



The Myasthenia Gravis Foundation
of Illinois, Inc.
The Myasthenia Gravis Foundation
of Illinois, Inc.

Conquer

"Strength in Hope"

275 N. York Street, Suite 401 * Elmhurst, IL. 60126 * Phone: 1-800-888-6208 * www.myastheniagravis.org

August 2015

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MG is coined the "Snowflake Disease" because it affects no two people the same.

MG 101: What Every MG Patient Should Know

Understanding how myasthenia gravis works and can be treated is important for every MG patient. Here is an opportunity to get a handle on myasthenia gravis symptoms, treatments, and promising MG research work. Join us Sunday, October 25, 2015 at Advocate Lutheran General Hospital in Park Ridge, Illinois, when Matthew Meriggioli, M.D., Professor of Neurological Sciences at Rush University Medical Center, will explain MG essentials. See the flyer inside for details.

3rd Annual Strides Against MG Walk



The MGF of Illinois family-friendly celebration to raise MG awareness was all set for June 7, but Mother Nature had other plans. Over 100 MG supporters came out to cheer our cause, while the other 100 registrants opted to stay dry and raise awareness at home. Even so, our awareness-raising and fundraising efforts were very successful. The local Elmhurst newspaper ran an MG story, the event was posted on many online platforms, and many new folks heard the MG message. We doubled our net proceeds compared to last year, too, raising \$21,000 to serve MG patients. Thank you, walkers, donors, and sponsors! See inside for pictures.

MGF of Illinois Funds Research

We're working with you to create a better future for MG patients. Myasthenia Gravis Foundation of Illinois research grants for 2015-16 have been awarded to:

- John Yi, PhD, Duke University, for his pilot study, "Profiling of ACHR-Specific B Cells in Myasthenia Gravis."
- Henry J. Kaminski, MD, George Washington University, for his pilot study, "Evaluation of IL-17A as a Therapeutic Target for Myasthenia Gravis."
- Betty Soliven, MD, University of Chicago, for second year funding of her pilot study, "Regulatory B Cells in Myasthenia Gravis."

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.

The Myasthenia Gravis Foundation of Illinois, Inc. 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.

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275 N. York Street, Suite 401
Elmhurst, IL 60126-1530
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From Your Executive Director

Occasionally people ask why they are still getting mail from us, even though they contacted the national Myasthenia Gravis Foundation of America about a change in status.

Like a number of MG patient support organizations, MGF of Illinois is an independent 501(c)(3) nonprofit, not connected to a national organization. We do all our own fundraising to provide strong local (Illinois and northwest Indiana) services in addition to responses and resources for all who contact us, **no matter where they live**. For Illinois and northwest Indiana patients, we offer face-to-face encouragement through local support groups, twice-annual patient seminars, and help with medical bills for those who struggle financially. Our local Medical Advisory Board members help us connect patients with area neurologists who are up-to-date on MG treatments. They also guide our research funding, answer patient questions, review our website, and provide articles to share with you.

We are grateful for help from individuals like you who make this happen. With a record number of walk participants and donations, and a strong response to our appeal letter, we're getting closer every day to our \$50,000 donation target (see page 8). If you haven't yet, please consider contributing to MGF of Illinois efforts, either online at www.myastheniagravis.org or by using the enclosed envelope. Your gift translates directly to services for myasthenia gravis patients. Thank you!

Wishing you good health,

Joan Wincentzen
Executive Director



Janet Bauer's Family and Friends Team raises MG awareness!



*Thank you,
Walkers, Volunteers,
Teams and Fundraisers!*



- Thank You,
Strides Sponsors!*
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GH FitLab
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Whole Foods





Activity Updates

MGF of Illinois Honors Volunteers

The Volpe Family was recognized at the MGF of Illinois May meeting for their service to MG patients. Geri Volpe has guided the West Suburban Support Group for years; her daughter, Deb Volpe, has served on the board, co-chairs the Strides Against MG Walk, and has cajoled dozens of family members and friends into volunteering for the event. Geri's daughter Karen Volpe is a key participant on the Walk Committee, too. Thank you, Volpe Family!

"Rise Above MG" Inspires

On May 3, over 50 attendees tapped into the inspiration of MGF of Illinois' "Rise Above MG" presentation at Elmhurst Memorial Hospital. Katie Jasmon spoke about her journey from college athlete to emergency room physician assistant where she has diagnosed others with myasthenia. Mark Grazman and Dr. Robert Heller from GH FitLab shared their experiences in helping disabled individuals improve their overall health with exercise plans that are "measured and dosed." Last, it was a joy to hear Marie Smith's cello performance as she explained adaptations she's made to still play the music that is her passion. This session was made possible through the generous sponsorship of AxelaCare.



Parading and Paddling for MG

Ben Maravilla is a one-man dynamo for raising MG awareness in Aurora, Illinois. He and his family entered a "Myasthenia Gravis" float in Aurora's Puerto Rican Heritage Parade in July. And for the fourth year, his team will construct and paddle a Myasthenia Gravis entry in the Fox Valley United Way Cardboard Boat Race. Way to go, Ben!



Motorcycle Ride for MG Awareness

On July 11, 2015, MG advocate Kelly Lozada led the "Motorcycle Ride for MG Awareness" with participation of the Latin American Motorcycle Association (LAMA) – Chicago South. MGF of IL chair Bob Rosecrans noted, "Kelly did an OUTSTANDING JOB of organizing the event. We had an Illinois State Police escort from Countryside to the Wisconsin border. The police blocked entrance on the I-294 until we passed, and it was something to see. At the Wisconsin picnic site, they had a DJ, as well as horse shoes and badminton. When Kelly spoke, it brought a tear to my eye and to a number of the riders." Thanks for a successful ride to raise awareness, Kelly! (That's her in the picture, smiling, left of the state trooper.)



Courtney G. Smith

Autoimmune Disease Advocate



MG patient Courtney G. Smith was profiled in the April 1, 2015 online article “Autoimmune Epidemic: Meet the Women Affected,” of SELF magazine. Courtney relates how she produced and directed the award-winning 2006 documentary in an effort to raise awareness about autoimmune disease. Her film “Beauty Does Lie: The Untold Story of Autoimmune Disease” explores the lives of seven African American women living with various forms of autoimmune illness.

She notes, “I really believe that autoimmune diseases should be included on every medical intake questionnaire. More research is also needed to determine what common denominators among women are causing our immune systems to attack us. On that note, I’d like for autoimmune diseases to be researched collectively instead of individually.”

When we caught up with Courtney, she explained that she’s been dealing with adenomyosis (a painful condition affecting the lining of the uterus), in addition to MG. “Healing is a lot of work,” she notes. Yoga has helped her with bone strength and pain. She has been writing a screenplay called “My Healing Journey” and meets with a support group. Her advice is to “find the determination to be active. If you don’t work those muscles, they won’t function properly. Even if it’s just sitting on the couch and waving your hands!”

Option Care is a proud sponsor of Myasthenia Gravis Foundation of IL

Option Care is a national leader, providing unmatched safety outcomes for home-based IG patients with autoimmune disorders, such as Myasthenia Gravis. Our patient-centered care, offering all brands of IG, focuses on education and communication.

Comprehensive support for IG therapy is provided by our expert staff of pharmacists, nurses and reimbursement specialists, who closely monitor patient’s tolerance and response to therapy.

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For additional information on immunoglobulin therapy:
Phone: 877.974.4844 Fax: 877.974.4845



Anesthesia and Surgery in Myasthenia Gravis Patients

By Kourosch Rezaia, M.D., Associate Professor
Department of Neurology, University of Chicago

Myasthenia gravis (MG) is an autoimmune disease caused by abnormal immune reaction directed against acetylcholine receptors or other proteins of the neuromuscular junction. As the result of neuromuscular transmission impairment, MG leads to weakness of eye movements (droopy eyelid, double vision), limb muscle weakness, swallowing difficulty, and breathing impairment. MG is also characterized by a fluctuating course and MG patients often have deterioration of symptoms when they are exposed to certain medications, and stressors such as infections, pregnancy, and surgical procedures.

MG exacerbation or crisis (i.e., life threatening respiratory impairment) may arise from the stress of the surgical procedure or as a result of general anesthesia. General anesthesia may cause MG exacerbation or crisis because:

- i. Neuromuscular blockers (NMB) that are commonly used in general anesthesia further suppress neuromuscular transmission, which is already impaired in MG;
- ii. There is a possibility of drug interaction between medications commonly used in MG patients (pyridostigmine and azathioprine), and certain anesthetics and NMBs. For example, pyridostigmine blocks the enzyme that is involved in the metabolism of some of the NMBs, therefore prolonging the duration of their action (muscle weakness).

Given the potential for MG exacerbation or crisis after surgical procedures, it is critically important to take appropriate measures to avoid or minimize the occurrence of these complications. The following measures are recommended:

The neurologist is to be informed when a surgical procedure involving general anesthesia is scheduled. On the other hand, minor surgeries or procedures such as colonoscopy generally do not pose a high risk of MG exacerbation.

- i. Elective surgeries (including thymectomy) are optimally to be planned when MG is in clinical remission. Patients with active MG and borderline pulmonary function, or those with history of MG crisis after surgical procedures may benefit from a protective course of treatment with either intravenous immunoglobulin (IVIG) or plasma exchange prior to undergoing the surgical procedure.
- ii. Anesthesia complications can be minimized by avoiding NMBs and if patients receive NMBs, close monitoring in the postoperative state. Some anesthesiologists have used medications that promptly reverse the effects of NMBs in the immediate post-operative period.
- iii. Depending on the circumstances, pyridostigmine may be withheld hours prior to the surgery and started in the recovery period.
- iv. Furthermore, use of local and epidural anesthesia is preferred to general anesthesia in MG patients when possible. On the other hand, postoperative pain is to be treated aggressively as the stress caused by pain itself may potentially cause exacerbation of MG.

Reference: Blichfeldt-Lauridsen L, et al. Anesthesia and myasthenia gravis. *Acta Anaesthesiol Scand* 2012; 56: 17–22

The Ice Maker Analogy

By Heather Weber

Today, when I was getting water from the dispenser on the fridge, it made me think about myasthenia gravis. That might seem quite odd, but the ice maker in this fridge is the perfect analogy to describe what it's like to have MG.

If you have an ice maker, you know that as long as it is working right, you will have plenty of ice to use how you please. On a hot summer day, you keep refilling that glass of ice water. No big deal.

But what if the ice maker breaks? What if you never know how much you will have or how long it will last? All you know is that you have to conserve the ice to last through that hot summer day. You have to pick and choose how to use it because when it's gone, you may not get anymore until tomorrow, or maybe even the day after that.

In MG terms, this means we have to plan our days and choose which activities we will participate in. Cooking, driving or merely talking on the phone all take a certain amount of "ice." We have to decide what is most important and only do those things, even if we are still functioning ok or "look fine." Some of us need to rest both before and after any activity to prevent a trip to the hospital. Literally and figuratively, we must avoid the heat.

Now every time I refill my water bottle and dispense that ice, I will probably think of MG, and I hope you do, too. It's a reminder of the need to conserve our energy for the most important things in life.

Thank You, Volunteers!

June Ballard-Beard

Tom Banks

Nick Bosch

Gayle Burg

Tammy Carter

SeAnn Collins

Nancy Crown

Dave DeFries

Ingrid Durham

Denise Feichter

Anne Flanz

Jeanne Fox

Jean Geisheker

Marlo Geist

Bill Grady

Deb Hawkins

Mary Kay Hoffman

Joyce Holste

Marita Janzen

Kristin Kuhnhofer

Toni Lance

Barb Lehman

Steve & Dorothy Litwitz

Pat McGonigle

Debbi & Mark Merrill

Gary Nelson

Erin O'Loughlin

Olivia Orwitz

Ron & Cheri Richards

Sam Stewart

Linda Tovella

Deb Volpe

Gerl Volpe

Karen Volpe

Lisa Volpe & daughter Megan Val, Kathy, Kamron & Kristen Volpe

Jeff, Ian, and Peter Wincentsen

Heidi Wolter



Calendar Club Winners

February to July 2015

February

The Chmielewskis

Donna Kroll

Anonymous (2)

March

Jennifer Steffgen

Bernadette Stewart

Anonymous (2)

April

Thomas Dammrich

Jane Horan

George Omwando

Cecil Stuart

May

Cindy Klidas

Frank Marquett

Heather Weber

Anonymous

June

Bruce Bosenbecker

Julie McCracken

Ashwin Patel

Anonymous

July

Eugene Deutsch

Helen MacLeod

Gail Olley

Darlene Perrone

Research Updates



Dr. Bryan Trayno, chief of Neuromuscular Diseases Research Section at the National Institutes of Health in Bethesda, Maryland, and his colleagues have compared DNA from more than 1,000 white, North American patients with AChR-positive myasthenia gravis to nearly 2,000 control samples. They were looking for genetic variations associated with a susceptibility to myasthenia gravis. In study findings published online February 2, 2015 in *JAMA Neurology*, Dr. Trayno and his colleagues report finding three different disease-associated loci in MG patients. One locus was at CTLA4,

and the FDA already has approved two treatments that target this site for rheumatoid arthritis and renal transplant patients. Their findings suggest these drugs could be considered for MG patients. Source: <http://www.medscape.com/viewarticle/839148?src=rss>; *JAMA Neurol.* 2015;72(4):386-387. doi:10.1001/jamaneurol.2014.4493

Researchers at Shandong University and Shandong Provincial Qianfoshan Hospital in China looked at the effects of cysteinyl aspartate-specific proteinase-1 (caspase-1) inhibitor on myasthenia gravis in rats. Caspase-1 appeared to improve symptoms of MG in the study animals. The study results suggest caspase-1 inhibitor may be an important drug target for MG and other autoimmune diseases. Source: *Journal of Neuroinflammation* 2015, 12:118 doi:10.1186/s12974-015-0334-4

MGF of Illinois funded two pilot studies for the grant period July 2014 to June 2015.

- **David P. Richman, M.D., University of California, Davis, “Monoclonal Antibody Treatment of Anti-MuSK Myasthenia.”** Dr. Richman reported that he and other researchers have noted that a subgroup of MuSK antibodies appears to improve, rather than block, the function of MuSK, improving the symptoms of MuSK myasthenia. The goal of his project was to produce and characterize purified antibodies that have only the effect of improving MuSK function. While studying the muscle wasting that characterizes MuSK MG, his team found they were also positioned to investigate lrp4 antibodies in seronegative MG. Using the monoclonal antibody system they had developed for MuSK MG, they also worked to develop and characterize a rat model of lrp4 antibodies. This work opens up new avenues to investigate whether the lrp4 antibody is a cause or biomarker of MG.
- **Betty Soliven, M.D., University of Chicago, “Regulatory B Cells in Myasthenia Gravis.”** With recent evidence suggesting that regulatory B cells (Bregs) play an important role in controlling autoimmunity, Dr. Soliven explored whether MG patients have abnormal frequency or function of Bregs. Her pilot study results found altered frequency of Bregs in human MG. With MGF of Illinois funding, she is continuing a second year of the study to provide further insight into the role of impaired Breg generation in MG. She aims to use an increased sample size to determine if there is a correlation between MG patients’ B cell frequency/function and their MG symptoms and treatment. She also will explore whether immunomodulating treatments can restore the frequency of Bregs or improve their function.

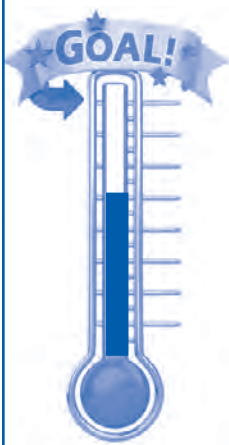
Generic Mestinon Timespan Now Available

Many MG patients take the medication Mestinon® to ease their symptoms. It comes in three forms: 60 mg tablets, 180 mg Timespan tablets, and a syrup. A generic form of Mestinon Timespan® is now available under the name Pyridostigmine ER (ER for extended release). Manufacturer Alvogen Inc. has noted it may take some time to get supplies to all locations. Although cost varies depending on your insurance plan, it will be lower than brand name Mestinon Timespan.

In Appreciation...

Special thanks to everyone listed who sent in a contribution from February 2015 through July 2015. Your continuing financial support keeps our organization going! We also thank those who requested not to be listed but support our organization's mission. *Please note: deaths of those listed in the "In Memory" section are not necessarily deaths due to MG.*

Joy Adams	Susan Craig	Patricia Gilmartin	George Koldenhoven
Vasiliki Afendakis	Victoria Crepeau	Kim Glascott	Christos Konstantelos
Frank Amato	Milly Crespo	Barbara Glenn	Holly Kost
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Jason Applebaum	Deborah Cunningham	Dick and Linda Green	Bill and Joan Kretz
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Carole and John Ballard	Jay Dahlin	Gary Grote	Tracy Kwit
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Lisa Ballard	Richard and Nancy Darnell	Jennifer Hack	Elaine Lackie
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Tom Banks	Celestina Davila	Jordan Hanson	Virginia Larsen
Sandra Baralli	Patricia De Chene	Michael and Ann Harrington	Maria Latorraca
Kenneth Barker	Dorothy and Paul DeBoer	Arlene Havlicek	Arthur and Faith LaVelle
Janet Bauer	Carole Deeds	Jim Hearn	Art and Ruth Lebeau
Char Beach	Peggy Delwo	Deborah Hecky	Thomas Leischner
MaryBeth and William Beiersdorf	Linda DeNovi	Cheryl Heldt	Chuck and Sylvia Leppert
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Vicky Benyr	Linda Dibblee	Shirley Hill	Al Licciardi
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Patricia Bradley	Kathy Dopke	Joyce Holste	Walter Litwitz
Arlene Brandt	Marjorie Duff	Vicki Hood	Lin Liu
Marga Breckenfelder	Dorothy Duranty	John Huff	Charles Lobodzinski
Elizabeth Breen	Ingrid Durham	Marcella Huff	Gail and Warren Long
Howard Brickman	Christine Dwyer	Kayla Hunter	Janeen Lord
Marcella Bridges	Joan and Warren Eagle	Illinois Tool Works Foundation	Dwayne Lucy
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Patricia M. Brown	Enshu (USA) Corporation	Donna Iozzo-Kroll	Martha Malloy
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Jon Bychowski	Jeremy Green	Irving A. Johnson	Catherine Micinski
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Fernando Calvarese	Anne Flanz	Jasmine Jones	Stefanie Mills
Scott and Colleen Campbell	Judith Flodin	Rosemary Jones	Mark and Mary Monson
Cal and Joan Cann	Heide Forbush	Ana Joyce	Heather Montell
Lorraine Carella	Corrine Freking	Beth Joyce	Kathryn Mullaney
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Neal Chadwick	Mona Garner	Pamela Kaufman	Dorothy Mykisen
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Mee Phon Chin Uhrik	Keirn Gawthrop	David Kelly	Loretta Nelson
Sandra Collins	Richard and Judy George	Marri Kelly-Banks	Joy Nemeth
SeAnn Collins	Matthew Gerdali	Alison and John Kessler	Kristen Nevdal
Megan Connolly		Ann Knutson	Christine Newman-Davis



Can You Help Us Meet Our Goal?

Our mission is to improve the lives of MG patients with consultations, newsletters, new patient packets, support groups, and online resources like our website and YouTube channel.

Your contribution will make a difference!

2015 Target: \$50,000

Amount raised to date: \$34,957

Patient Assistance Program

Launched in 2014, the MGF of Illinois Patient Assistance Program will help cover the cost of medical bills and prescription drug costs up to \$1,000.*

You may be eligible if you are an MG patient, reside in Illinois or Indiana, and can show proof of medical hardship. Costs do not have to be MG-related. Contact us (800-888-6208 or info@myastheniagravis.org) for the application.

*To the extent funds are available.

In Appreciation (continued)

Christine Newman-Davis
Karen Norquist
Gabriela Nunez-Reagan
Megan O'Brien
David O'Bryant
Tom O'Callaghan
Donna Olewinski
Felicia Oliver
April Osborne
Bonnie Ostarello
Glen Ostdiek
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Don and Marilyn Wood
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Ann Marie Zaccaro
Guy Zigante

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In Honor of Joyce Holste
In Memory of Michael J. Jamen
In Honor of Paul Later, MD
In Memory of Raymond Mostek
In Memory of William R. Prather
In Honor of Bob Rosecrans
In Memory of Lorraine Schohn
In Honor of Ken Shelton
In Honor of Joanna Sherrod's birthday
In Honor of Joan Wincentsen
In Memory of Adel Zavagnin and
in Honor of Geri & Deb Volpe

Joyce Scher
Sherrie and Bill Murray
Michael and Sally Pope
Bill Gwodz
Betty Frederick
Lillain Gaba
Joan Gebhardt
Michael Golding
Kay Keith
Ida Jamen and children
Ruth Smith
Irene Mostek
Carolyn Grebner
Toni and Sharon Keene
Joel Schohn
Marie Nelson
Esther Eisenstein
Dr. Susan Engel-Arieli
Ford Campbell

MGF of Illinois Support Group Meetings



Our support groups are:

- A place to go for information about your particular problems.
- A group of special friends - good listeners who care about your concerns.
- A group of people like you who share a common problem or interest in acquiring information on a particular issue or need.
- A place to receive assurance, comfort, friendship and social support.

Several people have contacted MGF of Illinois about starting a Quad Cities support group. If you are interested in this or in starting another group, contact our office at 1.800.888.6208.

*** ~ ● ~ ***

A new Chicago-Central MG Support Group began in February 2015. Rush University Medical Center is hosting the group and it is being led by a licensed clinical social worker. You're welcome whether or not you're a Rush patient.

SUPPORT GROUPS

AREA	2015 DATES	TIME	LOCATION
Chicago - Central	Thursdays, Sept. 3, Oct 1, Nov 5, Dec 3	1:00 pm - 2:00 pm	Rush University Medical Center Professional Building, Conference room 1119 (11th floor), 1725 W. Harrison St., Chicago IL. Parking garage is at SE corner of Harrison and Paulina.
Chicago - North / Near No. Suburban	Sunday, Nov. 15	1:00 pm – 2:30 pm	Glenbrook Hospital, Conference rooms B&C, 2100 Pflugsten Road, Glenview, IL. Use center entrance and adjacent parking.
Chicago - South Suburban	Sunday, Nov. 8	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.
Chicago - West Suburban	Sundays, Aug. 16, Nov. 15	1:00 pm – 3:00 pm	Central DuPage Hospital, 25 N. Winfield Road, Winfield, IL. Meet in Conference Room 3 on first floor. Enter at NW entrance, Women & Children's Pavilion. Valet parking is available plus additional parking in Visitor Lot 3.
Peoria	Discontinued		Thank you Toni Lance, for your years of leadership and compassionate support!
Rockford	Saturday, Oct. 10	1:00 pm – 3:00 pm	St. Anthony Medical Center, St. Francis Room, 5666 E. State St., Rockford, IL. Use main entrance.
Springfield	Sundays, Aug. 16, Sept. 20, Oct. 18, Nov. 15	3:00 pm – 5:00 pm	Parkway Christian Church, 2700 Lindbergh Blvd in Springfield, just east of the Parkway Point Shopping Mall. Use main entrance.
NW Indiana	Saturday, Oct. 3	10:00 am – 12:00 pm	Schererville Public Library, 1001 W. Lincoln Highway, Schererville, Indiana. Ask at the front desk for meeting room.

Board Members Needed

Would you or a family member consider serving a term on the MGF of Illinois board? The board makes decisions about MGF of IL programs, outreach efforts and fundraisers. The commitment involves 5-6 meetings in Elmhurst, Illinois. Call 1-800-888-6208 to learn more.

The Myasthenia Gravis Foundation of Illinois, Inc.
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