



# Myasthenia Express

## Myasthenia Gravis Manitoba Inc. March 2011

### Vol. 1 No.30



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### **Presidents Report** **By Diane S. Kowaliuk**

Our next meeting will be held on May 17, 2011 at 7 PM.

In November we had our annual elections and on our website <http://mginc.mb.ca> is the list of our new executive. I would like to take this time to thank all the executive members for their support, co-operation and hard work, another fabulous job. Also to our members and families who take the time to attend our meetings and share their experiences, trials and tribulations.

At our meeting in November, we had a Tai Chi Instructor, Frances Irving do a presentation. Having Myasthenia Gravis makes it hard for our members to exercise due to the muscle fatigue. But this provided options that are not very hard and can be done at your own pace. It was a great meeting with lots of fun.

Our bake sale was cancelled in January due to unforeseen circumstances but we are investigating other options for another fundraiser. Due to the trials and tribulations of the illness the fundraiser cannot be too taxing on our members. We are looking into the possibility of selling Grey Cup pool tickets in the fall which is always a popular

fundraiser. Other suggestions are greatly appreciated!

For our March meeting we decided to have an actual support group meeting to share our trials and tribulations and get caught up on upcoming events etc. In the last few months we have had several new members and they need information from our existing members on how to cope with Myasthenia Gravis.

We are planning our spring get together for our May 17, 2011 meeting day, as a social function since we did not have a Christmas Party in January. Bring some great suggestions on restaurants, locations, parks and bring your calendars! Watch our website for updates on the location of this event and time.

I would like to take the time to reflect on what a fabulous support group we have and how important it is to bring your family and friends to our meetings. This is an education process for all of us, which provides us with a buddy system, a person who you can contact to talk, cry, vent and laugh or just listen to you. So don't be shy come on out and enjoy a wonderful evening with friends.

**Diane S. Kowaliuk**

# Caring for the Caregiver

As a group we spend a fair bit of time focusing on helping the MG patient directly. This newsletter I want to spend some time focusing on the other side of the equation – those who live with or support the patient with MG. As a patient, I have had to ask for help, even resented the help I've been offered because it reminded me I was no longer as independent. But what about how MG affects those who love and support me? How does the added pressure make them feel? They have their own problems and possibly health issues too...why should mine take precedence?

When I was diagnosed in 1994, I was a young university student sharing an apartment with my best friend, J. I had no immediate family nearby, so much of the burden of my day-to-day adjustment to my MG reality fell on her shoulders. I was engrossed in a “why-me” pity party, complete with regular meltdowns and resentment for the fact that she was normal and could easily complete the “advanced” level of our work out videos, while I would fall flat on my face trying to do more than two push ups. In my mind, my world had fallen apart and she just seemed annoyed that I claimed cleaning the tub was well beyond my capabilities? Why did she question the realities of my condition? In retrospect, it was pretty heavy stuff for my 21 year old roommate to be expected to handle. It wasn't fair of me to not consider how hard all this was on her.

The turning point for J. and I was when she decided to tag along with me to an MG support group meeting. Through the group she learned about the disease. She began to understand the difference between muscle weakness vs. laziness. She understood the unpredictability of the symptoms. She understood my anger, my fears and my frustration. Before long we worked out a division of housework that made sense, she listened when I needed to vent, encouraged me to fight back and not let this

thing take over my life and most importantly, we started to share some laughs again.

We continued living together through the first three years of my illness; our friendship survived and most definitely flourished – all resentments dissolved away. Even though we definitely don't see each other nearly enough, J. is still one of my most treasured supporters.

Of course, MG is not the only disease that affects the family and loved ones of the patient. Our modern health system is stretched to the brink, leaving more and more of the burden of care falling squarely on our loved ones' shoulders. Gone are the days of long hospital stays. Regularly newborns are sent home with their exhausted moms in less than 24 hours after birth, many more surgeries are done on an outpatient basis, and our aging demographic means longer and longer waiting lists for spaces in care homes and assisted living facilities. All this equates to a burnt out segment of society who is still trying to raise their own families, earn a living and care for a chronically ill spouse, child, parent, or other relative. Too often, the caregiver neglects themselves, the stress and exhaustion builds until caregiver ends up being the one requiring the care. It's time to change the “superhero” mentality and remember that to truly help others, caregivers need to look after themselves first.

This newsletter includes an article titled, “Living with Myasthenia Gravis: A Caring Partner's Point of View” by the late Esther Leslie of the UK. It is a compellingly honest piece that paints a vivid picture of the life of the caregiver and the effect of MG on her entire family, not just her husband. Thank you to the MGA of the United Kingdom for granting us permission to reprint this inspiring piece.

**Corinne Elson**  
Newsletter Editor – Email: [scelson@mymts.net](mailto:scelson@mymts.net)

# Living With Myasthenia Gravis: *A Caring Partner's View*

*By Esther Leslie*

I live with Myasthenia; at first it seemed to rule my life, all our lives. I do not have the illness - my husband Jim is the one who has MG. At first all help advice and comfort went to allay his fears and get him back on his feet again.

What about the fears of the FAMILY, at first getting a name for the illness was a great relief, no more "24 hr/48 hr/72 hr virus", "it's all in his mind" etc, etc. We would get help now or so I thought. Month after month going to Hospital and seeing a Neurologist while Jim got worse, I could see him going from a person who could climb mountains to a person who could hardly walk around the garden. Why was Jim not responding to the treatment? Life got worse for all of us, where would it all end? Our GP finally arranged for him to go to the Royal Free Hospital in London. He had to go to London on his own by train; thank goodness we have friends in London who would meet him at the station, I was so worried, I could not leave the children and I felt so guilty, putting Jim on the train by himself as he was so ill.

Would he come back to us, or if he did what would he be like? My chin had to go up & up. A brick wall was slowly being erected around me, trying to be the strong one in the family for my husband and the children; it had always been Jim who looked after us all.

I knew nothing about the illness. Worry is not an easy bed fellow. Thank goodness I have good friends, I could go and have a good cry and get my worries off my chest. It was a very long six weeks, I was now back in the working world after a break of 15 years, I was not feeling very well and our GP thought I had burned myself out with all the worry, I began to lose weight. By the time Jim came home I had lost one stone, I was diagnosed as having Thyrotoxicosis.

When Jim came home he was not very well, but better than he had been, but changed. No longer the healthy out-going person; mood swings, black moods all very hard to understand. I was so tired and still working, the children at school not understanding what had happened to their father, a mother who was tired and shouting WHY? WHY US? The hospital gave Jim a booklet telling us about MG. This helped to explain what was happening to Jim, but at the same time did not lessen my fears - respirators, wheelchairs - where did it all end, what would become of us.

Our eldest daughter Karen would not talk about her father's illness, our son Ewen became very angry, our youngest daughter Clair went off the rails slightly. The worry and not feeling well, the rows, the arguments, all this did not make happy families, I was at my wits end, trying to keep us together as a family. Friends were very good at listening to me, but they did not understand about MG. One day I found myself in the basement kicking a cardboard box, tears streaming down my face (I have to admit now that it got rid of a lot of frustration). Another day after yet another row with our youngest daughter I went to get the car out of the garage, I sat in the car and turned on the engine thinking how easy it would be to end it all here and now. Realization set in. This would not be fair to Jim, he needed me more, but life was so bad nothing seemed real. What was going to happen to us. For six months he had been off work, what did the future hold.

I sat down the next day and had a good long think, there must be something good in my life, what? Look for one good thing, Jim still loved me, the children were not bad, I had good friends - there were three good things in my life! Yes I would take it from there, one day at a time - look for something good each day. I was now

feeling better, I was in balance with the Thyroid. Karen had passed her "A" levels, Ewen his "O" grades, we were all coming to terms with MG. We were pulling together, being there for each other, Karen still not talking about her dad's illness, Ewen less angry, Clair still a worry at times, yet life went on. We all came to terms with MG each taking a different route. A long year had passed and Jim went back to work, I stopped working full-time and began a part-time job, hopefully my worries were over. I came home one lunch time to find Jim ill again and a very worried Clair. I telephoned our GP and went back to see Jim, I knew at once that something was very wrong, his throat muscles had collapsed, a 120 mile dash to the Southern General Hospital in Glasgow followed. The worries came surging to the surface again, can I cope? Can I be strong again? At least this time I could drive to Glasgow to see Jim.

While Jim was in hospital the ward sister asked him if he would like to have a chat with a gentleman from "BAM" (now MGA), the gentleman introduced himself as Alex Jenkins the Scottish Councillor. The upshot of this meeting was Alex came to visit us at Fort William along with the late Christina MacMillian then Care Officer for Scotland. What a wonderful day that was, Christina and Alex put our fears to an end, Jim had a good chat with Christina and I with Alex. He had been in the same position as myself, as his wife had MG, Alex knew exactly what I was talking about. I could see quite clearly now there is life after MG. I repeat there is "LIFE".

Jim was asked by Christina and Alex if he would become a representative for the Highland and Islands, we became part of the MG family. After two years Alex stepped down as Scottish Councillor and Jim was voted in. This was a huge step as he still tired easily and could not travel very far, but we could keep in touch with everyone by letter or telephone. By this time Jim had retired from work, Karen and Clair married and Ewen working, all fundraising for MGA along with friends, a Sponsored Walk one year, a Fancy Dress Climb of Ben Nevis next year, life was jogging along, fears and worries sliding to the back of our minds. Once again MG reared its head and again Clair was in the house when Jim's throat muscles collapsed, thankfully he did not go into hospital this time. Clair has been a great help to me, from being such a worry she has turned into such a caring person and will listen when I am worried about her Dad, it has taken Karen a long time but she can now talk about her Dad's illness and Ewen is always there to help. Jim has had quite a good spell during which we set up the Scottish Forum bringing the branches and representatives together. Then Jim was asked to become a Trustee for the Charity by Geoff Buckley, he accepted (what a long way he had travelled in fifteen years). One draw back was that he could not travel such a long way on his own, so I had to go with him, later I was asked to become a Trustee, what a daunting thought, what could I bring to the Charity? Then I knew "the families" I could talk to them, listen to their fears and worries, let them know you can have life after MG. Take life one day at a time, it may not be the life you hoped for but you can go on holiday, to weddings etc, say yes to all invitations, we will be there if Jim is well, do all you want to do on the good days, lie low on the bad days, change, adapt, adjust your lifestyle, have lunch out if you can't go out for dinner. Jim can drive again, at first it was only a short distance then he could do a bit more, but we always share the driving even when he is well.

I now find life can be good, but it is the simple things in life that gives me most pleasure, having my husband and family (which has grown, we now have eight grandchildren). In fact living with Myasthenia is not as bad as I first thought, we have all pulled through, the family all involved in some way. Clair did the drawing for our RAG DOLL logo, Karen, Ewen and Clair along with friends have just done a parachute jump to raise funds for MGA. I know life with MG will have its up and downs but it will never take me down with it again, I have the MG Family behind me, I only have to make a telephone call and I have all the help and support I need to take me through the next crisis. But mostly I have learned to live with MG.

*Reprinted with permission from the Myasthenia Gravis Association (UK)*  
[www.mga-charity.org](http://www.mga-charity.org)



## Family/Friends

Most myasthenics put a high value on support from friends and family. If that's you, know that your help is appreciated—whether you bolster an MG patient's spirits or offer much-needed physical aid.

### First, try to understand:

- It takes time for a person to accept that he or she has an illness. A person may face loss of health, limits on activity, body image changes from medication and more. These losses may prompt anger, denial, fear, and confusion before acceptance sets in.
- Uncertainty is stressful. When MG symptoms appear, your friend may be on pins and needles wondering, "What's next?"
- There's a ripple effect. It takes time to figure out how MG affects a person's place in the world, for instance, with:
  - Relationships, including marriage, friendships, parenting.
  - The ability to work, attend school, run a household, care for children.
  - The ability to pursue activities, hobbies and travel.
- It's difficult for a previously able-bodied person to ask for help.

### What can you do?

- Listen. Accept what the person has to say. Try to listen without diminishing or making light of their concerns. (Avoid responses like these: "I feel tired, too." "It could be a lot worse." "Everyone's eyesight gets worse with age.")
- Be patient. A person talks when he or she is ready.
- Be flexible. Plans may have to change from day to day depending on how a person with MG feels.
- Offer help. Repeatedly.

### Can you help with any of these tasks?

- Rides to doctor visits
- Rides to hair appointments
- Lawn mowing
- Driveway shoveling
- Grocery shopping
- Preparing a meal
- Help with insurance or other paperwork
- Housecleaning
- Laundry
- A weekly phone call
- A trip to the movies or social event
- Babysitting

Source: Myasthenia Gravis Foundation of Illinois website  
[http://myastheniagravis.org/mgfi\\_family\\_friends.aspx](http://myastheniagravis.org/mgfi_family_friends.aspx)

If you haven't any charity in your heart, you have the worst kind of heart trouble.

- **Bob Hope**

If a friend is in trouble, don't annoy him by asking him if there's anything you can do. Think of something appropriate and do it.

- **E. W. Howe**

# Blog Bites...

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### **How to Best Prepare for IVIG Treatment OR “What the Doctors and Nurses won’t tell you but you need to know about Immune Globulin”**

*By Jen Walsh\**

I have a love/hate relationship with IVIG. I love that it has kept me out of the hospital, preserved my muscles that allow me to breathe, and those that I use to swallow. I hate that it takes six hours to infuse every two weeks and that it doesn’t always work consistently to manage my other symptoms. I also hate the cost, but love the donors who make it possible for me to receive this saving treatment.

I have an autoimmune neuromuscular disorder called Myasthenia Gravis which takes away my ability to open my eyes, walk or grip things at its mildest and can literally cause my diaphragm to stop working at its worst. Fortunately there are treatments, but there is no cure. And so, my physician team decided that I would be a good candidate for IVIG. Some other diseases that IVIG treats include, but are limited to, Multiple Sclerosis, Kawasaki Syndrome, Primary and Secondary Immunodeficiency Syndromes.

This is my guide for new patients undergoing IVIG Treatment – or those who don’t feel their treatment is going so well. I have been receiving IVIG since December 2009 and my current protocol is every two weeks.

- Hydrate, Hydrate, Hydrate – I don’t care if you don’t drink water, this is a MUST! You must start hydrating at least 48 hours prior to infusion and for the following 48 hours, not to mention during the procedure. If you are not well hydrated you are increasing your risk for blood clots, aseptic meningitis (aka the world’s most excruciatingly painful headache) and an extreme feeling of flu.
- Take Benadryl and Tylenol – Most doctors will order this in what they call “pre-meds”. Ask your nurse first so you don’t double dose. If you aren’t getting it in your IV, make sure to take it by mouth. The Benadryl gives you a better chance of not having an allergic reaction which can set off the immune response thus rendering the whole treatment useless. The Tylenol will reduce the achy, flu like feeling as your body processes the high volume of healthy donor immune cells.
- Get a good night’s sleep before and after - Anyone with an autoimmune disorder knows a poor night’s sleep can worsen their symptoms. Well, I have found that my IVIG works better if I get a good night’s sleep the night before and the night of the treatment.
- Prepare many snacks to eat during treatment – I tend to crave protein based foods but anything healthy is good. It will help to stave off a head or stomach ache. My recommendations include: cheese and crackers, nuts, bananas, clementines, or an everything bagel with cream cheese and tomatoes slices. Prepare whatever you like the night before so you don’t have to worry about it the day of the treatment.
- Avoid Stress at all costs – Stress sets off the immune response and will render the treatment less effective because your faulty immune system wins the fight, so to speak. I have found when there is high stress, my treatments do not work so well.

So, that about wraps it up. While I am sorry to hear you have to have IVIG, I truly hope this helps.

*\*Jen Walsh is a Great Lakes Chapter Member from Grand Rapids, Michigan who has published multiple articles and blogs on her experience with Myasthenia Gravis.*

## **MG Manitoba Inc. Executive List - 2011 - 2012**

<b>President</b>	Diane S. Kowaliuk	444-7802
<b>Vice President</b>	Verna Kapkey	586-6784
<b>Secretary</b>	Maureen Silk	667-3630
<b>Treasurer</b>	Maureen Silk	667-3630
<b>Telephone Committee Chair</b>	Frances Irving	488-8471
	Mary Ross	488-0477
<b>Fund Raising Committee Chair</b>	Verna Kapkey	586-6784
	Sandra Penner	204-348-2960
<b>Education Committee Chair</b>	Verna Kapkey	586-6784
<b>Hospital Visiting Committee</b>	Ken & Joan McGregor	667-0323
<b>Social Committee Chair</b>	Connie Chubaty	582-8491
<b>Newsletter Editor / Assistant</b>	Corinne Elson	231-1158
	Connie Chubaty	582-8491
<b>Resource</b>	Doreen Amadatsu	888-8628
<b>Video Production</b>	Gary Parker	896-6444
<b>Coffee Committee</b>	Karen Riehl	895-7398
	Maria Choquette	293-1008
	Rubina Sancho	582-2882
<b>Brochure Distribution</b>	C.J. Emmonds	786-5000 (Pager # 1532)

# **Wanted:**

## **Your stories, feedback and comments**

Please contact me at [scelson@mymts.net](mailto:scelson@mymts.net) if you would like to share your story and experiences, suggest topics for future newsletters or just to provide feedback. Everyone's MG experience is different, and we can all learn so much from each other. Thank you for taking the time to read this publication and I hope to hear from you soon.

*Corinne Elson, Editor*

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## **Resources:**

MG Manitoba Inc. Website: <http://www.mginc.mb.ca>

The third edition of the book, You, Me and Myasthenia Gravis, by Deborah Cavel-Greant, is available for purchase for \$20.00. Contact Verna Kapkey at 204-586-6784 or [mginc@mts.net](mailto:mginc@mts.net)

Our drug alert card has been printed “**Drugs that worsen the symptoms of MG**”  
If you have not received this card contact Verna at 1-204-586-6784

## **Myasthenia Gravis Manitoba Inc.**

### **Membership Fees:**

\$10.00 -- Family

\$ 5.00 -- Per Person

### **Please submit your fees or donation to:**

Myasthenia Gravis Membership  
Maureen Silk  
614 Munroe Avenue  
Winnipeg, Manitoba  
R2K 1H8

### **Literature**

If you, or someone you know has Myasthenia Gravis and needs information on the illness, we do supply literature, in the form of previous articles, pamphlets, etc. for members and their families. Contact, Verna Kapkey at 1-204-586-6784 or [mginc@mts.net](mailto:mginc@mts.net)

### **Please note:**

This newsletter is intended to provide the reader with general information to be used solely for educational purposes, and that any medical views expressed in this newsletter are those of the individual author and do not reflect any official position of the Myasthenia Gravis Manitoba Inc. Chapter.

Always consult your physician or health care professional for medical advice.

