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Fall MG Support Meeting

Sunday, October 22nd at 1:00 pm

2805 Kingsway, Vancouver, B.C.

- Sandwiches and healthy food will be available for your enjoyment.
- Our new President will tell her MG story and we welcome MG stories from the floor.
- Our Medical Advisor will be presenting and taking questions.
- Meet Our Fellow Dr. Laura Marulanda, congratulate her on becoming our fellow and learn why she has an interest in MG.
- Questions to our presenters.
- Friends, relatives, health professionals and other interested parties are welcome to attend.
- This meeting is a support group meeting, no business will be conducted.

**PLEASE HELP US REDUCE PRINTING AND POSTAL COSTS BY
READING THE NEWSLETTER ONLINE ON OUR WEBSITE –**
[**https://myastheniagravis.ca**](https://myastheniagravis.ca)

Articles contained in this newsletter are for information only. The MG Association of B.C. does not give medical advice in matters of medical treatment. Patients should consult with their physicians.

OUR BOARD

**Myasthenia Gravis
Association of B.C.**

**2805 Kingsway,
Vancouver, B.C.
V5R 5H9**

(604) 451-5511

**President Kelly Carson
at ext. 1284**

- Kelly Carson - President
- Linda Briggs - Treasurer
- Joel Oger - Scientific Advisor
- Stephen Baker - New Vice President

Board Members at Large:

- David Sutherland
- Nancy Headley
- James Postnikoff

New Office

[Pic #1] President Kelly Carson (left) and Treasurer Linda Briggs (right) along with

[Pic #2] Linda's grandson after the move into our new office space. Same address, new space with awesome windows.



1



2

The current treatments for MG are sufficiently effective that the outlook for most patients is bright. Although the treatments will not cure MG, most patients will have significant improvement in their muscle weakness. In some cases, MG may go into remission for a time, during which no treatment is necessary. There is much that can be done, but still much to understand. New drugs to improve treatments are needed. Research plays an important role in finding new answers and treatments for MG. Your support can make a vital difference in the research for a cure for Myasthenia Gravis. To make your donation:

Please refer to the Donations Form on the last page of this Newsletter.



From Our Scientific Advisor

– By Joel Oger

Dear members of the Myasthenia Gravis Foundation of British Columbia, My name is Joel Oger, I am a retired neurologist with a special interest in MG. The Board of MGABC has offered me to be the Scientific Advisor for the group. I already sit as a Scientific Advisor of the MGF of Canada. These are volunteer positions and I am honoured to have been offered them. I will try to be a translator/interpret between Scientists and Members.

I will take my walking orders from my reading of the scientific literature, but do not hesitate to write to me with your questions through the website. For the first of a new series of Newsletters, I have chosen the subject of Thymectomy. As you know, thymectomy is generally recommended early in the treatment of patients with recent onset of MG who have antibodies to the acetylcholine receptor, if they have generalized disease and are under the age of 65. The majority of these patients will have lymphoid follicular hyperplasia (LFH) of their thymus. A small number will have a tumor of their thymus which generally is also operated on. The benefit of removing the thymus in case of LFH has been well demonstrated in an earlier clinical trial where patients who underwent thymectomy did much better over the following 2 years than their controls who did not have thymectomy done.

Fifty-two patients from Vancouver volunteered for that trial. I am reminding you of these results because a group of physicians from Harvard has recently published a study where they found that patients (non-myasthenic) who had thymectomy done for removal of a thymic tumor later developed twice as many cancers than the controls who had not had surgery done. This could have been of concern for MG patients who had also had their thymus removed. Together with the other MG Foundation of America Scientific Advisors from all over the world, we looked closely at their publication and noticed that the patients who were studied all had surgery for removal of a tumor of their thymus. We conclude that this was a major difference with patients with MG. As 90% of MG patients have hyperplasia and that these new observations can only be applied to the less than 10% of MG patients who had thymectomy done to remove a tumor of the thymus. One simply cannot extend to all MG patients the increased risk of developing cancer which has been found in patients with a tumor of their thymus gland. A new specific study would be needed to know if their observation would even apply to the rare MG patients who have a tumor of the thymus.

Joel Oger D. en M., FRCPC, FAAN, FANA.

Recruitment of patients to the Myasthenia Gravis Association of BC.

New Diagnoses of MG in B.C.

Zarah Pakzad, one of Joel Oger's students has counted how many new diagnoses of MG are made in BC. This represents "incidence". How many patients are alive with MG represents the "prevalence". Prevalence should be obtained from the Health ministry and we don't have access to this. However from her data we can calculate an approximate incidence.

How did she do? As a marker she took the number of names with a first AchRAb positive tests in one year. Numbers calculated from the data of the Neuro-Immunology lab at UBC*

Calculations are as follows:

In 1984-1989 was 54 per million, seniors = 54 new AchRAb+ /year/million.

Extrapolate to population of 2022 = 54 becomes 59.

Add all ages = 59 becomes 89.

There is still 10% AchRAb negative = 89 becomes 97.

Among oculars 25% are negative = 99 becomes 124.

Let us state conservatively around 125 new diagnosis/ year.

Reference: Pakzad Z, Aziz T, Oger J. [Increasing incidence of myasthenia gravis among elderly in British Columbia, Canada.](#) Neurology. 2011 Apr 26;76(17):1526-8.

In contrasts with those numbers, MGA of BC a.k.a. MGA of Canada presently has 210 members registered. And we have only recruited approximately 12 new members in 2022. Lots of work ahead.

Patient Stories

On May 25th, 2023, I had a thymectomy which removed a thymus measuring:

Lobe 1: 10.4cm x 4.9cm x 2.2cm
Lobe 2: 13.5 cm x 3.4 cm x 1.2 cm

This would produce a maximum volume of 168cm3

Research for my age group indicates that a thymus measuring 2 cm x 1 cm x 0.5 cm could be expected. This would be a volume of 1 cm3.

My three chest CT with contrast previously to the surgery showed nothing abnormal. This very large thymus was completely *invisible*, and this stretched from my thyroid gland in my neck down to my diaphragm. It was connected to my pericardium and was compressing my major arteries above my heart.

Before and after pictures below:



Before



After

You can see my face was edematous prior to the surgery. I struggled to find glasses to fit my very round large face and head. 5 days after the surgery, you can see the swelling in my face and neck had disappeared. I now have a chin and jawline!

The salient piece here is that I have seronegative MG, and my diagnostic journey was extremely challenging to say the least. Many well intentioned and very knowledgeable neurologists along this journey dismissed my symptoms and recommended that I see a good psychologist! The neurologists were fixated upon test results, and they were not interested in the positive ice pack test for my left eye ptosis or my positive response to mestinon.

They had no time to listen to me even though my symptoms were classic generalized MG. Everyone thirty years ago was seronegative by default, as antibodies had not been discovered. However, many neurologists seem to have forgotten this.

ARE YOU INTERESTED IN VOLUNTEERING?

- * Are you an IT person;
- * Communications;
- * Newsletter Editor;
- * Fundraising;
- * Stuffing envelopes;
- * Start a local MG support group;
- * Help with meeting setups/ takedowns;

Go to our website, shoot us a message, or send us a message when you pay your dues, help us ensure that no Myasthenic needs to feel alone.

Tips for Taking Your Medication Properly

Keep a list of all the medications you take - include the name and dose, when you started taking the drug and why you take it. Include herbal or nutritional supplements.

Keep a list of allergies that you have - Many patients believe that they are allergic to a medication when in fact they are experiencing a side effect that may be expected for that drug.

Be aware of the signs and symptoms of an allergic reaction - You may be allergic to a drug if you experience skin redness, rashes, hives, itching, flushing swelling of the eyes, face, lips, tongue and throat, feeling of faint, a rapid heart beat, difficulty breathing wheezing, or difficulty breathing. (Severe allergic reactions can be life threatening)

Luckily, I was able to use all my knowledge and experience to navigate the healthcare system and was able to find a neurologist to 'listen' to me' and provide me with the opportunity of treatment. If I had not had this experience, I would have been lost in the system, undiagnosed and untreated, and ultimately died.

I do not believe that I am special in any way, so this begs the following questions? How many other people are out there in BC with MG, especially seronegative struggling to be believed by their Primary Physician and or neurologist that these symptoms aren't psychological? How many people in BC are seronegative and undiagnosed? How many other people are out there with a completely invisible enlarged thymus?

It is seventeen weeks since my surgery and I am slowly seeing an increase in my strength and stamina. This very large thymus, for me, was validation. All these symptoms weren't all in my head after all!!!

-Stephen B

DONATIONS as of September 30, 2023...

- Provincial Employees Fund
- Tom Barret
- Roxanne Bennet
- Jane Bryans
- James Postnikoff
- Linda Briggs
- Alan Thorp
- W Van Linden Tol
- United Way
- Mark Revell
- Gayle Wilson
- Daniel Samson
- Jean Carncross
- Lorne Holyoak
- Velma Cotten
- Brenda Kelsey
- Michael Shirley
- Stephen Baker
- Lisa Brink
- Anonymous
- Anonymous
- Kelly Carson
- Eileen Maltinsky

PayPal Giving Fund: No access to donor names, but you know who you are and we thank you.

Donations In Memory of...



*Beverly Craig, in memory of
her Loving husband*

Alfred Craig

Corporate & Research Donations

- Joel Oger
- Nora Moore
- Rosa Tesler

WE APOLOGIZE FOR ANY ERRORS OR OMISSION

Many Thanks to All!

Take medications exactly as prescribed - by your doctor. Do not change or stop taking medication, change the dose or how often you take the medication without direction from your doctor.

Know the side effects of your medications - All medications have side effects. It is important to know what to do if you experience bothersome, continuous or serious side effects. Many medications should not be stopped abruptly unless the side effects are serious. Discuss side effects with your doctor.

Get rid of old and used medications - Medications can become ineffective over time: check the labels for expiry dates. Labels can be confusing so check with your pharmacist, a nurse or doctor. Medications should not be thrown out at home. Most pharmacies will take your old medications and dispose of them properly.

Do not share your medication and keep out of reach of children.

Store your medication Correctly. Many medications are affected by temperature, light and moisture.

Inform your doctor if you are pregnant or are thinking of becoming pregnant. Many medications can be harmful to the fetus.

Interim Editor:

Glen Skidmore!

College of Nursing
University of Saskatchewan



**PARTICIPANTS NEEDED FOR
RESEARCH IN *Myasthenia Gravis***

We are looking for volunteers to take part in a study
of
*experiences of individuals living with Myasthenia
Gravis in seeking disease-related information.*

As a participant in this study, you would be asked to:
participate in in-person or online interviews via
Zoom.

Your participation would involve *four to six* sessions,
each of which is approximately 60 minutes.

For this study participants will need to be between
eighteen and sixty years old, living in British
Columbia, Alberta, Saskatchewan, or Manitoba, and
have a confirmed diagnosis of MG for at least one
year.

For more information about this study, or to volunteer for
this study,
please contact:

April Fox, RN, Graduate Student
College of Nursing, University of Saskatchewan
Email: apf002@usask.ca

Noelle Rohatinsky, RN, PhD, Associate Professor
College of Nursing, University of Saskatchewan
Email: noelle.rohatinsky@usask.ca

**This study has been approved by the University of
Saskatchewan Behavioural Research Ethics Board**



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LITERATURE ORDER

Name _____

Address _____

LITERATURE AVAILABLE:

1. Myasthenia Gravis Facts
2. MG Glossary: Definitions of medical terms used in M.G.
3. MG Survival Guide
4. Drug pamphlets: (a) Mestinon (b) Imuran (c) Prednisone (d) Cyclosporine (e) Cellcept
5. Drugs that aggravate MG - 2012
6. Tacrolimus* - New drug for immunosuppressive medication
7. Plasmapheresis
8. IVIG - Intravenous Gamma Globulin
9. Ocular MG
10. Nutrition for Healthy Bones
11. Dentistry and the Myasthenic
12. Pregnancy and Myasthenia Gravis
13. Myasthenia Gravis in Children and Adolescents - **NEW**
14. Congenital Myasthenia Gravis
15. Emergency Care of Myasthenia Patient
16. Mestinon - A possible emergency measure
17. Assessment & Management of Speech & Swallowing in Myasthenia Gravis
18. Hospital Package: Nursing Care of the Myasthenic; Hospitals Can be Dangerous; Anesthesiology Drugs
19. Practical Guide to MG
20. Dr Oger's book for Family Physicians - free to MG members
21. MG ID Emergency Alert Card
22. Providing Emotional Support for patients with MG
23. Myasthenia Gravis Information for GPs **NEW**
24. Tips on applying for CPP Disability Benefits
25. Disability Tax Credit - Form T2201 **must be** downloaded at www.cra-arc.gc.ca/E/pbg/tf/t2201

BOOKS AVAILABLE:

My Imaginary Illness - Dr. Chloe Atkins, A Journey into uncertainty and prejudice in medical diagnosis.
(for short term loan or purchase through your local bookstores)

Please note: General Myasthenia Gravis information is now available in Mandarin. If you would like a copy, please contact our offices.



MEMBERSHIP & DONATIONS

MGABC'S membership year is January 1st to December 31st. Membership received after October 1st will be good for the following year. To donate, please complete the form below and return it with your cheque or money order (we cannot accept credit card payments and we ask that you do not send cash in the mail).

Your donation and membership fees help defray operating costs, and entitles you to the following; Newsletters biannually..., MG literature and pamphlets, and Notice of meetings...Up-to-date information on MG.

You can Help find a Cure !

Your support can make a vital difference in the research for a cure for Myasthenia Gravis.

Please make your donation by cheque or money order payable to:

University of British Columbia
Research Services
Att: Myasthenia Gravis Research
Grant ID GR015331 Cost Centre CC01858
Fund FD200
102-6190 Agronomy Rd.
Vancouver, B.C. Canada V6T 1Z3

OR

MYASTHENIA GRAVIS ASSOCIATION of BC
– MG Research
MGABC
2805 Kingsway
Vancouver, BC V5R 5H9

Last Name _____ First Name _____
Address _____ Prov. _____ Postal _____
Code _____ EMAIL _____ Phone _____ MG Patient Yes No

Membership \$20.00 Donation:

TOTAL AMOUNT ENCLOSED

\$ _____ (no tax receipt will be issued) \$ _____ (a tax receipt will be issued for
donations) \$ _____

Have you moved? Please send in the information as soon as possible!

Last Name _____ First Name _____
Address _____
City _____ Prov. _____ Postal Code _____
Phone _____ E - MAIL _____