



VOLUME 2, ISSUE 1

Myasthenia Gravis
Minnesota

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mgMN

Board of Directors

Diane Tower, Chair

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Barbara Corner

Lianne Anderson

Shirley Kramer

mgMN Mission

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

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mgMN Voice

Myasthenia Gravis Minnesota Inc

A Splendid Day!

Highlights from mgMN's First Annual Meeting and State Conference

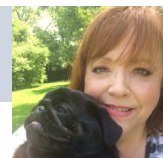
mgMN's First Annual Meeting and State Conference took place on Sunday, September 25, 2016, at the Best Western Hotel and Conference Center in Shoreview, MN. The conference was well attended and everyone reported having a great time. While coffee and pastries were made available, the morning began with a brief business meeting. Diane Tower, mgMN Chair, presided. After warmly welcoming everyone to the conference, Diane introduced the Board of Directors and called upon the members to ratify their election. She gave a brief update of the history of our new organization and referred people's attention to the formal committee reports in their packets. Barb Corner, Chair of the former MGFA MN State Chapter, formally recognized and thanked the Chapter's board members for their years of outstanding service. The business meeting was adjourned. *Then the door prizes started happening! This year there was a special \$25 gift card for the member who brought the most guests to the conference. There was a tie between Rose Pleski and Jaime Rodriguez. Rose won the gift certificate in a tie breaker. Congratulations! We encourage everyone to bring more guests with you next year, perhaps there'll be a bigger prize?*

Our wonderful support group leaders Lianne Anderson, Ellen Walle and Barb Corner spent a few minutes updating attendees on their groups. Dianne Willer-Sly, a Doctorate level Nurse Practitioner, was the morning speaker. Her presentation, titled, "Who's On Your Medical Team?" was a warm, engaging and thoughtful study of the various

(continued on page 2)

Chair Speak

by Diane Tower



Hello again, I hope this finds you well. Since my last Chair Speak mgMN has had its First Annual State Meeting on September 25, 2016, it was good to see so many of you at the conference. I would like to thank all the volunteers, who donated their time and skills to make it a success. Also, a big thank you to everyone who donated items for our bucket raffle, and of course all of you who attended and participated in the bucket raffle. The bucket raffle brought in \$828.00, which averages out to \$28.00 per item, a higher per item figure than the 2015 State Chapter's Silent Auction. This was our first fundraiser and it was a success!

The mgMN website has launched, please visit the website at mgMinnesota.com. The first time I googled mgMinnesota I got the car club. However, when I googled mgminnesota.com, it went right to our home page. It may take a while for google to recognize the website.

In the interest of saving printing and mailing costs, we would like to start emailing the newsletter and other announcements to you. Please take a minute to go to the website and enroll on our mailing list. We will be using a mailing list service which requires each recipient to electronically request to be added to the mailing list. For those of you that do not have email we will continue to mail the newsletter to you via the US postal service. Please fill out the and return form in this newsletter with your updated information.

For those of you who don't attend a support group,, I'd like to hear from you about why you don't attend and what we can do to better serve you. Please feel free to email me, my email address is: ditower@gmail.com. You can also call me at (952) 942-8775. I'd really like to hear from you. Rest assured, you will remain anonymous, but the information you share may help guide us in developing other types of support activities, enabling us to reach out to more people with MG. That's really what we're all about.

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.

conference highlights continued . . .

physicians, therapists, specialists, community members and others who could be brought together to diagnose, treat and care for people who have myasthenia gravis or other complicated, chronic diseases. Dianne encouraged everyone to add to her list and quite a resource resulted. Her experience as a clinician and as a professor at the University of MN enabled her to share a breadth of experience with us that was both genuine and insightful.

Vicki Engelen announced the exciting launch of mgMN's new website (see accompanying article in this newsletter for more details). Brunch was excellent and, of course, *there were more door prizes!*

Dr. Gaurav Guliani, a Neurologist with Health Partners, spoke in the afternoon. Dr. Guliani is well known and respected for his work with people who have myasthenia gravis. He gave a very clear and thorough overview of the disease, treatment options and current research. Dr. Guliani answered many questions after his presentation and was very responsive to people's concerns. Soon Health Partners will be opening a large Neurology Specialty Clinic of which Dr. Guliani will be the Director.

This year, instead of a silent auction, a bucket auction was held. What a fun time! Individuals donated approximately 36 themed baskets or items. Members bought tickets (or chances) to win items by placing a ticket in a jar in front of the item they wanted to win. At the close of the auction a winning ticket was drawn from each jar, and the winner was announced—Dave Schlieff did the honors (most honorably), assisted by Shirley Kramer. There were some great prizes, a table top gas grill, an MN apple basket, a margarita basket, 3M baskets, Slow Cooker Stew Basket, and many more. Perhaps the most exciting was a lottery ticket basket, won by our own Board Chair, Diane Tower.

Then, to top it all off, *there were more door prizes!* What a great day! What a great way to start a new year for a new organization! Thank you everyone! Thank you for coming and please come again next year. It will be even more informative, and even more fun. *There might even be more door prizes!*

(Anyone wishing a copy of the Committee Reports or Diane Willer-Sly's Resource List can send a request to the mgMN P.O. Box, Attention: Shirley A. Kramer. Both presentations were recorded by Jerry Smith and copies can be made available for viewing.)



Getting to know your board members . . .

Vicki Engelen, Secretary

When her mother was diagnosed with MG in 2004, Vicki found information about the MG Twin Cities support group online. She and her mother and sister attended and felt right at home. They were relieved to learn from others with MG that the disease can most often be managed. Vicki and her sister also gained insights as family members, and really enjoyed the people they met.

Vicki's mother died of pancreatic cancer four years ago (a disease unrelated to MG). But Vicki continued attending the annual conferences and maintained membership. When the new organization was formed, Vicki wanted to help it get off the ground and running smoothly, because of the value she and her family found with their involvement. She wants others with MG, and their family members, to find the same fellowship and comfort that she and her family found.

Beyond her role as secretary, Vicki wrote, organized and posted the content for the mgMN website. Over the years, she has served on several nonprofit boards—including the American Cancer Society (Ramsey county and the Minnesota division) and the local chapters of the American Marketing Association and the International Association of Business Communicators. She also serves on the board of trustees of the Wayne State College Foundation. Following 16 years as a writer, editor and corporate communications manager at three major corporations, Vicki has had her own communications business for more than 20 years. For the past two years she has been volunteer coordinator for a home for teenage homeless mothers. She also volunteers at a hospice home in Edina. Her hobbies include travel, photography, biking, reading and coloring.

Making the most of your donation . . .

If you or your family members participate in a company's Corporate Matching Gift Program, please change your donations from the former Minnesota Chapter of the MGFA to our new organization's name, Myasthenia Gravis Minnesota (mgMN). The new organization should be listed within all the current Corporate Match databases, so please update any automatic donations as well as single donations.

November 17, 2016 is Give to the Max Day in Minnesota. Each year, generous supporters like you celebrate Give to the Max Day by making an online donation on GiveMN.org. Your generosity on this day makes a difference. Please join us on November 17, 2016, for Give to the Max Day and support Myasthenia Gravis Minnesota. See link to Give to the Max Day on our mgMN website: mgminnesota.com.



Your donation on Give to the Max Day also may help us receive an additional donation of \$1,000. How? On November 17, every gift made on GiveMN.org will be entered into an hourly drawing for a \$1,000 GiveMN Golden Ticket to be awarded to a nonprofit organization. Here's the really exciting part: Two donations made on GiveMN.org during the Give to the Max Day campaign will be randomly selected to receive a \$10,000 Super-Sized GiveMN Golden Ticket for their organization! The more gifts we generate on GiveMN.org during Give to the Max Day, the more our chances increase to receive that additional \$10,000 donation.

Be sure to mark your calendar and make your gift on November 17 by visiting GiveMN.org and searching for Myasthenia Gravis Minnesota or go directly to the website here: <https://www.givemn.org/organization/myasthenia-gravis-minnesota> It will be open for donations during the entire month of November, so please consider a donation anytime during the month. Your donation is tax deductible.

A SMALL TIP: CONNECTIONS MATTER TO ME MAYBE MORE THAN WHEN I HAD MORE ENERGY, BUT ARE DIFFICULT WHEN THE ENERGY FIZZLES SO QUICKLY. RECENTLY I BOUGHT AN ASSORTMENT BOX OF GREETING CARDS. IT WAS FUN TO STAND AND SIFT THROUGH ALL OF THE OFFERINGS IN A CARD SECTIONS BUT IS NOW TOO DRAINING. ADDING A LITTLE NOTE HELPS ME REACH OUT TO OTHERS IN A MANAGEABLE WAY. ELAINE MARTIN, TWIN CITIES SUPPORT GROUP



mgMN Support Groups

MID-MN SUPPORT GROUP (BRAINERD, MN)

Contact Person: Barb Corner (218) 562-4594 or mgcorn@uslink.net

The support group meets in September, October and November, and then in March through June. The support group will not meet in December 2016, or January and February 2017. 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

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

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. There will be no December meeting. 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

Website is up and running !!!

mgMinnesota.com made its debut at the mgMN annual conference in September. This website was developed to:

- convey information and links to resources about myasthenia gravis (MG),
- connect people with MG—and their families, friends and caregivers—to local support groups, and
- communicate news and information to mgMN members and other interested parties.

The home page welcomes visitors and strives to quickly connect people with support group and membership information. There is also a space for timely information that should change every few weeks. Content is grouped under several categories listed at the top of the home page. For example, the “About” category includes information about the organization, myasthenia gravis, board members, how to connect with others who have MG (support groups), and more.

The site provides links to information about the disease from people regarded as experts in the field. While relevant links are included in written material throughout the site, there is also a section titled “Resources and Links.” The list of resources will be updated as we learn of new, relevant material.

In the “Get Involved” section, site visitors can request membership information or indicate their interest in mgMN volunteer opportunities.

Want your newsletter by email . . .

go to mgMinnesota.com and enroll in our mailing list. We are using a mailing list service which requires each recipient to electronically request to be added to the mailing list before we can start emailing you. So enroll now! For those of you who do not have email we will continue to mail via the US Postal Service.

CARING ABOUT CAREGIVERS

by Laurel Meyer and Shirley Kramer

Laurie writes - By chance I happened upon an ad for a Caregiver Support Group in my neighborhood newsletter. That got me thinking about caregivers, an under celebrated group. I decided to check to see what is available for caregivers. Starting online, I found a lot of stuff that was quite helpful. Some organizations are very specific about which populations they service, such as cancer or Alzheimer's. Two sites, Lutheran Social Services and The Wilder Foundation had a lot of opportunities for the caregiver. Also, I thought some faith communities would have caregiver support groups, so I called around to some churches in my area but mostly I just got answering machines. So here is my idea - we should put place and times of caregiver support groups in our newsletter and people can let us know what they think about them. If people do not have computers and need someone to help check stuff out for them, I can help do that.

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

Shirley responds - So let's create a space in the newsletter dedicated to caregivers. It will have three basic parts. First, we can begin to gather a list of support groups for caregivers, those that you and I identify and those that we learn about from others and print them in this section. You have also volunteered to help people who do not have computer access to find support group resources near them. Second, we will try to identify and publish in this section notices of any special programs, blogs or upcoming speakers related to care giving and/or caretaking. Third, we will reserve part of this space in each newsletter for a short story, or comment, or thought written by someone who is a caretaker, or support person of someone who has MG. Maybe something funny or inspirational. Maybe something that is a struggle or a loss. Maybe a helpful hint. They can choose to sign their name or remain anonymous, but either way, be respectful. They can email me at skannkramer@comcast.net or send to my attention at the mgMN P.O. Box 8203, St. Paul, MN 55108-0203.

Shirley Kramer is a sister of a person with MG.

Resources:

Caregiver Support Group
Meets every 4th Monday, 3-4 pm
Shalom Home East, 740 Kay Ave, St. Paul
Open to all faiths

Wilder Foundation
651-280-2000

Lutheran Social Services
651-642-5990
1-800-582-5260

CAREGIVERS - THIS IS YOUR SPACE - A PLACE FOR YOU

We are updating our Membership and Mailing Lists -

Please fill out this form and return to the address listed below. Remember you need not become a member to receive our mailings or participate in a support group. However, contributions and membership dues support the work that we do. Volunteers are greatly appreciated. If you would like to know more about our organization or have other questions please call mgMN Chairman, Diane Tower at (952) 942-8775 or email **mgditower@gmail.com**. Thank you!

Name	
Street Address	City and State Zip
Home Phone	Cell Phone
Email Address:	Newsletters and communications WILL be sent via email. Please check to receive by postal service <input type="checkbox"/>
Please add me to the Mailing List ONLY <input type="checkbox"/>	Request dues waiver information <input type="checkbox"/>
\$ 15.00 Annual Dues <input type="checkbox"/>	Additional Donation \$ <input type="text"/>
\$ 100.00 Lifetime Dues <input type="checkbox"/>	Additional Donation \$ <input type="text"/>
TOTAL enclosed \$ <input type="text"/>	

mgMN is a 501(c)(3) charity and as such donations are tax deductible. If you would like to make a donation in honor or in memory of someone, we can send an acknowledgment (no amount indicated). Please complete the following:

In honor of: _____

In memory of:

Occasion: (birthday, holiday, anniversary, etc)

From: _____

Please acknowledge to: _____

Address _____

Please mail this completed form with your check payable to:

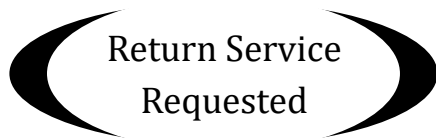
Myasthenia Gravis Minnesota Inc.

Torri Johnson, Treasurer

P. O. Box 8203

St. Paul, MN 55108-0203

Please Consider —mgMN is a brand new organization and we need your energy and help. There are lots of fun and exciting opportunities available for those who are interested in volunteering. Please contact Diane Tower at mgditower@gmail.com. Thanks for your support!



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.