



Myasthenia Gravis Association of Queensland Inc

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Messages

MYASTHENIA GRAVIS ASSOCIATION OF QUEENSLAND INC.

DECEMBER 2019

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.

PRESIDENT'S REPORT

Another year nearly over! The Christmas Function held on the Gold Coast was a happy day of meeting old and new friends. The committee enjoyed the opportunity to simply socialise after yet another outstandingly productive year.

The 2019 highlights have been many and varied. Our hard working management committee plus some energetic volunteers have ensured that we have met our commitments outlined to Queensland Health and circulated to members in our Annual Operational Plan. Significant highlights include completing and having accepted our new Rules (Constitution) at the AGM, more formal and informal contact with members through the work of our co-ordinators, continuing to upgrade our website and its capabilities after gaining a grant from the Gaming Community Benefits Fund, streamlining our financial and membership details management, extending our Coffee and Chats in the Brisbane area, producing more fact sheets for members, working through the MAA to get the eNID project phase one towards completion and hosting a very successful National Conference in Brisbane. Many ongoing projects will keep us all very busy and engaged next year.

Thanks must go to the medical professionals who we consider to be Friends of the MGAQ. Dr Cecillie Lander, Dr Stephen Reddel, Dr Stefan Blum, Prof. Pamela McCombe, Dr Katherine Buzzard always give their time and expertise very freely and are always there should the association need advice.

The MGAQ wishes to acknowledge the Red Cross and Blood Bank for all the work they continue to do to supply blood in various forms which are necessary for the production of products necessary for people with Myasthenia. Their wonderful work which helps with the levels of wellness of people with Myasthenia was highlighted during Blood Donation Week when stories about two of our members from Townsville and Mackay featured in articles in the local newspapers. Their stories were very positive in relation to recognition of people who take the time to donate blood and encouraging others to think about doing the same.

It is very reassuring that we always have someone on the end of the 1800 number to talk to and send information to prospective members. It is also great to meet and greet long-term members as well as new members at our various get-togethers. We thank all our members for their loyalty. With the worry all of the bush fires and driving rain in the lead up to Christmas, we also hope that all our members and their families are safe.

The committee will now take a break and resume activities in February. Their work throughout this amazing year is much appreciated by me. I wish them a well deserved rest and a happy Christmas. The management committee also wishes everyone a Christmas filled with family, love, laughter and, most importantly, good health.

Cheers, Carol

Supported by



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Myasthenia Alliance Australia President's Annual Report

1 November 2018 – 30 October 2019.



Yet another amazing year for the Alliance! The MAA Board are extremely proud to report that, through the past twelve months, they have been very active and have remained highly focused on the diverse agenda of this organization.

Regrettably, after 6 months of this term, Dianne Herbert was unable to continue in her position and we express our thanks to her for her support to the Alliance and wish her well for the future. The Board is currently operating on a complement of 5 members. Sincere appreciation is expressed to Carol Buchanan, Glenda Bidner, Ian Hollingworth and Robert Dadge for their invaluable input through this fifth year of operation. Sincere thanks must also be extended to the MGNSW and MGAQ Committees for making the conference achievable.

The objectives of this organization include providing support and advocacy via a united position for all Australians. Work this year has encompassed bringing people together for support and education, fostering research and creating awareness with a focus on Federal Health policies.

A third National Conference was hosted in Brisbane on August 3rd. With 147 registrations and a very full and varied programme it stretched the Alliance resources to capacity. Much gratitude must be expressed to Dr. Stefan Blum for facilitating this collaborative opportunity. The work was paced over an 8 month period and he thoughtfully responded at every step of the process and to every request including an ABC media opportunity. All the feedback indicates that both speakers and guests thought the day a huge success. Connections were made and potential projects identified. These have been followed up.

CSL were strong supporters of the Conference and took a keen interest in the work of the MAA and the State Associations. On-going discussion has brought forward several opportunities and we look forward to bringing these to our community. The MAA remains very committed to partnering with Rare Voices. Susan attended the Rare Diseases Day Function hosted by Nicole Millis (CEO Rare Voices) in Canberra in February and met with Minister Hunt, his key Assistant Sam Develin, and Parliamentary Friends of Medicine

MPs John Alexander and Dr. Mike Freeland. We were thrilled to have Nicole agree to be a key speaker at the Conference. She guided us to successfully bringing about the changes we seek. Working collaboratively continues to be a priority.

Pursuit of gaining PBS access to Rituximab for the treatment of myasthenia continued throughout the year. With support from Dr. Blum, Dr. Reddel and Prof. McCombe a submission was sent to Minister Hunt. A prompt response was received encouraging the MAA to work through a process. This we continue to do with on-going higher-level conversations with the Therapeutic Goods Administration (TGA), the Pharmaceutical Benefits Advisory Committee (PBAC) and with Roche who produce the drug. Individual members approached local Federal Politicians who in turn approached the Minister with regard to this question. Supporting information continues to be gathered and the quest continues.

A constant question for the State Associations has existed around giving advice regarding the safe use of medicines when people suffer with myasthenia. Sufferers had become fearful and the ignorance of practitioners remained. A lengthy attack of this problem resulted in Dr. Blum (MAA Medical Advisory Board Member) working with us to produce a new guideline for all Australian sufferers. We thank him for supporting this initiative and happily report that it is available on the MAA website for everyone and also through the State Associations.

RPP Group, sponsored by Terumo (makers of Plasma Exchange Equipment), approached the MAA to participate in a conversation to the Australian Government regarding the Use of Therapeutic Plasma Exchange in Neurological Conditions in Australia. The MAA considered that enhanced offering of all suitable forms of treatments for Myasthenia is a priority. Susan and Carol have worked with RPP Group to ensure a comprehensive conversation around this treatment form. A Position Paper was written and this has been presented to MP Dr. Mike Freeland. This is an on-going project for RPP Group and the MAA are kept informed of developments.

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Research continues to be a top priority for the MAA. When people with an interest in our condition register with the MAA website and the State Associations it empowers the Board to offer wide reaching and effective communication with the Australian Myasthenia community. This is a significant strength for any rare disease and is very encouraging to researchers.

- The eNID project progressed slowly during the year but with strong support from the MAA it has not stalled and the next stage is expected to be reached early in 2020.
- The MAA has been a keen advocate of a Physiotherapy Research project undertaken through the University of Queensland and supported by the MGAQ. Special presentations and access to sufferers was organized as a part of the conference. The first stage has been completed with more research following.

- The RBWH and UQ Patient Survey remains an important project and is supported by the MAA.
- Several additional approaches have been made to the MAA by assorted researchers. If suitable they are referred to the Medical Advisory Board. The gene work of Amplobiotechnologies is being closely followed and a link to the website is found on the MAA site.

A new MAA website was developed. It is one that can do so many things! How fortunate that a Myasthenia sufferer who happens to be a web designer offered to rebuild the MAA website as a gift in preparation for the conference. Our most sincere appreciation is expressed to Anna Wilen-Clarke. The new website is a fabulous asset and development is continuing.

Financially the MAA is in a stronger position following a successful conference and generous donations from several individuals.

Susan White, MAA Chairperson

**Follow the work of the Alliance by registering at the website
www.myastheniaallianceaustralia.com.au**

MGAQ members targeted in email scam!

A few MGAQ members were targeted by an email scam which aimed to get the members to transfer money to a hacker posing as a trusted party.

These scam e-mails can be difficult to catch because they appear to be harmless, have a normal, friendly tone and no links or attachments. They may appear to come from a Committee member (such as our MGAQ President) and ask you for sensitive information, or, to initiate a funds transfer.

Some things to watch out for:

Non authentic email addresses. Watch out for non-authentic email addresses like: mgagpresident@gmail.com, or Carol Buchanan <presidentmeboxnewmail@gmail.com>. Note: all official MGAQ correspondence should come from a position@mgaq.org.au email address.

A hurried tone. Scammers will often ask you to send money or information immediately, stating that they're busy or in a meeting, and can't do it themselves.

E-mail only. Since the scam relies on impersonating a trusted party via a fake, yet similar email address, they will ask you not to call with questions and only reply through e-mail.

If you receive an e-mail that you suspect to be part of a scam, or, if you are unsure of an e-mail's legitimacy, please do not respond. Instead, forward the email to: mgagit@mgaq.org.au

Remember, nobody from the MGAQ will ever request personal information, usernames, passwords, or money from you via email.

MGAQ Inc. Christmas Function

Sunday, 15 December at Southport Sharks Club

Once again the Gold Coast group proved that they enjoy getting together, having fun and bringing about lots of lively conversation. For those who travelled from Brisbane to enjoy the annual MGAQ Christmas Party on the Coast, they were well rewarded with good company, a very comfortable venue, Christmas chocolates and first access to some new MGAQ product! This group of 30 gathered together for almost three hours.

Thank you to Nader (Gold Coast Co-ordinator) and Anita (MGAQ Committee member) for organising such a delightful time.





Myasthenia Alliance Australia – Conference 2019

Break-Out Session from the MAA Conference



Kristen Eales
Master of Physiotherapy

Physiotherapy Rehabilitation Sessions for Myasthenia Gravis

"Kristen graduated from the University of Queensland with a Master of Physiotherapy studies in 2014. Her clinical practice entails a combination of hands-on therapeutic techniques and exercise rehabilitation within the scope of musculoskeletal complaints, neurological conditions and post-operative orthopaedic surgeries. She has undertaken further training in the use of Pilates informed exercises for neurological conditions." She explained how her skills are applied in the physiotherapy practice to support people with Myasthenia.

The first session assesses general strength and mobility, discusses goals and then develops a program based on these assessment findings and goals.

Subsequently there is a run-through of basic exercises that may be included in an introductory session/program. It is explained how a combination of small props including balls, therabands, small hand weights and Pilates informed exercises on spring loaded equipment will be utilized.

Discussion will focus on how exercises can be assistive and resistive to address bone density, increasing strength and stability and improving balance for falls prevention."

Kristen spoke about the benefits of any form of movement and exercise, setting goals and working slowly towards them. She spoke of the benefits of Rehabilitation Physiotherapy (Pilates) which is individually tailored. Kristen demonstrated to the group the use of some of the equipment that can be used and how small movements can bring significant advantages. Examples included using basic tools like stretchy bands or balancing on one leg whilst holding onto a bench.

She stressed that having a programme designed especially for you and what you are hoping to gain from the exercise is critical to success.



Welcome to our new members

Annette H,
Brookdale,
WA

Yvonne L,
Byford,
WA

Alexander F,
Mountain Creek,
Qld



COMPETITION WINNER



THE WINNER OF THE KITCHEN
BUNDLE OF ENJO PRODUCTS IS...

JODY

*Congratulations to the winner and thank you to
everyone who shared their conference highlights!*

MAA MYASTHENIA CONFERENCE ATTENDEE HIGHLIGHTS

Personal highlight was my husband joined me and WOW the day was so insightful for him. As we live six hours away from my specialist, run a business, have a family, we rarely have the opportunity to travel together to do weekday appointments. So to educate him 8 years after a diagnosis was such an eye opener. A weekend together with MG being our primary focus was a first for us. He walked away with a new appreciation and understanding of the disease. It allowed my hubby and I to go crap this is bloody hard and it is a fight everyday to just wake up and start again and see what the day might bring. Mg impacts my life on a daily basis. Every movement, every outing is calculated and planned and risks are assessed. He has a new respect for the days I do get out of bed and for pushing myself when and where I can. He learnt it was good to push the barrow as long as I listen to my body. My husband was constantly worried about me overdoing it and would rather cover me in cotton wool than to let me walk to the beat of my drum on those days where I feel I am capable.

Which leads me to my highlight, meeting Professor Blum. He was my wow factor. I am grateful he attended and really added clarity when he articulated that point beautifully. Push yourself to do what you can without overdoing it.

I am forever grateful for a number of things we both learnt. Thank you. Keep up the wonderful job. Forever in your debt. - **Jody**

An unexpected highlight for me was the 'ooh's' and 'aah's' being heard as participants shared personal stories about their journey with Myasthenia Gravis - lightbulb moments everywhere! - **Cheers Carol**

One of my highlights was meeting the lady, who had never meet any other Myasthenia sufferer before and was so overwhelmed that she had a little cry. She said she felt like she had found her special family. - **Cheers, Denise.**

Good morning, I am writing to describe my "unexpected highlight" at the 3rd National Myasthenia Conference. "I have now attended all three National Conferences with my friends. The organisation was of the highest standard - but that was as experienced previously. Also the knowledge and enthusiasm of the presenters - particularly the new emerging talents - was overwhelming. But that also continued previous experiences.

The unexpected highlight that is large in my memory is the manner in which the presenters and sponsors were so willing to share their knowledge and time in informal discussions with all attendees during the meal and break sessions. We felt very privileged to have had these opportunities." - **Kind Regards, Allan.**

"I was very impressed with the quality of the presenters and of the information provided. The conferences keep getting better. The breakout session with Dr. Stefan Blum was very interesting.

"Thank you for arranging this Conference. I look forward to the next." - **David**

I found the Conference well presented and rather enlightening, in particular, the section on The Broken Heart. There was very little to criticise, on the whole, perhaps, one secessions was a little long. During the lunch break, we met a young- newly diagnosed suffer, who seemed to be encouraged by seeing fellow suffers living a fairly ordinary life. I feel this is very necessary as one can feel alone when told one has MG. - **Jeannine**



WHAT'S NEW FOR THE MGAQ

Consistent with its Rules the MGAQ, through its Management Committee, has always had a focus on growing the benefits available to its member community.

One of its present projects, which shall be released progressively through 2020 and beyond, involves the production of a group of audio and video podcast series. The project targets enhancing the knowledge and awareness of MGAQ

members about myasthenia gravis (MG) and on approaches for how best to live with MG.

To facilitate this activity, the MGAQ sought and was granted funding from the Queensland Government to purchase equipment, inclusive of hardware and software, to enable the production of these audio and video podcasts. Currently five (5) series are planned.

They include:

Series 1 – Web deliverable Video Library Series

Series 2 – Ask the Expert Series

Series 3 – My Journey with Myasthenia Gravis Series

Series 4 – Medical Presentation Series

Series 5 – Building Health & Fitness with MG Series

Over the next six months we will be discussing, in the Newsletter, with the MGAQ Community what is proposed through each of these various series and seeking the assistance of the MGAQ community, as required, to make each series as effective as possible to the members needs.

We note that whilst the Queensland Government's generous funding has helped with the supply of hardware and software, it is still up to

the MGAQ community to produce these audio and video podcasts.

For this, **HELP will be required**. If you or a family member has an interest in being involved with this project, please contact the MGAQ Helpline to indicate that interest.

A podcast program team member will call back to discuss potential opportunities with the interested person.

Mark White



NEWS FROM AROUND QUEENSLAND

News from Cairns

Cairns had a good attendance at the final gathering for the year. We look forward to seeing everyone again in 2020.

For more information, please contact Donna on 0414 397 462 or donnaformosa64@gmail.com

News from Townsville

The next lunch will be held on **Saturday, 29 February, 2020 at 12 noon, at The Avenues Hotel, Kirwan.**

Members and friends enjoyed our Christmas lunch. We would like to thank all committee members for their work with MG.

For details contact Daphne on 0400 778 637 or daphclay@gmail.com

News from Mackay

For information for the Mackay region, please contact Muriel on (07) 4954 1221.

News from Hervey Bay - Wide Bay Burnett Region

For more information please contact Jan janpowell3@icloud.com

News from Gladstone – Wide Bay Region

For local support in the Gladstone – Wide Bay region, call Garth on 0408 155 954 or (07) 4973 7983.

News from the Sunshine Coast

For more information about the Sunshine Coast group, call Colleen on 0409 491 789 or email colleen4551@gmail.com

News from the Gold Coast

Hi Everyone. Our Gold Coast MG group had their Christmas celebration gathering with Brisbane head office at Southport Sharks Club on Sunday December 15.

Our next get together will be on **15 February, 2020 at the Kurrawa Surf Club, 10am.** I look forward to seeing you all.

Merry Christmas and a happy New Year. For more information about the Gold Coast group contact Nader on 0415 834 401.

News From Brisbane

Coffee & Chats are a good opportunity to connect with people in your area. All are welcome.



Ipswich

Saturday, 2 February at 10am -

Queens Park Café, 10A Merle Finimore Ave.

For more information, Contact Anita on 0414 588 312

*The Myasthenia Gravis Association of Queensland Inc.
Committee would like to wish everyone a*



*Merry
Christmas*

and a safe and happy New Year!

MessaGes will take a break over January and looks forward to resuming in February 2020. Thank you to all contributors during 2019.