



VOLUME 3, ISSUE 1

**Myasthenia Gravis  
Minnesota  
P.O.Box 8203  
St. Paul, MN 55108**

**mgMN**

**Board of Directors**

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Dan Formato, Vice Chair

Vicki Engelen, Secretary

Torri Johnson, Treasurer

Barbara Corner

Lianne Anderson

**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

## The Same but Different, Congenital Myasthenia Gravis

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

by Laurel Meyer

There are some rare, but recognized, types of myasthenia gravis which are often clustered together and referred to as myasthenic syndromes in the literature. One such rare form is congenital myasthenia gravis. The Mayo Clinic website defines congenital myasthenia gravis syndrome "as a rare hereditary condition resulting from a deficit at the junction where your nerve stimulates muscle activity. That deficit causes muscle weakness. This syndrome can affect nerve cells, muscle cells or the space between the nerve and muscle. There are one to two cases in every million live births, and boys and girls are equally affected. Symptoms appear within the first two years of life."

Congenital MG is a genetic disorder. It's symptoms are similar to MG, which is a neurological, autoimmune disorder. A diagnosis of congenital MG depends on a negative antibody test and an electronic muscle stimulation test. Ten variations of the congenital syndrome have been identified. The drugs that people with MG depend on to relieve symptoms do not work with congenital MG.

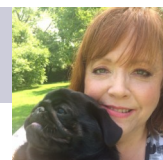
There are two individuals in the Twin Cities Support Group with this disorder, Julie Berns and Connie Osterkamp. Both women told me about breathing problems, asthma and both share the frustration that goes with this difficult to diagnose and treat disorder.

Julie told me it took 36 years to get a proper diagnosis. She pointed out to me that

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## Chair Speak

by Diane Tower



***Happy Spring!** Spring is a time of renewal and new beginnings. For me it's time to regroup and think about how I can best conserve my energy at this time of year. It seems that as the weather gets nicer, I want to do more things. Spring cleaning comes to mind . . . It is so easy to get started and deep going even after you know you need to stop. Anytime that I am feeling stronger, I tend to over do it. So, I pledge here and now, to let things (spring cleaning) go, and not push to get it done.*

*Our Board has started planning our 2017 mgMN State Meeting. We have some ideas about speakers, but would like to hear from you. Please email me at [mgditower@gmail.com](mailto:mgditower@gmail.com) with your ideas. What subjects would you like to hear about? I'd be delighted to hear from you.*

*Stay happy and healthy!*

the same but different , continued . . .

her symptoms have been with her since birth. It is “normal” for her to have MG symptoms. With autoimmune MG the onset of symptoms occurs later in life and tend to wax and wane. So the difference between what’s normal and MG is apparent.

Connie described what life was like for her as a child. Learning basic skills like walking were delayed and she had severe vision problems that needed several surgeries to correct. Participation in school activities was limited. Connie’s mother and grandmother also suffered from what we now know as congenital MG but was not diagnosed at that time.

Thanks to Julie and Connie for talking time to talk to me and help me understand more about congenital MG and it’s challenges.

Good information about congenital MG is available on the web from these reliable sources:

MAYO Clinic

Muscular Dystrophy,UK

Myasthenia Gravis Foundation of America

American Association of Neuromuscular & Electro Diagnosis Medicine

### Want your newsletter by email . . .

go to mgMinnesota.com and enroll in our mailing list. Even though we may already have your email address we are now 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. **PLEASE NOTE:** This means we can not just transfer the information we already have. So visit the website and enroll now! For those of you who do not have email we will continue to mail via the US Postal Service.



### Getting to know your board members . . .

**Barbara Corner, Communications Committee Chair**

Currently Barb serves on the mgMN Board of Directors as the Communications Committee Chair. You may recognize her, however from the many years she served as the MGFA MN State Chapter Chair. Barb says that when people look at her they often question what is wrong with her eye, that it stays mostly closed. She has her answer ready, “I did not have a stroke, I have a neuromuscular, autoimmune disease called myasthenia gravis.

Barb was diagnosed with MG as a teenager, more than 50 years ago. At that time, “I told my parents I would not let this rare disease stop me, and it hasn’t,” she says. With a thymectomy and other treatments Barb has gone on to live a pretty “normal” life. By that she means both a bachelor’s and master’s degree in Elementary education, 33 straight years teaching, a husband, three wonderful children, seven grandchildren and one very active great grandson.

Barb started attending the annual meetings of the state’s MGFA chapter in 1990. A couple of years later she started (and still leads) the Mid-Minnesota support group. Barb also started a lending library for people with MG in 1995 and published this newsletter for many years.

She offers this advice to others with MG - to be able to live with MG it is important to find out as much as you can about it. Most importantly, Barb encourages everyone to be connected with a support group, to talk with others who have MG. If you can not do it face-to-face, use technology to reach out to others from your home.

**A SMALL TIP:** KEEP A 24 INCH WOODEN KITCHEN STOOL IN YOUR KITCHEN. WHEN YOUR LEGS GET TIRED YOU CAN SIT DOWN AND CONTINUE WORKING ON WHATEVER IT IS YOU ARE DOING AT THE TIME. JEAN HAYES, MID-MINNESOTA SUPPORT GROUP (THIS TIP IS ALSO GREAT FOR A WORK ROOM OR IN A GARAGE.)



## mgMN Support Groups

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

**Contact Person:** 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:** Di 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)

## 2016 mgMN DIRECT DONATIONS AND MEMORIALS

### DIRECT DONATIONS:

Wayzata Lyons (John and Ann Ryan)

Walt and Lois Ortman

Lynette Eckdahl and Dawn Moody

Robert Wilebski

Evelyn Jensen

Harold Johnson

Kathy Oppel-Overtoom

Glenn and Marg Fishbeck

Ellen and Dave Walle

Murphy Oil

Liz Jamison

Linda Garbers

Al and Diane DeVries

### MEMORIALS:

Barbara Corner

Marilyn Coulter

Vicki Engelen

Linda Lee Johnson

Bonnie Kuehne

Kathryn Raidt

Wayne Richardson

Various Donations

In honor of Alex Stalker, M."Doc" Speckman, Rosemary Edson and Dick Holman

In honor of Linda Garber's Birthday

In memory of Loretta Root

In honor of Sandra Lemmer's Birthday

In honor of all MG people who have passed

In honor of Ellie Singer's Birthday

In honor of his mother

Memorial to Ken Schwalback

mgMN'S BOARD OF DIRECTORS WISHES TO THANK EVERYONE FOR THEIR SUPPORT AND GENEROSITY.

## CARING ABOUT CAREGIVERS

by Laurel Meyer and Shirley Kramer

**Some thoughts from Laurie** - I have heard the phrase "caregiver burnout" enough times that it has finally gotten my attention. What do our caregivers, usually people we care about, need from us? They need respect for being the kind of person that has the capacity to show love by supporting us. They need cooperation so they know we are not working against them. They deserve clear, honest communication without mixed messages. They also need to know we appreciate them for who they are and not what they can do for us. On days when I am not at my best it is easy to be selfish and crabby. For the sake of our caregivers we must be as positive, polite and good humored as possible. It doesn't take physical strength to be grateful for the support we receive. To be aware of the needs of others is a good way to put the MG into a more reasonable perspective. Laurel Meyer is a member of the Twin City Support Group and has MG.

**A reminder from Shirley** - caregivers, I encourage you to share your thoughts, stories, resources, inspirations, suggestions or struggles as a caregiver through the use of this space. Maybe a helpful hint. You can choose to use your name or remain anonymous. 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

## let's keep in touch . . .

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You can use this form to sign up for our mailings, join a support group, become a member, volunteer, or make a donation or memorial.

It is important to note that 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](mailto:mgditower@gmail.com). Thank you!

Name	
Street Address	City and State Zip
Home Phone	Cell Phone
<b>GO TO THE mgMN Website and sign in to receive communications electronically. mgMinnesota.com</b>	Newsletters and communications <b>WILL</b> be sent via email. <b>PLEASE CHECK TO RECEIVE BY POSTAL SERVICE</b> <input type="checkbox"/>
Please add me to the Mailing List <b>ONLY</b> <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"/>
<b>TOTAL</b> 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:

**Please Consider —mgMN is a young organization. We've passed our first birthday and are gathering momentum. There are still lots of things that need doing. To stay strong and vital we need your support. Learn about the interesting and fun opportunities available by contacting Diane Tower :**



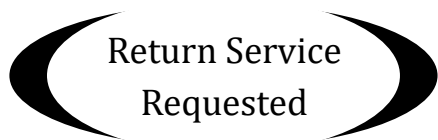
**[mgditower@gmail.com](mailto:mgditower@gmail.com). Thanks for your support!**

**Myasthenia Gravis Minnesota Inc.**

**Torri Johnson, Treasurer**

**P. O. Box 8203**

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



## 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.