicals outside the building — went down for days at a time. Still, internal inspection reports reveal few violations of federal health and safety regulations, other than citations for failing to properly label hazardous chemicals. Heather Woolwine, MUSC media relations director, said that there have been "no reports of significant indoor air problems or chemical exposures in the Children's Hospital facility."

The myasthenia gravis letter in 2005, however, described at length employees' concerns that they might have been exposed to something that triggered their illnesses. The letter writer said that three employees developed symptoms of myasthenia gravis during the late 1990s, and that the facility had ventilation problems that may have exposed them to lab chemicals and other vapors. The letter writer noted that the disease was relatively rare. Estimates vary, but researchers believe that 14 per 100,000 people in the United States have myasthenia gravis. That makes it more common than Lou Gehrig's disease (Amyotrophic lateral sclerosis), which affects one or two people per 100,000, but not something doctors typically see. "It's not super rare, but it's very uncommon," Gibson said. "So we said, 'Yeah, we need to look at this.'"

Cluster investigations have long been an important tool for epidemiologists. But cluster investigations can be tricky. “Random does not mean evenly distributed,” Gibson said. “Any random pattern of dots will look like it has clusters. The challenge is to distinguish clusters that happened from chance from the ones that have causes in space and time.”

The only proven cluster in South Carolina was discovered in the late 1990s when residents in Charleston’s Neck area told DHEC they were concerned about the high number of cancers in their area. Using the state’s then-new cancer database, DHEC researchers found elevated rates of five types: colo-rectal, stomach, lung, laryngeal and pleural. The pleural cancers stood out the most. Researchers found four times as many as what would typically be expected in the area. And this type of cancer provided them with a key clue:

It usually is triggered by asbestos exposure.

Researchers eventually found that two-thirds of the pleural cancer cases involved people who once worked around asbestos at the former Charleston Naval Shipyard. Six months after they began their investigation, cancer registry researchers determined that a cluster did exist and that it was related to the shipyard, not where people lived.

The vast majority of cluster investigations, however, turn out to be busts. In the 1990s, the Centers for Disease Control performed one cluster investigation after another without finding causes of diseases.

“They concluded that it wasn’t a good use of tax dollars, not a high yield for the cost of the activity,” Gibson said. “But now and then you learn something really interesting and helpful. So they’re worth doing if you have the resources.”

That’s why Gibson thought it was worth investigating the letter writer’s concerns about myasthenia gravis at MUSC.

There were three people who were working at MUSC and they appeared within a space of a few years to come down with a fairly unusual condition. If it turned out to be a real cluster, perhaps there was something in the building that was causing the disease, he said. “There are two benefits there: Maybe you could get rid of what’s causing it — prevention — and secondly, myasthenia gravis is a big mystery; nobody has really figured out what triggers it. So it’s a chance to understand what one of the triggers might be. So there were a lot of benefits: You can make people feel better, prevent new cases and understand the disease.”

Investigation begins

After discussing the matter with his colleagues, Gibson asked the National Institute for Occupational Health to study the letter-writer’s allegations, but the agency declined. He then contacted Ray Greenberg, president of MUSC, who agreed to help with an investigation. “Greenberg is a smart guy and understood that even if something was found that implicated something in the (building’s) environment, they were much better off finding it and correcting it than covering it up, so he immediately wrote back and said, ‘Yes, we’ll cooperate fully,’” Gibson said.

Gibson formed a committee. Because the state had no money set aside to fund such an investigation, all agreed to do it on a volunteer basis. Joining staffers from DHEC were researchers from the University of South Carolina Arnold School of Public Health, a representative from the federal Centers for Disease Control and Prevention and Dr. Daniel Lackland, a professor in MUSC’s neurosciences department who specialized in epidemiology. All signed agreements that

essentially put them under DHEC's legal umbrella, a move to reduce their exposure to lawsuits should any arise from their work.

The first step was to verify whether employees on the floor in fact had myasthenia gravis.

To determine this, researchers needed detailed reviews of patients' medical and work histories. He and Gibson said that one patient was extremely cooperative but two others declined to release the needed records or do in-depth interviews.

"They weren't comfortable releasing their medical records, so in the end it was a dead end," Gibson said.

Despite the inability to obtain the employees' medical records and cooperation, other members of the committee acquired data on medical records from the state Office of Research and Statistics, which records diagnoses of diseases throughout the state.

The database search generated some possible new clues: Between 1996 and 2005, 73 patients had myasthenia gravis in South Carolina. And of those 73, eight cases — 11 percent — involved MUSC employees.

Meanwhile, Charleston and Richland counties both recorded 12 cases, far more than any other counties in the state. That's roughly twice as the state's average rate, said Khosrow Heidari, a top DHEC epidemiologist also on the team. Still, Heidari cautioned that it's difficult to draw statistical conclusions from such a small number of cases. Gibson added that although Charleston had 12 cases, that number was still within what is normally found in other parts of the country with similar population levels.

By late 2006, the investigation was losing steam, mainly because the committee couldn't verify the myasthenia gravis diagnoses, and therefore, whether there was in fact a verifiable cluster at the Children's Hospital.

"There were dwindling levels of enthusiasm," Lackland said.

The investigation chugged along for two years. Investigators learned that a fourth employee in the Children's Hospital also may have myasthenia gravis, but they weren't able to verify that diagnosis, either. In an e-mail to Gibson in 2008, Erik Svendsen, a USC professor, wrote that he didn't think the numbers, statistically speaking, constituted a cluster.

"This still appears to be just a few unfortunate cases who happen to share the same employer," he wrote. "I still do not believe that this small cluster alarm warrants a public health investigation, especially given the current economic constraints which our government and agency are currently facing — this could likely be a waste of valuable time and resources which could be better spent on public health issues which threaten larger populations in S.C."

In the end, Lackland said, the team "gave it our best effort. Even though we're all volunteers, we were all very dedicated, (but) it just didn't build up and get legs. Is there something we missed? Possibly. But I didn't see it. Clusters sometimes just happen."

Since the letter landed on Gibson's desk five years ago, the myasthenia case investigation has become the epidemiological equivalent of a cold case. MUSC has made extensive repairs to the Children's Hospital. Labs on the sixth floor were converted into office space. As in any large organization, many employees have moved on. Trying to reconstruct what might or might not have happened in the late 1990s would be a massive research undertaking. Only the questions about what did or didn't happen in the building remain.

MEET THE MEMBERS – TOWNSVILLE 12 MARCH 2011

The following flyer has been distributed in the Townsville region in notice of our 'Meet the Members' event :



Myasthenia Gravis

Association of Qld Inc.

Do you suffer from

or

Do you care for someone with

or

Do you have an interest in

Myasthenia Gravis?

If you answered "Yes" to any of these questions then come and enjoy a morning with members of the Queensland Myasthenia Gravis Association.

Committee members are coming to Townsville especially for this meeting and would love the opportunity to meet anyone impacted by MG.

Find out some helpful and important information about how to live with this manageable disease. Share your ideas on how the Association could help members in your part of Queensland.

Cowboys Leagues Club, Flinders Mall, Townsville

Saturday 12 March 10am

Please RSVP on 1800 802 568 (Shirley) or 0418 748 849 (Carol)

"Professionals Welcome"

If you can't make it but would like to know more please email or phone to get in touch with our great volunteers.

PO Box 16, Mt Gravatt. QLD 4122 mgag@qil.com.au