



Messages

MYASTHENIA GRAVIS ASSOCIATION OF QUEENSLAND INC.

SEPTEMBER 2016

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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PRESIDENT'S REPORT

G'day all,

By the time you are reading this, I will have relinquished the Presidency of this great support organisation. It has been a privilege and pleasant experience to have held the position.

I thank everybody who has assisted me over the past year, in particular the Management Committee members.

The MGAQ is in good shape

and the list of achievements continues to grow.

I wish the incoming committee all the very best for the coming years, and to the members of the MGA, thank you for your continuing support of the Association.

I look forward to catching up with you at future functions.

Cheers
Graeme

Meet the MGAQ Office Bearers for 2016-2017



Carol
President



John
Vice-President



Anita
Secretary



Denise
Treasurer



Shirley
Information Officer



Anita
Committee



Susan
Committee



Rosalyn
Committee



Donna
Committee

For more news from the 2016 M.G.A.Q. Annual General Meeting - See pages 7 & 8

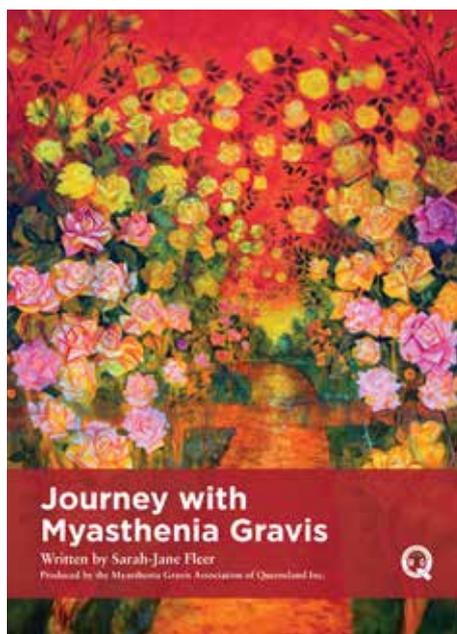
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“JOURNEY WITH MYASTHENIA GRAVIS” - A BOOK BY SARAH-JANE FLEER



Raising awareness of Myasthenia is as important as always. The book demonstrates the uniqueness of each journey with the condition. It aims to support those affected as well as their families and friends.

Contact the Association on 1800 802 568, email at info@mgaq.org.au or go to our website www.mgaq.org.au if you wish to purchase a copy.

MYASTHENIA ALLIANCE AUSTRALIA



Myasthenia
Alliance Australia

who are we?

Myasthenia Alliance Australia was formed to support the needs of myasthenics from all states, particularly on issues and items of national importance. At this stage, Queensland and New South Wales have signed the agreement but any state which has a group registered as an association is welcome to apply to join this alliance.

The objectives of Myasthenic Alliance Australia are to:

Support people sharing unique and differing

experiences with the myasthenic syndrome.

Foster meaningful and distinctive dialogue amongst the associations through direct sharing of new information.

Develop and implement co-operative initiatives through a national platform that provides 'one voice' on issues pertaining to myasthenia.

Unify Australians with this condition and provide a pathway and voice for myasthenics throughout Australia

Promote an understanding and awareness of myasthenia through education and pressing for practical solutions through advocacy.

Promote and support research into this condition.

Ensure that each individual association continues to operate with full autonomy.

Follow the work of the Alliance by registering at the website

www.myastheniaallianceaustralia.com.au

PROJECT UPDATE

RESEARCH UPDATE

“eNID” (the electronic data registry project for neuro-immunological diseases being developed in Australia) continues to progress through the establishment phase.

It is in the third round build phase at the present. More details will be released when it is launched. Hopefully this will occur in the next few months.

MYASTHENIA GRAVIS FOUNDATION OF AMERICA

LATEST NEWS

Thymus Removal Effective Treatment for Myasthenia Gravis

The long awaited study results from the Randomized Trial of Thymectomy in Myasthenia Gravis were published August 11th in the New England Journal of Medicine. This study, partially funded by the Myasthenia Gravis Foundation of America, compared patients who received a thymectomy plus prednisone to a group which received only prednisone.

Those who received surgery plus prednisone had an overall reduction in muscle weakness and required lower daily doses of prednisone, 44 mg versus 60 mg for those taking prednisone alone. You can find the New England Journal of Medicine article here. In addition, visit this video summarizing the key findings here. The NIH has also done a summary announcement. This trial has provided strong support for thymectomy a result that's been many years in coming.

The study was led by Gil Wolfe, MD former chair of the MGFA Medical/Scientific Advisory Board and included many members of that group as well as MGFA board member Henry Kaminski, MD.

Comments from Robert Ruff, Chairman, MGFA Medical/Scientific Advisory Board

The Thymectomy Trial definitively demonstrated that thymectomy is a beneficial procedure for people with myasthenia gravis (MG) associated with antibodies to the acetylcholine receptor.

The study demonstrated that people who had a thymectomy had less disturbing symptoms and required lower doses of glucocorticoid treatment. Coordinating an international study is difficult and requires extreme wisdom, exquisite planning and diplomatic skills for the study to reach successful completion.

Dr. Wolfe and others involved in directing this study deserve high credit for their work in maneuvering this study to completion. This study carries enormous importance for patients with MG because it firmly documents the therapeutic value of thymectomy in treating MG.

Insurance coverers will not be able to deny coverage on the basis of thymectomy not being demonstrated to be efficacious. This study was supported by National Institutes of Health, the Myasthenia Gravis Foundation of America and the

Muscular Dystrophy Association.

The publication of the completed International Thymectomy Trial came at high cost to people who championed this issue.

Fred Jaretzki, a thoracic surgeon at Columbia University, championed the need for a thymectomy trial and was involved with early planning of the Thymectomy Trial.

Fred was a member of the Board of Directors of the Myasthenia Gravis Foundation of America and along with Henry Kaminski convinced the Myasthenia Gravis Foundation to fund early study groups that developed the fundamental structure of the Thymectomy Trial.

Sadly, Fred died before the thymectomy trial was completed. The Chairman of the Board of Directors of the MGFA, Sam Schulhof, and Henry Kaminski advocated the importance of the Thymectomy Trial to the NIH. The Thymectomy Trial was eventually supported by the NIH.

The initial lead of the Thymectomy Trial was John Newsom-Davis. John was a phenomenal charismatic neurologist who motivated people around the world to join the study.

John died in a tragic car crash on a trip to recruit centers to participate in the trial. John's early leadership was critical to flaming the interest in thymectomy trial. I doubt that the Thymectomy Trial would have been funded by NIH were it not for the initial work done by John.

When John died it was essential for others to take up the gauntlet. Gil Wolfe was extremely effective in advocating for the trial to NIH, MGFA and MDA, he recruited additional centers and he kept the many centers motivated to successfully complete the study.

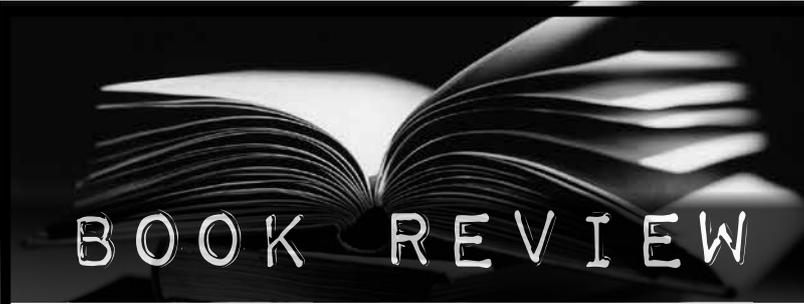
A possible criticism of the study is that the procedure used was transternal thymectomy. As the trial was being planned, less invasive robotic techniques came into use, but those procedures are still evolving and it would not have been possible to have a standardized robotic surgical technique or other thymectomy approach for the trial.

The significance of the Thymectomy Trial was not the way that thymectomy was done, but that removal of the thymus benefits patients with MG.



Article courtesy of the Myasthenia Gravis Foundation of America

To find out more about this article, use this link <http://myasthenia.org/Research/Latestnews.aspx>



BOOK REVIEW

"Attacking Myasthenia Gravis - A Key in the battle Against Autoimmune Diseases"

by Ronald E. Henderson, M.D.

This book has been gifted to the Committee by a member as a tool to be shared amongst our community.

For this opportunity, the Committee thanks Dianne Brooks and advises that it will be made available to members via our library service.

Loans of material are available to financial

members of the Association and the loan period is 1 calendar month.

Postage out is paid by MGAQ and return postage is the responsibility of the member.

To request a loan, please contact John on (07) 3269 5066 or email jam3740@optusnet.com.au

This book was first published in 2003. The author is a Medical Practitioner in the USA and describes his experiences with developing, accepting, controlling and living with Myasthenia Gravis.

The story also shares the experiences of three other people affected by the condition. As usual, the experiences are quite different and all are life changing.

Dr Ron Henderson was and still is a very dynamic man and many of his frustrations resonated with me.

He is keen to support research into this condition and discusses some ideas that are being explored.

More significantly for me, he reflects heavily on the effect of stress in our lives contributing to the onset of such conditions as MG and possibly genetic responses to stress.

He has a strong faith and shared how nurturing his spiritual side was helpful. He writes very openly and honestly and the book is easy to read.

Including the additional three stories made it all the more interesting. It is segmented so that particular sections can be read independently. Experiences are also presented in summary form. This would make it easy to share small parts with family and friends. It is a book of compassion with a genuine desire to help others affected by chronic conditions and to also encourage the medical profession to reflect upon current practices.

I am confident in recommending this book to others.

**- Reviewed by Susan White
(MGAQ - Committee Member).**

COMMITTEE NOTICE BOARD

**YOUR ASSOCIATION
URGENTLY NEEDS A
SECRETARY!**

**Can you help in any way?
Please see pages 7 and
8 for further details**



MGAQ Discussion Forum is a "Closed Facebook Group which allows people to communicate between each other in a safe Australian forum".

**To join the conversation:-
www.facebook.com/groups/mgqld/**



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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Trevor writes...

My Take On Exercise

As everybody knows exercise is not an easy thing with Myasthenia. I think I now have a reasonable program developed and would like to share just in case it may help others. Remember this is just my take, check with your doctor first. I have never been a sports person as I was a bad asthmatic when I was a child. Fortunately, the asthma is under very good control these days – I am now 65.

My exercise program started at about age 50 when I was put on a disability pension due to spinal problems. Looking back, the myasthenia was already rearing its ugly head, but very mildly and not diagnosed. I did a pain management course at Lismore Hospital as well as seeing many physiotherapists. This gave me a bunch of stretching type exercises which I do twice daily. A 10 minute session in the morning starting while in bed, then I go for a 10 minute walk, breakfast etc. This starts my day. I also finish my day with stretching exercises, about a ½ hour session. This is critical to being in less pain the next day.

I believe that stretching also relaxes the muscles elevating some of the muscle fatigue allowing me to do a little more. When walking or swimming, I often stop and stretch. I do ½ hour walk 2 to 3 days a week when I can, mostly in winter these days as the summer heat really drains the energy levels. How much I do is not set in stone, as everyone would understand it depends on the energy levels for the day. Every day of course it takes a certain amount of "mind over matter" to get started and to get through it. It never comes easy, but the benefits are big.

I believe that as I started the exercise before the myasthenia set in, it's made it easier to keep it going. However, I believe it was possibly also a deterrent in getting an early diagnosis. I sometimes wonder if being in heavy physical work or a sports person prior to myasthenia makes it harder to get the diagnosis.

One big thing I want to share here is using a snorkel when swimming laps. This is something I only just started using as I was having problems with my neck, caused by breathing only to one side; I swim 3 days a week. I had tried unsuccessfully to teach myself to breathe to both sides. I first tried the snorkel that comes up the side of the head, but it kept getting too much water splashed in. Then I saw a lady with a snorkel that came up the front of the face and curved backwards over the head which keeps the water out.

Using the snorkel has improved my stroke as well as lung function, allowing me to increase the number of laps, improved stroke also means less fatigue. I feel all the exercise I do has subsequently improved due to the improved lung function. It is probably still always going to remain a case of 'mind over matter' approach to keep up the exercise. Use it or lose it so to speak.

Most days I have to force myself to exercise. If the energy levels are low then I just cut down the input on the day ie. A set of 10 exercises may become a set of 2 or 3 or whatever. My swim may drop from 10 laps to 4 or 5. The important thing I feel is to just maintain what you can do on the day. Exercise helps physically and mentally. I have also found that for me at least, there are two stages of fatigue.

The first one may start as soon as you start the exercise, or a little after, then the real fatigue sets in some time later. Usually, I can work slowly through the first stage of fatigue using mind over matter, then going into what I call the Drone Zone.

Before the real fatigue sets in, the real fatigue can't be ignored. On a couple of occasions before I had been diagnosed, I tried to ignore it and finish my 60 laps. This was a bad idea as when I got out of the pool, my legs almost buckled under me and I barely made it to a bench to sit. There I had to stay until I had the energy to get to the change rooms. Being a bit on the stubborn side, it wasn't until after the second time that I admitted defeat and decided I had to cut down the number of laps. This was a bit scary as at that point, I had not been diagnosed. Thankfully, it was only a couple of months later that I got the MG diagnosis and finally knew what the hell was going on.

Anyway, I hope that this may help or encourage others. I'd also love to hear other people's take on exercise. I did at one stage try Pilates which was very good but a bit expensive to have regular lessons when on a pension.

Just a note, I'm managing quite well on 60mg Mestinon on its own (particularly during winter, not looking forward to summer) 2 tabs three times a day. I was on prednisolone for a short period with a lower dose of Mestinon until the debacle of having to change neurologists which some of you may remember me writing about previously. So my MG may well be mild compared to others.

NEWS FROM AROUND QUEENSLAND

News from Cairns

The local MGAQ group in Cairns meet every couple of months at the Cairns RSL Club Boardroom. This is a wonderful opportunity to meet with others with MG and carers and chat.

The final get together for 2016 will be on Saturday 19th November.

For more information, please contact Donna on 0414 397 462.

News from Mackay.

The dates for our get-togethers for the rest of the year are: Sunday, 13 November, 2016 for our Christmas Party at Souths Milton Street, 12 noon.

All M.G. Association members, carers and interested people are welcome to attend.

For more information on any of these events, contact Bill, Area Co-ordinator, 07 4954 1221, Mobile 0429 729 685

News from Townsville.

Our next lunch meeting is on Saturday, 24 September, 2016 at 12 noon at The Avenues Hotel, 270 Kern Bros Drive, Kirwan, Townsville. Regards Daphne.

Mobile: 0400 778 637 or Email: daphclay@gmail.com

News from Rockhampton

For more information, contact Jeanne Harp. jharp08@hotmail.com or 0437 048 361.

News from Wide Bay (Hervey Bay)

Unfortunately, Jan Powell is unable to continue as Re-

gional Co-Ordinator for Wide Bay (Hervey Bay) due to health reasons.

This area will now merge with Wide Bay (Gladstone).

For all enquiries, please phone Garth on 0408 155 954.

The management Committee would like to take this opportunity to thank Jan for her contribution to the MGAQ.

News from Wide Bay (Gladstone)

If you would like to find out if there are any upcoming functions, or get-togethers, contact Garth, the local support Co-Ordinator for Gladstone-Wide Bay on mobile 0408 155 954 or (07) 4973 7983

News from the Sunshine Coast Group

If you have any queries, please contact: Colleen McLean 0409 491 789. colleen4551@gmail.com

News from the Gold Coast

While Nader is away, Angela is filling in. Angela's contact number is 0427 752 956.

News from Darling Downs

Love to hear from anyone whom I can be of assistance to in anyway.

Debbie Hawkins, Email debsy570@yahoo.com or phone (07) 4628 6103 or mobile 0457 148 486.

Please leave a message and I will return calls or reply via email.

YOUR ASSOCIATION NEEDS A SECRETARY – CAN YOU HELP, P ????

At the Annual General Meeting held on 11 September, the position of Secretary was vacant and no one was appointed to that position on the day. Since that meeting, one of our current management committee members, Anita Jackson, has been appointed to the position so that we meet our Constitutional and Legislative requirements.

However, she has agreed to do this only on the proviso that we endeavour to find someone to take up the position on a longer-term basis.

The MGAQ is a dynamic and progressive organisation and your commitment to the team will be well rewarded. Meetings are held once a month, on the second Saturday morning of every month, except January. Outside of this, work is completed in advance of the meeting by email correspondence. Microsoft Word and Excel are the major software products used by the MGAQ. The full support of the management Committee will be provided to whoever takes up the position.

Please call the immediate-past secretary, now President, Carol Buchanan, or our 1800 free call number if you have questions about the role and duties of Secretary of the MGAQ.

You will be given full and truthful answers to enable a fully informed decision. Please urgently consider, if not yourself, if there is a friend or family member, who would like to assist. The Secretary is not required to be a financial member of the association.



NEWS FROM THE MYASTHENIA GRAVIS ASSOCIATION OF QLD INC.

ANNUAL GENERAL MEETING

SUNDAY, 11 SEPTEMBER, 2016

The recent AGM held on Sunday 11 September 2016 was very successful with over 30 members, new and old, attending.

Nicole Millis, Executive Officer of Rare Voices Australia, gave an informative presentation on the history of that association and how it is endeavouring to support and advocate for people across Australia with many and varied rare diseases.

Her presentation was recorded and the DVD will be forwarded to current financial members when it becomes available.

Election of Office Bearers for 2016-2017

The following were elected to the Management Committee until the 2017 AGM:

President	Carol Buchanan
Vice-President	John Noble
Secretary	Anita Jackson
Treasurer	Denise Hannay
Committee Members	Shirley Johnston, Anita Jackson, Susan White, Rosalyn Holland, Donna Formosa

Subsequent to the AGM, the Management Committee took steps to address the situation of the vacant Secretary position. The relevant legislation under which the MGAQ operates, the Associations Incorporated Act 1981, and the MGAQ Constitution and By-laws, provide for the Management Committee to appoint a Secretary if the position is vacant.

Anita Jackson, a member of the management committee, offered herself for the position of Secretary. She was appointed as Secretary unanimously by the management committee through a telephone voting process.



PRESENTATION BY NICOLE MILLIS

All current financial members will receive by post a DVD with Nicole Millis' presentation to the AGM.

Nicole is Executive Officer of Rare Voices Australia and her bio appeared in August's edition of MessaGes.



This month, we welcome the following member:

Elsie
Burleigh Waters,
Queensland