Meet your new Logo developed by Odette Montelibano, MG Canada Director of Communications, with input support from all your MG Directors and Adam Senour. Hope you agree it is beautiful and inspirational. Highlights of this issue:

- Our New logo for Myasthenia Gravis Society of Canada
- MG Support Canada Facebook conversations
- International Congress on Neuromuscular Diseases, July 5-9, 2016, Toronto, Canada (ICNMD2016)
- ICMND2016 – this is a really big deal & how you can be part of MG Canada’s participation in the July 5-9, 2016 International Congress as an MG Canada Volunteer–coordinated by MG Director Tara Buonpensiero
- Speech by Dr. Doug Brodie, made January 30, 2016 on ”Getting Older Hopefully” – a Valentine to Yourself.
- Summary of MG Canada Christmas Support meeting featuring Professional Massage Therapist Christina Gutierrez, RMT.

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President’s Message—Continued from Page 1

I followed up my New Year resolution to trim down a bit. So far so good. Pants are starting to get looser. Shocked Betty by suggesting a walk on Sunday afternoon all the way to ‘Red Bulb’ for coffee and back. Farthest I’ve walked with her in years. Felt good. Walking sticks helped.

I hope you can make our February 14, MG support meeting. Join the conversation – in person. Besides it’s Valentine’s Day, February 14. A little love can go a long way.

Sincerely, Cap Cowan, MG Canada President and Editor of ‘Contact’ Newsletter.

CapCowan@MGCanada.org 905 642 2545 Call anytime

Prestigious International Congress on Neuromuscular Diseases Coming to Toronto

The next International Congress on Neuromuscular Diseases will be held in Toronto from July 5 – 9, 2016. Dr. Vera Bril and the organizing committee are very excited to be hosting this important conference in Toronto. The Congress has been located in Europe for its meetings excepting the inaugural meeting in Vancouver in 2002. They hope to follow in the successful footsteps of the meetings in Vancouver, Istanbul, Naples and Nice.

A fabulous program is planned for the over 1,000 Neurologists attending. Sessions range across the spectrum of neuromuscular disorders, including sessions on Myasthenia Gravis. The Myasthenia Gravis Society of Canada will be taking an active supporting part.

See Page 4 for information on how you can help at the Congress.
Myasthenia Gravis Society of Canada

MG Support Meeting

Sunday, February 14th, 6 - 8 pm

Support Meetings are for those living with Myasthenia Gravis, caregivers, family, friends & interested others to meet.

All Welcome!
Tai Chi Presentation by Fung Loy Kok Taoist Tai Chi of North York
Nicole Morency will spearhead the volunteers.

Loblaws Community Meeting Room, Bayview Village Mall, 2877 Bayview Village, North York, M2K 2S3.
(The Meeting Room is located upstairs, S/W corner of the store, Elevator access.) Public Transit Access, subway access at Bayview Station on the Sheppard

For this meeting, we request those members who are able, with last name starting M-Z bring a food item to share. Loblaws has asked that any food served come from their store.

Info at 905 642 2545           www.MGCanada.org
Myasthenia Gravis is a neuromuscular disease that affects the muscles of the body. It is caused by a problem with the way the immune system works. The immune system is supposed to protect the body from foreign invaders, but in people with myasthenia gravis, it can also attack the muscles. This can lead to weakness and fatigue in muscles throughout the body. Treatment usually involves medication, surgery, and physical therapy.

Laughter is the Best Medicine  After an accident, a woman stepped forward and prepared to help the victim. She was asked to step aside by a man who announced, "Step back please! I've had a course in first aid and I'm trained in CPR." The woman watched his procedures for a few moments, then tapped him on the shoulder. "When you get to the part about calling a doctor," she said, "I'm already here."

Happy Valentine's Day

Laughter is the Best Medicine  After an accident, a woman stepped forward and prepared to help the victim. She was asked to step aside by a man who announced, "Step back please! I've had a course in first aid and I'm trained in CPR." The woman watched his procedures for a few moments, then tapped him on the shoulder. "When you get to the part about calling a doctor," she said, "I'm already here."
Getting Older Hopefully
– Dr. Doug Brodie, MD, Stouffville, Ontario, Canada

Editor’s Note: Presented as a speech to Stouffville United Church Men’s Fellowship Breakfast, January 30, 2016. Text material supplied by Dr. Brodie as content of his speech. Dr. Brodie continues to practice medicine in the Greater Stouffville area, in particular focusing on geriatrics at Bloomington Cove Nursing Home, Whitchurch Stouffville.

Getting old is not a disease. You don’t die of old age. You die of tangible something. Getting old is the maturing of body, mind and spirit helped by optimism - a positive attitude challenged by the 5 D’s. Deflation. Disease. Depression. Dementia. Death.

1) Deflation: This is my term for the wearing out of each of the five senses

   Vision may dim, but you will always remember those beautiful sunsets.
   Your health may become impaired but you will always remember your favourite songs or music.
   Your sense of smell may diminish but you will always remember the smell of your favourite flower or your morning coffee.
   Taste may become less discerning but you will always remember mom’s apple pie or a single malt scotch.
   Touch – this sense you never forget. You always enjoy a hug – or the encouragement of a pat on the back.

2) Disease: This is anything that interferes with the quality and perhaps the quantity of living. There are broadly 3 types of disease. Treatable. Resolvable. Terminal. The amount a disease process interferes with living depends on two facets. The Physical disability. The Psychological stress it produces.

   This is exemplified by the big “C”, Cancer. Although Cancer’s 5 year survival rate has greatly improved over the past 10 to 15 years in almost all types, we fear this diagnosis, at times almost unrealistically.

With disease we go through five stages of grief:

   Anger. “Why me! I have done nothing to deserve this!”
   Denial. “Not me! I’ve always lived a healthy life. I need a second opinion.”
   Bargaining. “Maybe I have neglected or abused myself in some way. I promise to reform. Let me live!”
   Depression. This can be the product of any disease and lead to apathy - indifference. We give up. Disease conquers us.

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Acceptance. This is the stage which unfortunately some never attain. It’s living again within our known physical restraints. This is for some, the time for the “Bucket List”

3) Depression of Loss: As we mature we are all going to have losses.

Failing health and body resilience.
Loss of loved ones, friends, pets.
Loss of job, Retirement and some loss of purpose for living.
Loss of disposable income
Loss of home and resultant relocation
Loss of self worth which robs you of effective productivity

Don’t let Depression frustrate and produce fear. This leads to anger, isolation and loneliness, even in a crowded room.
Don’t Isolate – Communicate
Realize and empathize - there are always others around you in the same boat.

4) Dementia: This is the slow progressive loss of “reality and reason”. It effects 8 to 12% of people over 75 years to the extent of requiring full time assistance for (A.D.L.) - Activities of Daily Living.

Causes of Dementia are many and varied. In any paper on Dementia one would have to begin with systematic classification of etiology – how boring.

Congenital - genetically pre-existing.

Acquired. Infection, Vascular, Neoplastic, Traumatic, Autoimmune, Degenerative and Endocrine, can be causes.

Just like the ‘Big C’ instills fear and apprehension, the ‘Big A’, Alzheimer's disease runs a close second.

Most dementing conditions (diseases) are diagnosed after the fact. This is when a Neurologist describes a set of symptoms – say apathy and decreased cognition in the living patient and sets out to find at post-mortem, brain findings – finds them (questionably) attaches his or her name and voila – Alzheimer's Disease, as in the case of Dr. Alowishus Alzheimer in the early twentieth century. This disease is highly over diagnosed by our friends and relatives, sometimes incriminating us.

One important thought – Psychiatrists often use the diagnosis of Pseudo-dementia to describe people who are depressed, so try not to complicate things.

Caveat

Because Physical and Cognitive problems can be sudden in onset, we all should be prepared – with four legal documents to be made known our wants, needs and desires.
These are:

1) **The Living Will** – this tells family (or significant other) what we expect as we leave. “May we live as long as we want to, but want to as long as we live.” What measure of heroic care do we want? CPR? Respirators? Catheters? Stomach tubes? – your choice.

These three others are: 1) **Power of Attorney for Personal Care.** 2) **Power of Attorney for Financial Care.** 3) **Will and Testament** - are all legal matters. But remember, nothing causes family dysfunction more than ‘unplanned for’ exit.

5) **That leads to the final “D” – Death. This is the most personal of all the challenges because it is the only one that is universal.** For that reason I believe that you need some degree of Spiritual maturity to cope with it.

In my father’s generation, death approaching, meant cramming for the finals: Perusal of Genesis to Malaki and Matthew to Revelations, seemed to be a prerequisite, though not as applicable today to find questions, answers, peace and hope.

What is Spiritual maturity? Good question. My personal answer – is to have definition or understanding of three things.

Sin. What is sin? It’s always finding a congruency between what you do, and what you know is right.

What is Faith? It is total allotment of control and since death is the ultimate loss of control through faith, it can be the ultimate adventure.

What is God? More books have been written in the Western World on this, I’m sure, than any other subject and I have read more than a few. One answer I finally discovered came at my grandmother’s knee as a preschooler. It’s from first letter of John, Chapter IV, Verse XVI.

God is Love.

In summary: Getting old is not a disease, it is the maturity in Body, Mind and Spirit – with a positive attitude. We must be prepared to face up to the “5D’s” challenge.

Only then will ‘**Getting Older Hopefully**’ be met.
What is Massage Therapy and It’s Scope of Practice?

Massage therapy is an ancient therapeutic technique considered to be one of the oldest forms of treatment known to man.

The practice of Massage therapy is the assessment of the soft tissue and joints of the body and the treatment and prevention of physical dysfunction and pain of the soft tissue and joints by manipulation to develop, maintain, rehabilitate or augment physical function or relieve pain.

Massage therapy is a clinically-oriented healthcare option that helps alleviate the discomfort associated with every day and occupational stresses, muscular overuse and many chronic pain conditions.

Examples of Conditions that Massage Therapy Can Help:

- Headaches/Migraines
- Whiplash
- Muscle Spasms/Strains/Sprains
- Nerve Compression Syndrome
- Poor Circulation
- Post Injury Rehab
- Back, Shoulder and Neck Pain
- Stress and Tension
- Tendonitis

Benefits of Massage Therapy

- Relaxes the whole body
- Relieves Tired and Aching Muscles
- Alleviates Chronic Pain
- Lowers heart rate
- Assists in recovery from injuries & illness
- Reduces tension headaches
- Promotes restful sleep
- Loosens tight muscles
- Increases Flexibility
- Calms the nervous system
- Lowers BP
- Strengthens the immune system
- Reduces mental stress
- Aids in mental relaxation

What is Myasthenia Gravis?

MYASTHENIA GRAVIS (pronounced My-as-theen-ee-a Grav-us) comes from the Greek and Latin words meaning “grave muscular weakness.” It is a chronic autoimmune neuromuscular disorder caused by a defect in the transmission of nerve impulses to muscles. It is not directly inherited nor is it contagious. It is characterized by fluctuating weakness of the voluntary muscle groups. Muscle weakness caused by MG worsens as the affected muscles are used repeatedly; therefore symptoms usually improve with rest.

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How Can Massage Help MG Continued

Alleviate Chronic Pain
Enhances the immune system
Improves concentration and focus
Eases Depression and lessens anxiety
Improves the tone of weak or atrophied muscles
Improve range of motion
Enhances quality of sleep
Reduces fatigue
Reduces cramps and spasms
Improves concentration and focus
Reduces fatigue
Enhances the immune system
Improves the tone of weak or atrophied muscles
Improves proprioception

Check With Your Doctor
Before getting a massage or any exercise program, it is important to check and get an approval from your doctor/physician.

*Massage and exercise when MG is not stable can worsen its symptoms and increase the risk of injury.*

Examples of Postural Exercises

**Chin Tucks**
Begin sitting or standing tall with your back and neck straight, shoulders should be back slightly. Tuck your chin in as far as you can go without pain and provided you feel no more than a mild to moderate stretch. Keep your eyes and nose facing forwards. Hold for 2 seconds and repeat 10 times provided the exercise is pain free. Repeat 3 - 5 times daily.

**Shoulder Blade Squeezes**
Begin sitting or standing tall with your back and neck straight. Squeeze your shoulder blades together as far as you can go without pain and provided you feel no more than a mild to moderate stretch. Hold for 5 seconds and repeat 10 times provided the exercise is pain free. Repeat 3 - 5 times daily.

**Neck Rotations**
Begin sitting with your back and neck straight and your shoulders back slightly. Turn your head looking over one shoulder as far as you can go without pain and provided you feel no more than a mild to moderate stretch. Then repeat the exercise turning your neck in the opposite direction. Keep your neck straight and don't allow your head to poke forwards during the movement. Repeat 10 times to each side provided the exercise is pain free. Repeat 3 - 5 times daily.

Frequently Asked Questions

**Does Massage help MG patient?**
In general massage is good for overall wellbeing and it will definitely help MG patient.

**How often and how long do I get a massage?**
Consult your specialist to make sure that there’s no contraindication. Once or twice a week of 30 minutes will be good.

**Why do I get pain or soreness in my body after the massage?**
It is normal to have soreness for 1 or 2 days after the massage as we release toxins (metabolic waste) from our muscles.
Why do I get muscle spasm?

Medications can deplete the Magnesium level in our body which is the muscle relaxant. Since it is contraindicated, increasing water intake can help in muscles’ rehydration.

Is drinking water good after the massage?

Yes, it is good to drink plenty of water after the massage to flush out the toxins that were released from the muscles.

What kind of massage is best for us?

Swedish massage is best recommended as it is one of the most common massage technique for relaxation. Level of pressure can be adjusted to clients’ tolerance.

Christina Gutierrez, RMT

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**It Pays to Keep in Touch:**

**IN PERSON: Upcoming Events:**

- **Sunday, February 14th, 2016. Myasthenia Gravis Society of Canada Support Meeting**, Loblaws Community Meeting Room, Bayview Village Mall, 2877 Bayview Avenue, North York, M2K 2S3. 6-8 p.m.

- **Thursday, March 17, 2016 Myasthenia Gravis Manitoba Inc. Support Meeting** 7-9 pm Location is at St. Boniface Hospital, 409 Tache Avenue, Basement South Entrance, Rooms AG001 & 2. e-mail: mginc@mts.net

- **Thursday, May 19, 2016. Myasthenia Gravis Manitoba Inc. Support Meeting** Location is at St. Boniface Hospital, 409 Tache Avenue, Basement South Entrance, Rooms AG001 & 2. e-mail: mginc@mts.net


- **Tues.-Sat, July 5-9.** Volunteer to help Myasthenia Gravis Society of Canada at the International Congress on Neuromuscular Disease in Toronto, Contact Tara Buonpensiero, buonpensiero@yahoo.com or by phone at 905-702-0022.
## Ways to Connect….

### BY PHONE: The Peer Support Group.

Whether you have recently received the news that you have Myasthenia Gravis, or you have been living with MG and want to share your experience, these members have offered their support. Please feel free to contact them to discuss your experience.

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<tbody>
<tr>
<td>Ages under 40</td>
<td>Tiina Elder, Mississauga</td>
<td>(905)-565-5875 email: <a href="mailto:tiina.stuart@gmail.com">tiina.stuart@gmail.com</a></td>
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<td>Jill Thomson, 9804 – Avalon Rd. S.E., Calgary, AB, T2J 0V6</td>
<td>(403) 286-0056</td>
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<tr>
<td>Ages 41 – 60</td>
<td>Phillip Sanderson, P.O. Box 206, 27 Adelaide St., Harriston, ON, N0G 1Z0</td>
<td>(519) 338-3356</td>
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<tr>
<td>Ages 61 – 74</td>
<td>Fernanda Nascimento, 2-7 Gibson Place., St Catharines, ON.</td>
<td>(905) 937-9762</td>
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<tr>
<td></td>
<td>Florence Pye, 11-126 Sussex St., Carleton Place, ON, K7C 1P8</td>
<td>(613) 257-1847</td>
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<td></td>
<td>Vikki LeDez, 26 Jones Street, P.O.Box 237, Sunderland, ON, L0C 1H0</td>
<td>(705)-357-0377 email: <a href="mailto:vledez@yahoo.ca">vledez@yahoo.ca</a></td>
</tr>
<tr>
<td>Age -- Over 74</td>
<td>Ondra Shuwera, 5 -615 Whitaker St., Peterborough, ON, K9H 7L5</td>
<td>(705 976-8481)</td>
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### ONLINE: Myasthenia Gravis Support Canada

On Facebook, you can connect with others affected by Myasthenia Gravis through the Myasthenia Gravis Support Canada Facebook page, another way to learn more through discussion, posting and comments. Use this URL:

https://www.facebook.com/groups/1380379838949713/ and link text is Myasthenia Gravis Support Canada.

## Drug Maker May Make a Medicine Too

### Expensive for Patients Affected by CMS (Congenital Myasthenic Syndrome)

Dr. Hans Katzman, University Health Network, recently sent us a link to a December CTV news story about a possible major hike in an effective CMS drug that could raise patient cost from $1200 per year to $60,000 per patient. We support in principle, his and 80 other Doctors who are trying to get a solution before their current and future patients face an impossible cost jump. See link on CTV interview:

# Myasthenia Gravis Society of Canada

**Formerly known as Myasthenia Gravis Ontario (Chapter)**

## MEMBERSHIP APPLICATION

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In order to reduce postage costs I would like to receive the quarterly newsletter “Contact” via e-mail, rather than by regular mail:  Yes ______ No ______

Would you like us to call you?  Yes ______ No ______

**For “Myasthenics Only” and for statistical purposes (held in strictest confidence):**

My Neurologist is Dr. __________________________

Neurologist’s Telephone No. _______ - _______ - _______

## ANNUAL MEMBERSHIP FEE

- $20.00 + $2.60 HST = $22.60  $ ________ (12 months – Individual or Family)
- $50.00 + $6.50 HST = $56.50  $ ________ (36 months – Individual or Family)

**Donation** $ ________ (optional)

**Total** $ ________

*Please complete as much of the form as possible.*

*All information will be kept in the strictest confidence.*

It is important to keep your membership and record of information up to date and accurate each year. Please advise any changes during your renewal period.

Questions or Changes? Call 905 642 2545 or e-mail to membership@MGCanada.org

**Mail completed form and payment to:**

**Membership Coordinator – Myasthenia Gravis Society of Canada**

c/o 247 Harold Avenue, Stouffville, Ontario, L4A 1C2.

Please make cheque payable to: Myasthenia Gravis Society of Canada
MG Support Canada Facebook recent excerpts:

- “Well my fellow snowflakes the time has come Monday I'm about to start my first of four day IVIG treatments. Hoping to get some relief. Also hoping I tolerate the treatment well. I will be putting in to action all I have read from all of you Thanx

- “I am considering having Reflexology and I'm wondering if any of you have experienced it? And what are the pros and cons?”

- “Does anyone experience a freq sore throat with Mestinon? I have one almost all the time now....

- “Met up with another fellow MGer on a business trip to Orlando. Proving it is not all work and no play. Both kicking MG in the butt and no longer defined by it.”

- “We just got home. We did the IVIG for 3 days last week and once we got home she caught the flu. After a week on IV and breathing monitors they let us go home but we go back next week for her MRI. Since she's 2 they have to put her to sleep. Any advice for being put under anaesthesia? I'm pretty nervous because they want to keep her for the weekend.”

- “I have to say for myself in BC, I have had very good care and monitoring of my MG by Neuro in Van. and Victoria

Quotes offered anonymously in the compassionate interest of MG patients, MG caregivers and MG Health Care professionals.