

# CONQUER

News for our community

## Fall Patient Seminar Recap

On October 22, 55 myasthenia gravis patients and friends attended Conquer MG's Fall Patient Seminar at Advocate Lutheran General Hospital in Park Ridge, Illinois. Dr. David Randall, a neurologist from NorthShore University Health System and Assistant Clinical Professor for the University of Chicago, spoke about "Men's and Women's MG Issues." For women, he addressed how MG interacts with menstrual cycle, pregnancy, labor and delivery, the newborn child, and breastfeeding. For men, he covered medications that could cause low testosterone.



Neurophysical therapists Jennifer Ford and Angela Mackowiak, also from NorthShore, spoke about "Exercise and MG." They described how to begin an exercise routine after your MG becomes stable, as well as useful household and exercise equipment.

To see these presentations, visit our YouTube channel at [www.youtube.com](http://www.youtube.com) and search on "Conquer Myasthenia Gravis."

Join Us!

## Trivia Night!

Sharpen your competitive pencils, and get ready for a mouthwatering chicken/pasta dinner from DiLeo's!

Join us Saturday, February 24, 2018, at the Elmhurst American Legion Post, 310 W. Butterfield Road, Elmhurst, Illinois. Teams of six can sign up, and dinner is included for \$32 per person. Space is limited, so enlist your teammates, and give us a call at 800-888-6208. Details inside!



Happy Holidays from Conquer MG

## About MG

**Myasthenia gravis (MG)** can strike anyone at any age. MG is a highly misdiagnosed and undiagnosed autoimmune disease in which communication between nerve and muscle is impaired, causing weakness. Its primary symptoms are erratic, vary in severity and occur in any combination such as: droopy eye lid(s); double or blurred vision; weak arms, hands, neck, face, or legs; difficulty chewing, smiling, swallowing, talking; undue fatigue, difficult breathing or shallow respiration; or sense of balance difficulty. MG can masquerade as overwork, under-rest, anemia, vitamin deficiency, disease of the involved organ(s), or even emotional disturbances. Its cause is unknown; there is no cure.

**Conquer Myasthenia Gravis** was formed October 29, 1972, by a local group of caring individuals who wanted to help patients achieve the best possible quality of life, while living with and managing their MG. We are a volunteer-led organization.

**OUR MISSION:** To facilitate the timely diagnosis and optimal care of individuals affected by myasthenia gravis and to improve their lives through programs of patient services, public awareness, medical research, professional education, advocacy, and patient care.

### Conquer Myasthenia Gravis

275 N. York Street, Suite 401  
Elmhurst, IL 60126-2752  
800.888.6208  
[www.myastheniagravis.org](http://www.myastheniagravis.org)

## FROM YOUR EXECUTIVE DIRECTOR

### Happy Holidays!



During the holidays, do you begin too many sentences with "I have to..."? Whether it's "buy a gift for a co-worker," "put lights on the house," or "bake cookies for the neighbors/office/party," the I-have-to's can be exhausting. If you have myasthenia, your body may be giving you permission to say, "Not this time." To manage stress and put health first, you're allowed to savor what's meaningful to you and skip what's harmful.

This year, I'm determined to celebrate at least one day in my pajamas – and be happy doing it. How will you participate in the season – within reason?

Let's conquer MG together!

Joan Wincentzen, Executive Director

— “ —  
“Just when I think  
I have learned the  
way to live, life  
changes.”  
- Hugh Prather

### Conquer MG Patient Assistance Program

This Conquer MG program will help cover the cost of medical bills, prescription drugs and durable medical equipment up to \$1,000 per person per year. The program paid out \$10,000 in benefits in 2016, and still has funds available for 2017. You may be eligible if you are an MG patient, reside in Illinois, Indiana, or Wisconsin, and have some kind of financial hardship. Medical costs don't have to be MG-related. Contact the MG office (800-888-6208 or [info@myastheniagravis.org](mailto:info@myastheniagravis.org)) for the application, or find it on our website.



### Contact Update Form (PLEASE PRINT)

Mail to: Conquer MG, 275 N. York Street, Suite 401, Elmhurst, IL 60126

Name \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

Email \_\_\_\_\_

- ☐ Please note the above change in my contact information.
- ☐ Please remove my name from your mailing list.
- ☐ Please send **Conquer** via e-mail instead.

# Events & Activities

## ► Thanks Geri!



After guiding the Chicago West Suburban MG Support group for over 10 years, Geri Volpe is taking a well-deserved break. Thanks so much, Geri, for helping folks with MG find answers and support!

## ► New Videos on YouTube

Thanks to Briova Rx, video-recording sponsor, you can see Fall Patient Meeting presentations at <https://goo.gl/a1w9yA>.



## Calendar Club Winners

**August** – Helen MacLeod, Faye & Tom McManamy, Cheryl Thompson, Anonymous

**September** – Eloise Koulmenis, J. McCracken, D. Weber, Anonymous

**October** – Peggy Delwo, James Griffith, Bill & Barb Gwodz, Sandra Hasemeyer

**November** – Susana Guzman-Holland, L.R. Keyser, Cliff Zolna, Anonymous

## ► Calling All Volunteers



Chicago-area folks, could you offer your time and talent? Call the office at 800-888-6208 to help plan the 6th Annual Strides

Against MG Walk in June, or serve on the Conquer MG Board.



## ► MG Awareness at the Zoo

Myasthenia Gravis is part of Brookfield Zoo's Holiday Magic 2017. Thank you, Apex Management & Special Events, for sponsoring and decorating tree #429 with MG snowflakes!

## ► Calendar Club 2018

Join the fun and help us get vital MG information in the hands of over 1,200 people in the coming year. Donations to our annual Calendar Club fundraiser are \$12 per ticket or \$50 for five tickets. Each month we pick four lucky \$25 winners. And at year end, there's a Grand Prize (\$500!) and Runner-Up (\$100!). Call the office and we'll fill out your tickets and add them to the drawing box. This could be your year!

## ► Preparing for Flu Season



The Center for Disease Control (CDC) tells us, "Getting an annual flu vaccine is the first and best way to protect yourself and your family from the flu." The CDC recommends some groups especially get the

flu vaccine because they are at higher risk for severe complications if they get the flu. This includes those who have chronic neurological disorders and those who are taking immune suppressant medications. This year, higher-dose shots are available for older people.



## Jeri Aiello

### Chronic Illness and Value

Jeri Aiello is a retired nurse and psychotherapist. She has made, shown and sold art throughout her life. She uses her blog at [jeriaelloart.wordpress.com](http://jeriaelloart.wordpress.com) to write about making art within the limits of MG.

Jeri wrote this post in February 2016.



"If you have your health, you have everything. If you don't have your health, you have nothing." These words are part of a current commercial for a weight loss program. I blurted back at the TV, "I'm not nothing." Then I began to remember all of the times that I have heard people talk about the importance of having health. GET WELL SOON cards fill sections at the supermarket. Several of the Christmas cards that I received this year, said "HAVE A HEALTHY NEW YEAR." Healthy was double underlined. I know that the intention was kindness. I also know that I felt a sense of failure because I cannot follow this directive.

Humans (and other critters) have value when they are impaired. My health is diminished in several areas. Myasthenia gravis causes my eyes to droop. I have double/

triple vision that is corrected with a prism. It is difficult to speak because the muscles that move my larynx are quite weak. The muscles throughout my body are weak. I am fatigued. On a daily basis, I access my abilities. I choose one thing to accomplish and I do it. Today my thing is this blog.

Chronic illness means that the symptoms are ongoing. I realize that many people see sickness as something that should be healed or cured. Folks want there to be a food, surgery, or exercise that will fix illness.

Yes, a positive attitude is beneficial. Being hopeful is helpful. Accepting limits is equally helpful. Rather than waiting for a time of regained health, it is important to live each sick day to the fullest. Chronic illness can be

a time of gratitude and insight. It is not necessary to wait to "get well" to have value.

Equality is seen as important for gender and race. We have advanced our efforts in handicap accessibilities. Acceptance of chronic illness may be next. This does not mean giving up hope. It means people will no longer believe or say, "If you don't have your health, you have nothing."

— “ —

"I have learned  
that it's not how  
you fall, but how  
you get up that  
matters."

- Linda McMahon

# Useful Equipment for MG Patients

Jennifer Ford, MPT, NorthShore University Health System, suggests these practical tools for MG patients.

**First, Safety at Home.** To improve your stability and prevent falls, consider using the items listed here. A Serola belt can renew your pelvic strength and increase stability for daily tasks like housework or going for a walk. If you have trouble reaching down, try a shoe horn or sock aide. Ankle braces are helpful for improving side to side stability.

**Exercise equipment.** Consider starting with lightweight items. For example, resistance bands allow slow rebuilding of physical strength. Cuff and hand weights help enhance muscle tone and cardio. A foam cushion (airex pad) helps with balance. A filled-with-air Dyna disc is a great tool for the office work environment. It moves underneath while you sit on it and improves core stabilization. A stretch strap of course helps with stretching. These items are relatively inexpensive, portable, and yet very effective.



Serola Belt



Sock Aide



Dyna disc

## Household/assistive equipment

- Bed rail
- Grab bars
- Walker
- Cane
- Walking poles
- Cooling devices- vest/ collar
- Serola belt
- Shoe horn/sock aide
- Stretch strap

## Exercise equipment

- Resistance bands
- Cuff weights
- Hand weights
- Foam cushion (airex pad)
- Yoga mat
- Dyna disc
- Stretch strap

## Double Vision



I had made deviled eggs for years and normally made them look neat and fancy. With double vision there were double the eggs now and I kept missing the correct egg, making a mess of the dish. I cried with frustration from double vision problems. I also would run into door frames from seeing double because I couldn't judge which door way to enter. Depth perception was altered leading to more frustrations.

On the other hand, I had fun hunting mushrooms in the woods. My husband often laughs - he liked me to go along because I could find mushrooms better with the double vision... since I saw twice as many! If you look hard you can always find something positive.

- Gail Green, Hidalgo, Illinois

## Websites that Rate Physicians

Researchers at Tufts University in Massachusetts found serious information gaps in a study of 28 commercial physician rating websites such as Healthgrades.com, Vitals.com and RateMDs.com. Using a random sample of 600 physicians across 13 specialties, they found that 34% had no review on any site. Of those who were reviewed, the median number of reviews was seven, although many had only one review. Furthermore, few sites permitted searching by clinical condition (18%), sex of physician (14%), hospital affiliation (54%), languages spoken (11%), or insurance accepted (32%).

The authors noted that it's difficult for a prospective patient to find enough reviews that "accurately relay the experience of care with that physician."

JAMA. 2017;317(7):766-768. doi:10.1001/jama.2016.18553

# Support Groups



## Our groups offer:

- Information about myasthenia gravis and ways to cope with its symptoms
- Good listeners who care about your concerns
- Assurance, comfort, and friendship

AREA	2018 DATES	TIME	LOCATION
<b>Chicago - North Suburban</b>	Monday, Feb 19, Tuesday, March 27 Tuesday, April 24 Tuesday, Aug 21 Tuesday, October 9 Thursday, Dec 13	9:30 AM - 11:00 AM	Glenbrook Hospital, 2100 Pfingsten Road, Glenview, IL. 2nd floor conference rooms A1-A2. Use main entrance and South (Blue) Parking. December meeting is a holiday party
	Saturday, June 16	11:30 AM - 1:00 PM	Potluck indoor picnic, Rooms A1-A2.
<b>Chicago - South Suburban</b>	Sunday February 11 Other dates TBD	1:30 PM - 3:30 PM	Metro South Hospital, private dining room in cafeteria, 12935 S. Gregory, Blue Island, IL. Use ER entrance parking garage, off Union St.
<b>Chicago - West Suburban</b>	Sundays Feb 18, May 20, Aug 19, Nov 18	1:00 PM - 2:30 PM	Central DuPage Hospital, Conference room 3, Women & Children's Pavilion, 25 N. Winfield Road, Winfield, IL. Use NW entrance, park in Visitor Lot 3 or use valet parking.
<b>Rockford</b>	Saturdays Jan 13, Apr 14, July 14, Oct 13	1:00 PM - 3:00 PM	St. Anthony Medical Center, St. Francis Room, 5666 E. State St., Rockford, IL. Use main entrance and adjacent parking.
<b>Springfield</b>	Sundays Jan 21, March 18, April 15, May 20, July 15, Aug 19, Sept 16, Oct 21, Nov 18	3:00 PM - 5:00 PM	Parkway Christian Church, 2700 Lindbergh Blvd. in Springfield, just east of the Parkway Point Shopping Mall. Use office entrance and adjacent parking.
<b>Northwest Indiana</b>	Saturdays March 3, May 26, July 21, Oct 6	10:00 AM - 12:00 PM	Schererville Public Library, ask at desk for meeting room, 1001 W. Lincoln Highway, Schererville, IN. Adjacent parking.
<b>Quad Cities Iowa / Illinois</b>	Saturday February 10 Other dates TBD	10:00 AM - 12:00 PM	Davenport Public Library - Eastern Avenue Branch, Room A, 6000 Eastern Avenue, Davenport, IA. Use main entrance and adjacent parking. Co-sponsor: Conquer MG and MGFA.

## RESEARCH



A Yale University-led study is helping to explain why some myasthenia gravis (MG) patients with autoantibodies to muscle-specific tyrosine kinase (MuSK) relapse after initially responding to a drug called rituximab. Dr. Kevin O'Connor, associate professor of neurology and co-senior author of the report, explained, "While therapy with rituximab eliminates B cells, they remain abnormal after regenerating and contribute to relapse." It's hoped that disease relapse could be predicted in the future, and treatments could be tailored to the individual. This work was supported in part by a pilot research award from Conquer Myasthenia Gravis. Published September 7, 2017 in the Journal of Clinical Investigation – Insight doi: [10.1172/jci.insight.94263](https://doi.org/10.1172/jci.insight.94263)



# In Appreciation

**SPECIAL THANKS** to everyone listed who supported our mission from August 2017 through November 2017. Your continuing financial support keeps our organization going! We also thank those who asked not to be listed but support Conquer MG work. *Please note: deaths of those listed in the "In Memory" deaths are not necessarily related to MG.*

Jeri Aiello  
Kelly Amparo  
Janet Bauer  
Marilyn Bill  
Tammy Carter  
Howard Caywood  
Neal Chadwick  
Mildred Christopher  
Claudia Cox  
Bonnie Danielson  
John Davenport  
Peggy Delwo  
Carl Faingold  
Jane Ferrill  
James and Lillian Gaba  
Connie George  
Matthew Gerald  
Fred and Sharon Grabenhofer  
George and Jackie Green  
Tom and Lisa Griffin  
James Griffith  
Gary Grote  
Terry Haas  
Matt and Sara Hasemeyer  
Cheryl Heldt  
Carol Hirsheimer  
Mary Kay Hoffmann  
Louis and Irene Homberger  
Vicki Hood  
Jane Horan  
Carol Humes  
Idelle Idelman  
Donna Iozzo-Kroll  
Cathy Jackson  
Lois Johnson  
Cecil and Nancy Johnston  
Dianne Kaufman  
John Keating  
David Kelly  
Duane and Arlene Kilgus  
Cynthia and Michael Klidas  
Maria Kunca  
Michael and Linda Kyser  
Patrick Leach  
Danielle Lehman  
Steve and Dorothy Litwitz  
Charles Lobodzinski  
Linda Loland  
Gerald Mack  
Kenneth and Helen MacLeod  
John Manion

Toni Martinez  
Thomas McClain  
Julie McCracken  
Cheryl Meltzer  
Bill and Gina Meyer  
Dorothy Narcisi  
Gary Nelsen  
Carole Ostachowski  
Albert Paveza  
Michael Peer  
Mary Ann Pero  
Daniel Platt  
Bob Ratzel  
Darlene Renko  
Ed Rickert  
Gerald Robertson  
Dixie Robinson  
Sharon Ruddy  
Paul Samson  
E. Eleanor Shoaf  
Dwain Sims  
John Skarbek Jr.  
Lonnie Smith  
Ruth Smith  
Cindy Strama  
Mary Julie Szalko  
Thermo Fisher Scientific  
Robert and Cheryl Thompson  
Ronald Throp  
Bob Toton  
Amy Vahrenwald  
Katherine Vennetti  
Geraldine Volpe  
Vinnie Volpe  
Donald and Phyllis Weir  
Ted Wienski  
Bonnie Zivich

In Memory of  
Nicholas Albers  
Edward and Carolyn Albers

In Memory of  
Donald E. Bozzi  
Barbara Lazo

In Memory of P.J. Fitzgerald  
Bill Gwodz

In Memory of  
Sue Miller Foltz  
Suzanne Foltz

In Memory of  
Arthur A. Geary  
Jill Kolaniak

In Memory of George J. Heinz  
Marilyn Heinz

In Memory of  
Ralph M. Hoffmann  
Margherita and Mark  
Hoffmann

In Memory of Idelle Idelman  
Bossenmeyer-Wielenga  
Family Charitable Giving  
Fund

In Memory of  
Michael J. Jamen  
Ida Jamen

In Memory of  
Marianne Johnson  
Joe and Nancy Oswald

In Memory of Sylvia Lavini  
Dot and Morton Goldenberg

In Memory of  
George W. McKissick  
Barbara McKissick

In Memory of  
Mary E. Mechling  
Rob and Marilee Grove  
Nanette and Dylen Imel  
Allen and Geannine Kessler  
Karol Kessler  
Ron and Jean Kitchens and  
Family  
Robert McCoy  
Merle and Mary Mechling  
Gary and Melody Smith and  
Family

In Memory of  
Guadalupe Quintana Ocho  
Susana Guzman-Holland

In Memory of Ethyl Rogers  
Maureen McGrath

In Memory of  
Lorraine Schohn  
Joel Schohn

In Memory of Babe Tamanini  
Rosalie Muzzarelli

In Honor of  
Scott Adamscheck  
Steve and Sharon Adamscheck

In Honor of  
Becky Brantner Christianson  
Gladys Brantner

In Honor of Patricia Girard  
Ronald Girard

In Honor of  
Dr. Marita K. Janzen  
Bill and Hilda Grady

In Honor of  
Dr. Michael P. Merchut  
Jack and Judy Trevillian




In Honor of Vicki Slomiany  
Raluca Bruce  
Andrew Kasper

In Honor of Nancy Van Laten  
Arlene Sangmeister

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Upcoming Events

- JANUARY 13**  
Rockford Support Group meets
- JANUARY 21**  
Springfield, IL Support Group meets
- FEBRUARY 24**  
Trivia Night Fundraiser
- JUNE 3 - TENTATIVE!**  
Strides Against MG Walk