



VOLUME 4, ISSUE 1

**MYASTHENIA  
GRAVIS MINNESOTA  
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**mgMN**

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**mgMN Mission**

Our mission is to support individuals with myasthenia gravis and other myasthenic syndromes, and their families, through information, education and outreach.

**Newsletter Staff**

**Shirley Kramer - Editor  
Laurel Meyer**

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# mgMN Voice

MYASTHENIA GRAVIS MINNESOTA INC

## Such a Grand Day!

Highlights from mgMN's Second Annual Meeting and State Conference

Another year to celebrate! mgMN's Second Annual Meeting and State Conference was held on Sunday, September 24, 2017 at the Best Western Hotel and Conference Center in Shoreview, MN. Several people were heard to remark, "This is the best conference ever." Registration began at 9:00 am, as pastries and coffee were served. mgMN Board Chair, Diane Tower bid a cheery good morning to everyone and opened the business meeting. Formal minutes as well as the financial report were presented, amended and approved. People were directed to look at the formal committee reports as well as reports from the support groups in their conference packets. The business meeting was adjourned.

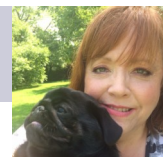
A special time was spent honoring Lianne Anderson, a long-time member with MG, board member and support group leader for her outstanding service and superior leadership over the years. In a small ceremony led by Barb Corner, Lianne was awarded a beautiful, inscribed table clock in recognition of her contributions. Lianne was unable to attend this year's conference due to illness, so a video was made of the ceremony. It will be given to her along with the clock, and our thanks and appreciation of her dedication at a later time.

Our first speaker, Karen Peterson, the Executive Director of Honoring Choices

(continued on page 2)

## Chair Speak

by Diane Tower



Hello! What a pleasure it was to meet and spend time with all of you at the Second Annual Meeting and State Conference. I was especially pleased to see more members from the Brainerd and Rochester areas. We even had one member from Iowa. Welcome! Maybe next year we should have a door prize for whoever travels the most miles to attend the conference.

I want to thank all of our volunteers and board members whose tireless work helped to make this year's conference a success. Remember everyone, this is your meeting, please let us know what type of speakers you would like to hear, or activities you would like to see. Perhaps you would like to volunteer to be on the planning committee?

Our Board is in search of a Fundraising Chair. If you feel that you could volunteer, please submit your name for consideration. Please contact me by phone (763) 942-8775 or by email at mgditower@gmail.com.

Stay happy and healthy!

### Days of Celebration and Faith

May the special days of the coming seasons bring warmth and joy and health  
to each of you and your loved ones.

what a grand day . . . continued

Minnesota was remarkable. Her organization reaches out to groups and individuals interested in learning about health care choices and health care directives. Every conference participant received a blank copy of a health care directive. In a very clear, practical and compassionate manner Karen explained the reason and purpose of every section and question. She spent a lot of time discussing with the group the importance of choosing their health care agent wisely. Karen emphasized how critical this was to insuring that the choices you desired would be carried out. Another thought Karen shared was that when thinking about what direction you would like to take, think about a general path and use that as a guideline. This organization is an excellent resource.

(Insert Pop-Up Door Prizes!)

A new brunch (or should we say lunch) menu was served this year - a sandwich bar! Yummy!

(Insert Pop-Up Door Prizes!)

Teri Kiresuk, DNP was our afternoon speaker. Teri is an associate professor, a doctorate level nurse practitioner, works for LIVIO Health Group an on-site health care partner providing medical assessments and services in the home, as well as a mom of a young woman with refractory MG. Teri talked about MG and it's relationship to other autoimmune disorders in general. Her comprehensive presentation covered technical aspects of MG as well as the day-to-day realities and challenges of living with the condition. When one uses the word fatigue when describing the symptoms of MG, Teri explored the question - what does fatigue really mean? What does it look like? What is it's impact? Teri has a unique and compassionate way of blending her technical knowledge with her nursing perspective to present a holistic picture of MG.

Auction Time! This year it was accompanied by coffee and chocolate chip cookies! Ooh la la! We had great auction items. Ticket sales were up! There were wonderful baskets; a beautiful coffee basket, a Kowalski's Fruit and Gift Certificate basket, The Bee's Knees Honey basket, some \$50 gift certificate bags, a lottery ticket basket, a mystery money envelope, even an Irish Soiree event to attend. Dave Schlieff once again performed the honors, ably assisted by Shirley Kramer. An entertaining pair. This year's winners seemed to fall into a unique pattern as they sat throughout the room, what are the odds of that? So much fun to watch.

(Insert Pop-Up Door Prizes!)

Thanks everyone for the great time. See you next year. We'll have even **more** fun!

*A SMALL TIP: EVEN THOUGH MG CAN CAUSE YOUR EYELIDS TO DROOP, IT IS STILL IMPORTANT TO CHECK WITH YOUR OPHTHALMOLOGIST ABOUT THE NEED FOR PTOSIS OR BLEPHAROPLASTY SURGERY AS YOU AGE. ESPECIALLY IF YOUR VISION IS NOTICEABLY COMPROMISED. TESTS CAN BE DONE TO DETERMINE THE MEDICAL NECESSITY OF THE SURGERY FOR REIMBURSEMENT PURPOSES. JANE TOWNSEND,*



## Getting to know your board members . . .

### Dan Formato, Vice Chair

When Dan's wife was diagnosed with MG in 1998, they read all the information they could find about MG. They attended a support group in Nevada, where they spent winters. Upon returning to Minnesota, they joined the Twin Cities support group, where they have met many people and made friends. They've learned from others about treatments and medications used to treat MG and maintain a quality of life. "I serve on the board because I want to further the effort to share MG information across the state," he says. During his career, Dan worked in the public sector as a city fire chief and emergency manager. He has served on a number of nonprofit boards.

## The Same but, yet again, Different - MuSK Myasthenia Gravis

*One of these things is not like the other, one of these things is not the same.*

by Laurel Meyer

MuSK is one of those words we hear when myasthenia gravis is discussed. What is MuSK? MuSK stands for Muscle Specific Kinase. We know about ten percent of people with MG symptoms do not have the antibodies in their blood which identify myasthenia gravis. We have since learned that of that ten percent, about forty percent turn out to be MuSK positive. Rose Pelski, a member of the Twin Cities MG Support Group, has been identified as having MuSK positive MG. She and her husband, Jeff, were kind enough to talk to me about her struggle with this form of MG.

**MuSK stands  
for Muscle  
Specific  
Kinase.**

Rose started with ocular symptoms and an eye doctor. As Rose became sicker a neurologist was consulted. MG was suspected but she didn't test with the correct antibodies. Rose was becoming desperately ill and Jeff became an aggressive advocate. He got Rose seen at the Mayo Clinic where it was discovered she had MuSK positive MG. That was not a happy ending. Rose was prescribed Mestinon and became even sicker. She became so weak that she needed help with daily activities like eating and grooming. Her breathing became compromised. Out of desperation, Jeff took a video of Rose and emailed it to the Mayo physician who had seen her. That action got an immediate response. Rose was taken off the Mestinon and put on prednisone and IVIG treatment. People who are MuSK positive react differently to some of the standard MG medications and treatment protocols.

It has been a long road back and now Rose takes prednisone and Cellcept. She has learned to balance rest and activity to keep herself feeling strong. Rose told me that most of the beginning of her illness is a blur. Jeff was supportive and an advocate for her. He is a good example of the type of caring support we all need sometimes.

### ...This Time of Year...

At this time of year, celebrations of many faiths focus around the coming together of family and friends to break bread together, share beliefs, traditions and give thanks. At the dinner table we often laugh and say that our eyes are bigger than our stomachs. Some of us quietly cry as we think, yes, and our hearts are stronger than our hands, and our minds are much more willing than our bodies.

This year, as you gather with those you love most in the world, let your eyes shine with happiness, let your heart overflow with love and let your mind fill with wisdom and just be who you are with the people you love in the spirit of acceptance, thankfulness and peace. Let someone else do the dishes.

Anonymous

## A DAY IN THE LIFE OF . . . Elaine Martin as told to Shirley Kraer

I'm usually up at 6:00am, by 6:15 I've taken two of my meds (Cellcept and Advair). Cellcept I need to take at least one hour before I eat, or two hours after. This is the first of five scheduled times I take medications throughout my day.

I spend some time chasing my cats so I can feed them.

Maybe an hour or so of meditating, or reading something contemplative, or spending time in prayer or in reflection. I map out my day. As I do these things, I begin to get a feel for how I am physically feeling.

About 7:45am I start my hardest chore of the day - putting on compression stockings - must rest between stockings. Must garner physical and mental resources to do this because it is so difficult and I dread doing it.

By 8:00am it is breakfast time which is served with more pills. Simple food, food I don't need to cook, food I can eat with a spoon or out of my hand is best for me.

Now the rest of the day is mine. However, how much energy do I have left? I need to finish dressing, resting in between garments. I never commit to any activity outside the house before 10:00 am. The exception being my adaptive yoga class on Tuesdays. Yoga is essential to my well-being. It brings me JOY. It is therapeutic and it is good for my body. Mind Body Solutions Adaptive Yoga is a community of accepting, joyful, humorous people all of whom are challenged with some type of pain or disability. They have become my friends and inspiration. Even though some days it is hard to get out of the house, I go.

Personally, I feel I have achieved a major goal if I am dressed and the bed is made by 10:00 am. I am proud of myself. My husband is very supportive and morning time is also spent with him.

Currently medical appointments are down to once a month and consist of routine check ups.

Once a week I volunteer at the University of MN Masonic Children's Hospital where I teach knitting and crochet to children and their families. It's fun to meet families and children from all over the world and listen to their stories when they are in great need. During the school year I volunteer as a homework helper one late afternoon a week. On those days I rest either before or after.

Lunch and dinner are also very simple microwave, make and freeze, single portion meals.

Pills again - Cellcept at 4:00 and Coumadin at 6:00pm. Lunch is pill free.

Walk labyrinth at hospital or meditate in chapel at hospital. Yoga stretches in the morning sometimes.

After dinner, relax, knit, visit with husband.

Bedtime, 9:00pm, more pills - Advair.

Quaker meeting at my house once a month.

Busy time, hot days I take my scooter.

I enjoyed my visit with Elaine. Elaine was diagnosed with MG of a refractory nature many years ago and has other health care concerns as well. She told me that the hardest thing for her was not being able to commit to something because of her health. Yet one of her greatest joys was the strength and sense of coming out of herself she experiences when she connects with and helps others with their own struggles.

## CARING ABOUT CAREGIVERS

by Laurel Meyer and Shirley Kramer

The thoughts below were sent into us by a family member of a person who has myasthenia gravis. As they say, "take what you like and leave the rest." We think you'll find what she writes insightful.

As defined by:

**Caregiving** is the act of providing unpaid assistance and support to family members or acquaintances who have physical, psychological, or developmental needs. Caring for others generally takes on three forms: instrumental, emotional and informational caring.

Caregiving, Definition(s) of | Work and Family Researchers Network

<https://workfamily.sas.upenn.edu/glossary/c/caregiving-definitions>

The Caregiver takes on many roles ranging from providing a ride to an appointment, running errands, assisting with household tasks, or just sharing a conversation to actually providing hands on help with daily hygiene needs, changing a bandage, or making sure they have food and medication. The role of Caregiver can be temporary or permanent.

Many of our family or friends may have an illness that has no outward signs, such as with myasthenia gravis and at times it can be hard to understand what they are feeling or the limitations that the disease is causing them. You want to help but you may not know when to step in or you may step in too soon. Also, they may not know when to ask for help because they believe they can still do everything, when in fact it may be fatiguing them more than they realize. There can be a fine line between being a caregiver or an enabler.

As a Caregiver we sometimes want to do everything for that person - when in fact, if they are able, they want just enough assistance to help them do the majority of it on their own. Doing everything for the person is an easy routine to fall into, we want them out of pain, we want them to eat and drink, we want them to have warm blankets or ice packs, the right volume on the TV, their favorite book or magazine close by.

For me, I've been a Caregiver at almost every level and I can easily say that being a Caregiver is one of the most rewarding experiences a person can have. Oh, yes at the same time it can get to be overwhelming or a bit frustrating and we need to remind ourselves - "it's not about me right now".

This may sound a bit odd, but being a caregiver is not for everyone and there should be no judgment or hurt feelings if it's not for you. There are so many resources available you have to set your pride aside and ask for help to become a caregiver or obtain the services needed.

Another word of advice - if you are the caregiver type, you need to develop your own style and be prepared for that style to change with every person you care for or as their needs change. I was helping with my mother's care and thought she really enjoyed lemon in her water. She said to one of my sisters "will you please get me water, I don't want her to know it doesn't taste good anymore when she puts lemon in my water."

Relax and enjoy being a Caregiver.

CAREGIVERS - THIS IS YOUR SPACE - A PLACE FOR YOU

Shirley Kramer is a sister of a person with MG.

Laurel Meyer is a member of the Twin City Support Group and has MG.

## New Research Studies Opening

For patients with Congenital Myasthenic Syndrome and MuSK MG

Catalyst Pharmaceuticals has a number of research studies and clinical trials either underway or in the process of enrolling subjects to study a new drug, amifampridine phosphate, trade name Firdapse. Catalyst Pharmaceuticals has an Expanded Access Program for amifampridine phosphate, which is an open-label pre-approval safety study where patients who are diagnosed with Lambert-Eaton Myasthenic Syndrome or certain types of Congenital Myasthenic Syndromes can receive the drug at no cost. They are also opening up other studies/ clinical trials involving Congenital Myasthenic Syndromes and MuSK MG. For more information about amifampridine phosphate, these trials and Catalyst Pharmaceuticals, go to their website at [www.catalystpharma.com](http://www.catalystpharma.com).



### mgMN Support Groups

#### MID-MN SUPPORT GROUP (BRAINERD, MN)

**Contact Person and Leader:** Barb Corner (218) 562-4594 or [mgcorn@uslink.net](mailto:mgcorn@uslink.net)

The support group meets in September, October and November, and then in March through June. Meetings are usually held on the **second Tuesday** of the month at Park United Methodist Church in Brainerd, MN, from 1:30 - 3:00pm. Current members should check for a notice two weeks prior to the scheduled meetings for updates from Barb. New visitors should contact Barb to verify meeting times. The Mid-MN Support Group welcomes new members and is open to anyone who is interested in knowing more about Myasthenia Gravis (MG).

#### TWIN CITIES SUPPORT GROUP

**Contact Person and Leader:** Lianne Anderson (651) 633-5465

**\*interim contacts:** Diane Tower (952) 942-8775, Shirley Kramer (952) 997-3485

Support group meetings are held on the third Saturday of the month, except in September when the Annual Meeting and Conference takes place. Support group meetings are held at the Midland Hills County Club, 2001 Fulham St., in Roseville, MN, starting at 1:00 pm. In addition to sharing personal stories and experiences, there are also speakers and educational programs offered. All participants and guests are welcome to come early for informal socializing and to partake of a buffet lunch served at noon. The lunch includes an entrée, coffee/tea and dessert for \$16.00 Including tax and gratuity. Other beverages are \$2.75 extra. This is entirely optional. Many members bring family or friends with them. New members and visitors are very welcome.

#### SOUTHERN MN SUPPORT GROUP (ROCHESTER, MN)

**Contact Person and Leader:** Ellen Walle (507) 206-0675 or [ellenwallw@gmail.com](mailto:ellenwallw@gmail.com)

Support group meetings are held on the third Friday of the month unless otherwise noted, from 1:00-3:00 pm at Zumbro Lutheran Church in the Kyros Room at 624 3rd Ave SW, Rochester, MN. Please check for cancellations if inclement weather is expected. New MG patients as well as family members and/or caregivers are warmly welcomed.

#### NE MN/NW WI SUPPORT GROUP (DULUTH, MN) NO OFFICIAL MEETINGS.

**Contact Person:** Georgina Wagar (218) 728-1511 or [MGFMNNE@aol.com](mailto:MGFMNNE@aol.com)



Let's keep in touch . . .

VOLUME 4, ISSUE 1

**GOTO** mgMinnesota.com and enter and confirm your email address to receive communications electronically.

**USE THIS FORM** to receive this newsletter by USPS, join a support group, become a member, volunteer, make a donation or memorial.

**It is important to note that you need not become a member to receive mailings or participate in a support group.**

Name	
Street Address	City and State Zip
Home Phone	Cell Phone

Yes, I would like to join -

☐ \$ 15.00 Annual Dues      ☐ \$ 100.00 Lifetime Dues      ☐ Request Dues Waiver Information

Please add me to the Mailing List **ONLY**

☐

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**Myasthenia Gravis Minnesota Inc.**

**Torri Johnson, Treasurer**

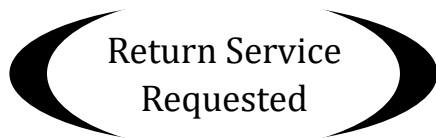
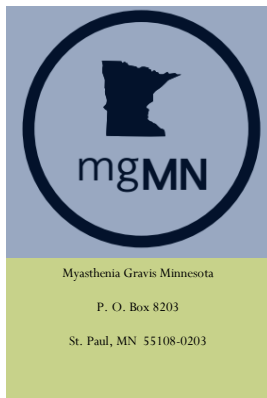
**P. O. Box 8203**

**St. Paul, MN 55108-0203**

**Please Consider —mgMN is a young organization. To grow strong and vital we need your support. Learn about the interesting and fun opportunities available by contacting Diane Tower, mgMN Chair: mgditower@gmail.com. Thanks for your support!**



**KEEP CALM**  
**AND**  
**REST ON**



# mgMN Voice

MYASTHENIA GRAVIS MINNESOTA INC

valuable outreach information communication education  
Speak up for mg

Please Note: Any views expressed in this newsletter are those of the individual author and do not reflect any official position of Myasthenia Gravis Minnesota Inc.  
Always contact/consult your physician, pharmacist, nurse, or other health care professional who knows your situation the best.