



Messages

Myasthenia Gravis Association of Queensland Inc

FEBRUARY 2015



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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PATRON
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Neurologist
Founder Member, of Brisbane

PRESIDENT'S REPORT

Welcome,

I hope you all have had an enjoyable Christmas and New Year with family and friends and if you travelled that you had a safe trip. The weather has not been very kind to us as it is very hard to cope with our Myasthenia Gravis in these extreme heat wave conditions.

Our first function for this year "Meet the Members" Picnic at MacIntosh Island, Surfers Paradise on Sunday 15th March 2015 with a meeting time around 10.30am. Hoping to see some new members as well as the regulars as we do not always have the time to chat to you all at the more formal gatherings This will be a very informal picnic with the opportunity to discuss many things.

The committee has had its first meeting of the year and it was good to focus on our projects again, both new ones and those that are still in progress. Planning for the Alliance Conference to be held in Sydney on 20 June 2015 is progressing well. Registration is opening with the form included at the rear of this newsletter. Be sure to act quickly to secure your place. Do remember to visit the Alliance website and register for automatic updates regarding issues of National significance.

I have been informed that an anonymous donation received by the Association is to be directed to Professor Pamela McCombe (RBWH) for the express purpose of supporting DNA testing. The database for this work has resulted from the Survey project. This donation is to be staged and includes defined clauses, guidelines and timeframes. I will keep our members informed when agreement is reached and as results occur. With such support from the public and from the Doctors we have a very hopeful future.

The committee has started working on plans for a transition to operating post Queensland Health funding. We will be sending out a survey requesting your feedback in relation to ideas we are working with. Please take the time to respond and give us your thoughts. We want to give you the Association that most suits your needs so you must use your voice and help us.

We are still looking for information for our Newsletter so please think about putting pen to paper and telling your story or if you are a carer you could do living with and caring for someone with MG.

Take care

Anita

Supported by



PROJECTS UPDATE

MYASTHENIA ALLIANCE AUSTRALIA

The Alliance is in action! Thank you to Glenda Bidner and Jan Trigg for joining with Carol Buchanan and Susan White to form the Alliance Committee. The ladies have been very productive since the inception of an Alliance. A website has been constructed, meetings hosted and a Conference which is open to anyone in Australia with an interest in the Myasthenic Syndromes has been organised.

To stay abreast of the work of the Alliance, visit the website www.myastheniaallianceaustralia.com.au and register for updates. Updates will only be posted when there is an issue of importance to all with Myasthenia. It is not planned to issue regular newsletters from this site. The web page will have current events listed.

ALLIANCE NATIONAL CONFERENCE

The Alliance Committee is very proud to confirm that the first National Conference for Myasthenics, their supporters/carers and for health professionals interested in this rare condition will take place on June 20, 2015 at The Brain and Mind Research facility Camperdown, Sydney. It is a full day programme with an interesting range of speakers.

Registration is now open and will close promptly by 31st March. It is expected that demand for the limited places will be high and Members should act quickly if they wish to attend. The Draft programme and the Registration Form are included with this newsletter. Please follow the instructions listed on the form.

The Committee would sincerely like to acknowledge the generous support offered by Dr. Stephen Reddel in making this event possible. We thank all the Speakers who give so freely of their precious time and look forward to sharing a little more about these professionals in the coming newsletters.

SURVEY UPDATE

Congratulations to Dr. Stefan Blum who has received news that the Myasthenia Survey Paper has now been accepted for publication in the Journal of Clinical Neurosciences. Dr. Blum described it as an involved process with the result that the papers have been combined into a longer summary paper giving "a cross-section of the highlights of the survey". More details on the content of this paper hope to be made available to members. Dr. Blum will be presenting at the conference. We are assured that the Data collection is ongoing. Dr. Blum remains involved with the project even though he has made some changes in regard to his working arrangements and we are informed that Professor McCombe also is committed to progressing research based around the Survey Data.



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	0262 852 661	CANBERRA ACT
MARILYN	0262 913 436	GOWRIE ACT
BARBARA	0295 249 224	CARRINGBAH SOUTH NSW
ROBERT	0266 526 745	COFFS HARBOUR NSW
MAX	0266 216 386	LISMORE NSW
PENNY	0248 682 213	MOSS VALE NSW
FRANK	0267 671 031	TAMWORTH NSW
KERRIE	0435 389 883	TWEED HEADS SOUTH NSW
MAUREEN	0244 763 734	NAROOMA NSW
CANDY	0268 473 732	WARREN NSW
ELLEN	0755 999 511	WEST TWEED HEADS NSW
DIANNE	0245 743 787	WINDSOR DOWNS NSW
ROLAND	0397 966 592	NARRE WARREN VIC
TAMARA	0409 186 809	HOPPERS CROSSING VIC
CORAL	0358 651 378	KATAMATITE VIC
DENNIS	0402 285 520	PATERSONS LAKES VIC
BARBARA	0397 764 985	SEAFORD VIC
DORA	0358 214 191	SHEPPARTON VIC
EDMUND	0395 098 920	CAULFIELD NORTH VIC
DIANE	0421 387 904	CARINE WA
RONA	0894 597 168	MADDINGTON WA
DIANE	0363 272 563	RIVERSIDE TAS
DAPHNE	0364 286 733	SQUEAKING POINT TAS
MARIAN	0362 571 272	ORFORD TAS
CRYSTAL	0459 472 165	ALICE SPRINGS NT
PROSPER	0882 857 016	ALICE SPRINGS NT

UPCOMING EVENTS

"Meet the Members" and Families - Picnic Gathering

Where: MacIntosh Island
at Main Beach Parade
Surfers Paradise

When: Sunday, 15th March 2015 from 10.30am

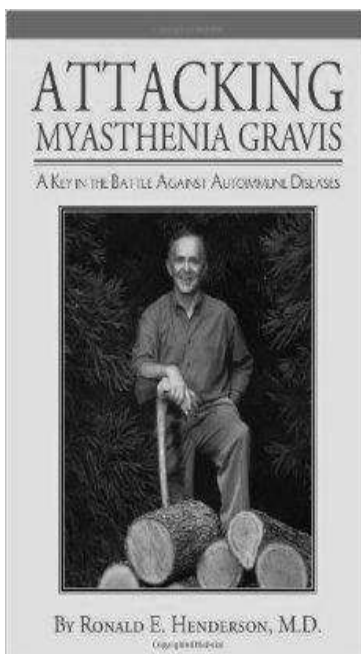
Please pack your picnic food or Barbecue and come and join us for a day of catching up with others. Look for the MGAQ Banners to find us. The beach is not far away so perhaps a swim could be considered. The committee is keen to see you.

Friends and family are welcome and it might be advisable to pack a chair.

Rare Disease Day (28th February 2015)

Rare Disease Day takes place on the last day of February each year where the main objective is to raise awareness amongst the policy makers, public authorities, industry representatives, researchers, health professionals and the general public about rare diseases and their impact on patients' lives. If you would like more information or to host an event, go to <http://www.rarediseaseday.org>

Book Review



Attacking Myasthenia Gravis by Ronald Henderson
Genre: Self-Help, Medical

"Using his insight as a long-time physician, Dr. Ron Henderson describes the productive life he lives despite having a rare autoimmune disease known as myasthenia gravis (MG). He also provides a forum for three other MG patients to share their inspirational stories. A disease unfamiliar to many, myasthenia gravis means "grave muscle weakness" and causes severe weakness and loss of strength in voluntary muscles in various parts of the body. Often debilitating, MG falls into the category of "autoimmune" diseases, which all involve problems related to the immune system. Explaining MG symptoms, treatments, research, and disease-management tips, this book becomes a useful guide for MG patients, their families, and their physicians. And the book goes further. Using MG as an example, Dr. Henderson and others provide tips to all who suffer from chronic health problems for which there are treatments but no cures. Forced by MG to retire eight years ago as an obstetrician-gynecologist, Dr. Henderson now enjoys improved health but realizes he can never expect to be well unless a cure is found for

MG. In this book, he announces plans to expand research into MG and other autoimmune disease through his founding of the International Autoimmune Disease Research Foundation."

This book can be found and ordered online on Amazon.com at <http://www.amazon.com/Attacking-Myasthenia-Gravis-Ronald-Henderson/dp/160306267X>

MEMBERS' FORUM

Welcome to New Members

The MGAQ welcomes Margaret from Morayfield, Ted from Burpengary and Wendy from Mt. Gravatt as new members to our association. We look forward to developing a worthwhile relationship with you all.

News from Cairns

Looking forward to catching up with our members and their carers at our next get-together on Saturday 21st February at 11.00am at the Cairns RSL Club, Esplanade.

Some of our members stay on for lunch afterwards in the restaurant (own expense). Any Myasthenic visitors to Cairns are also welcome to join us.

Donna Formosa – Cairns Coordinator

News from Mackay

Our Christmas get together was held at the Mt Pleasant Tavern on the 30th November 2014. Nine people attended and had an enjoyable time. All those that attended the Christmas lunch received a small gift. Thanks to Muriel for decorating our table, it was appreciated.

Hope everyone had an enjoyable festive season and have a happy year for 2015

The date for our May get together will be held on Sunday 10th May 2015. The venue will be advised later.

Bill Harris - Mackay Coordinator – Ph: 0749 541 221

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.

Editor's Note:

If you would like to contribute something to the Newsletter, please email me at Emily.sexton@live.com.au by the first Friday of the month to ensure that it meets the publishing deadline. Thank you!

Valentine Jokes

- A prince was put under a spell so that he could speak only one word each year. If he didn't speak for two years, the following year he could speak two words and so on. One day, he fell in love with a beautiful lady. He refrained from speaking for two whole years so he could call her "my darling." But then he wanted to tell her he loved her, so he waited three more years. At the end of these five years, he wanted to ask her to marry him, so he waited another four years. Finally, as the ninth year of silence ended, he led the lady to the most romantic place in the kingdom and said, "My darling, I love you! Will you marry me?" And the lady said, "Pardon?"
- A woman was taking a nap on Valentine's Day afternoon. After she awoke, she told her husband, "I just dreamed that you gave me a gorgeous and expensive diamond necklace for Valentine's Day! What do you think it means?"
"You'll know tonight," he said.
That evening, her husband came home with a small package for her. Thrilled, she opened it and found a book titled "The Meaning of Dreams."
- Two antennae met on a roof, fell in love and got married. Their wedding ceremony wasn't fancy. The reception, however, was excellent.

RECIPES



Cauliflower Popcorn

Directions:

1. Break a head of cauliflower into popcorn-like, bite-size florets.
2. Spread them on a baking sheet lined with parchment paper.
3. Spray the cauliflower lightly with butter-flavour cooking spray
4. Sprinkle lightly with turmeric, freshly ground pepper, and sea salt.
5. Bake 20 to 30 minutes until the cauliflower is slightly browned.

Editor's Note:

Please note that the following Programme is a *draft* only. At the time of publication, the full and complete details were not finalised. This draft is to show prospective conference goers the highlights, guest speakers and how they may expect the conference to flow. Thank you for your understanding.

Myasthenia Alliance Australia - Conference 2015
Conference Programme

8.45am:- Registration opens

9.15am:- Facilitator Welcome (Mr. Bill Synnot)

9.20am:- Conference Opening Address and Presentation - Dr. Stephen Reddel - "A Review of the Myasthenias" (50mins presentation, 10mins questions)

10.20am:- Dr. Paul Jansz - "Robotic Thymectomy" (20mins presentation, 10mins questions)

10.50am:- Morning Tea

11.20am:- Dr. Sean Riminton - "Safety and Risk Management with Immunotherapy" (40mins presentation, 10mins questions)

12.10pm:- Presentations from the NSW and Q'LD State Associations (10 minutes each)

12.30pm:- Workshop – small group discussions with a nominated leader and agenda

1.15pm:- Lunch

2.00pm:- Dr. Stefan Blum "MG Survey Update / Research Findings / Into the Future" (40mins presentation, 10mins questions)

2.50pm:- Mrs. Megan Fookes - "Why is the Rare Voices Organization Important to Me?" (20 minute presentation)

3.10pm:- Dr. Katherine Buzzard - "Advances in Treatment of the Myasthenias" (20mins presentation, 10mins questions)

3.40pm:- Ms. Sarah-Jane Flear - "A Journey with Myasthenia" Book Launch and Signing

3.30pm:- Summary and Closing Address

4.00pm:- Conference concludes. Tea and coffee provided.

5.00pm:- Venue Closed



Myasthenia Alliance Australia - Conference 2015

Thank you for showing interest in attending the Myasthenia Australia Alliance’s Conference to be held at the Brain and Mind Research Institute, Sydney on Saturday, 20 June.

Please complete the registration form and send it along with your registration fee of \$70 per person to either info@mgaq.org.au or MGAQ, PO Box 1287, New Farm 4005. Any cheques should be made out to The Myasthenia Gravis Association of Qld Inc. Bank details for direct deposits are BSB 124032 and account number 10263772 and Reference to include wording ‘conf’ and your full name. Please inform us by email at info@mgaq.org.au if you have paid your registration by direct deposit so this can be cross-checked. Your successful conference registration, along with any additional information, will be confirmed by mail.

Morning tea, lunch and afternoon tea plus the conference package are included in the cost of registration.

Participant/s Name/s

Please indicate if each participant is:

Name

Myasthenic/ Carer/Supporter/Health Professional (please circle one)

Name

Myasthenic / Carer / Supporter/Health Professional (please circle one)

Address

.....Postcode

Phone Number (home)(mobile)

Email Any

Particular Dietary Requirements Any

Particular Access Requirements

.....

THE CLOSING DATE FOR REGISTRATIONS IS 31 MARCH