



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](http://www.myastheniagravis.org)

**December 2015**

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## MG 101: What Every MG Patient Should Know



Seventy-five people were on hand October 25 at Advocate Lutheran General Hospital in Park Ridge, Illinois to hear Matthew Meriggioli, MD, share the latest information about myasthenia gravis. Dr. Meriggioli, Professor of Neurological Sciences at Rush University Medical Center, explained current understanding on topics such as why people get autoimmune disease, what happens in the immune system of an MG patient, antibodies that cause MG, and prevalence of thymus abnormalities in MG patients. Dr. Wayne Rubinstein, fellow member of MGF of Illinois Medical Advisory Board, provided support for the meeting and introduced Dr. Meriggioli. We're grateful to both doctors, as well as to attendee Dr. Julie Rowin, for sharing their time and expertise. For an expanded report, visit <http://www.myastheniagravis.org/recap-myasthenia-gravis-101/>. A DVD of the presentation will be available for purchase in February

## St. Louis Support Group Meeting

If you live in or near St. Louis, Missouri, and would like to learn more about managing your illness, then the upcoming St. Louis MG Support Group meetings may be a valuable resource. In 2016, MGF of Illinois will take turns with the Myasthenia Gravis Association – Kansas and Missouri in hosting four group sessions. MGF of Illinois will host the first meeting on Sunday, January 31, at the Glendale City Hall Auditorium, 424 N. Sappington Road, Kirkwood, Missouri, from 1:00 to 3:00 pm. The topic will be "Nutrition and Myasthenia Gravis." MGA-Kansas and Missouri will host the next meeting on Saturday, April 16, 10am to noon, at the same location. Watch for details about future St. Louis area meetings in our next newsletter.

## Consider Rx Costs for Medical Plan

Are you wrestling with the choice of medical coverage for the coming year? It pays to research coverage for your medications. Michelle Dulashaw, medical assistant for the MG Association of Western Pennsylvania, suggests contacting your top choices for insurance carriers directly so you're not caught by surprise. You'll want to find out if a medication is covered by the plan, and if so, at what level (or "tier").

*(Continued on page 5)*

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

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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## From Your Executive Director

Along with wishing you joy this season, we at the Myasthenia Gravis Foundation of Illinois wish you good health! Together we have a lot to look forward to in the coming year...such as the Olympics in Rio and the presidential election. At MGF of Illinois we're excited to be working with the Myasthenia Gravis Association – Kansas and Missouri in the months ahead to co-host support group meetings in St. Louis. Dates for other 2016 Illinois and Indiana support group meetings can be found on page 6. We're also planning a Trivia Night fundraiser at a soon-to-be-disclosed Chicago location, and a bigger and better 4th Annual Strides Against MG Walk in June. And flu shots...well, okay, maybe we're not looking forward to that one.

MGF of Illinois' tagline is "Strength in Hope." May your hopes give you inner strength to fight illness and keep your life on track.

All the best to you,

*Joan Wincentsen*  
Executive Director

*Happy Holidays!*

## Grapefruit? No thanks!

If your prescription carries a warning to avoid grapefruit (and juice), take it seriously. Research findings from 2012 (CMAJ 2012; DOI:10.1503/cmaj.120951) listed 85 medications that interact with grapefruit, including MG immunosuppressants cyclosporine and tacrolimus. According to the study, a natural chemical in grapefruit inhibits enzymes that affect how your body absorbs certain medications. WebMD notes, "With some drugs, just one serving of grapefruit can make it seem like a person is taking multiple doses of the drug."



## A Phase II Trial of "Rituximab in Myasthenia Gravis"

This study continues to recruit MG patients at multiple locations in the U.S. and Canada. The study's primary purpose is to learn if the drug rituximab will help people take less prednisone to manage their MG or possibly be able to discontinue prednisone.

Visit [www.myastheniagravis.org](http://www.myastheniagravis.org) to learn more about this study. If you live near Chicago, Illinois and would like more information about participating please contact Bartosz Jacher, Clinical Research Coordinator at Northwestern University Department of Neurology, 1-312-503-6868 or [Bartosz.jacher@northwestern.edu](mailto:Bartosz.jacher@northwestern.edu).

# Activity Updates



## Thank You Kelly and LAMA - Chicago South



On October 25, Kelly Lozada (pictured at the podium) presented MGF of Illinois chair Bob Rosecrans

with a check for \$1,500 to help MG patients. These proceeds were from Kelly's Motorcycle Ride for Myasthenia Gravis, which was held last July. Kelly's event was made possible with the support of LAMA (Latin American Motorcycle Association) – Chicago South. Pictured with Kelly are chair Bob Rosecrans, LAMA VP Frank Diaz, as well as Jesus Arroyo, Mimi and Mario.

## Pass the Pie for MGFI (Illinois)!



This season help MGF of Illinois support MG patients and enjoy mouthwatering holiday pies at the same time! Bakers Square Sweet Returns™ cards are \$15 each and can be redeemed for a pie of your choice. The cards have no end date and make great holiday gifts. To purchase, visit [www.myastheniagravis.org](http://www.myastheniagravis.org), or call the office with your credit card information, or mail us your request along with a check payable to MGF of Illinois.

## Calendar Club 2016

Join the fun and help get vital MG information in the hands of 1,200 MG patients, family members, and friends in the coming year. Donations for our annual Calendar Club Fundraiser are \$12 per ticket or \$50 for five tickets. Entries are drawn weekly for a prize of \$25. At year end, we pick a Grand Prize Winner (\$500) and a Runner Up (\$100). Donate online at [www.myastheniagravis.org](http://www.myastheniagravis.org) > Support the Cause > Calendar Club, or just call the office. We'll add your tickets to the drawing box.

## Snowflakes for MG



*Myasthenia gravis is called the "Snowflake Disease" because its course is different for each person.* These sparkling holiday snowflake ornaments are three for \$10.00 (includes shipping and handling). Sized 3-1/4" x 3-3/4", they come in various colors and are bedecked with flowers, holly berries and Christmas images. Purchase these lovely holiday accents by calling the office (800-888-6208); or visit [www.myastheniagravis.org](http://www.myastheniagravis.org) and click "Shop."

## Calendar Club Winners

August: Patrick Considine, Thomas Ehmann, Jr., Rosemarie Levy, Anonymous (1)  
September: James Gaba, Sr., Charles Lobo, Eleanor Sweeney, Anonymous (1)  
October: Jane Horan, John and Mary Ann Manion, J. McCracken, Anonymous (1)

**Fall Meeting Sponsor**  
**Thank you Option Care!**





# My Daughter and MG

By Tiffany Rivera

As a parent, you do everything you need to do to nurse your child back to good health when they are sick. Unfortunately, things are not always as easy as giving them an antibiotic or pain reliever to make them feel better. Sometimes, you are told that your child has a life-long medical condition and no matter how much you hug or



*Valerie as infant with MG, and today as a lively 4-year-old*

or kiss them, there is nothing you can do to make it better. That is exactly what happened when my 4½ month old daughter was diagnosed with myasthenia gravis in 2011.

Valerie was born in May of 2011. Though she was delivered by emergency cesarean section, for the first 3 months of her life she had no health issues. In early September I started to notice a change in her feeding and sleeping habits. Being that she was the youngest of five siblings, I was not too concerned with the changes. I thought she was going through a phase.

However, by late September her habits became more consistent with that of a newborn, she could no longer cry, and her facial features completely changed. She would look at me and her eyes would automatically go down like she was unable to focus.

In October, she was referred by her pediatrician to a neurologist at Children's Hospital of Wisconsin in Milwaukee. The neurologist immediately admitted her. (Talk about a parent's worst nightmare!) While they were getting her hooked up to all the machines, Dr. Sumit Verma, the neurology intern, sat with me to get additional information. After we talked he did a quick exam, turned to me and said, "I am going to order a series of tests to be performed in order to confirm but my theory is that she may have a neuromuscular disorder called myasthenia gravis. I am going to recommend starting her on a pyridostigmine bromide medication (Mestinon). If we see positive results then that will pretty much prove my theory is correct."

Within an hour, my daughter was her normal self. Her voice and tears returned, she was smiling and able to look at me again, she looked like Valerie. Dr. Verma explained to me what myasthenia gravis was and how there are different forms of it. He also referred me to a specialist, Dr. Terence Edgar in Green Bay, Wisconsin, for further testing. Valerie was on Mestinon for a year and a half and then was weaned off of it and she has been in remission ever since without any issues.

Since this experience, I have tried to educate myself as much as possible by getting involved with myasthenia gravis organizations in order to have an understanding of what she may be up against in the future. The problem is the disease is so different for each person that it is hard to know if she will go through the same experiences. I am grateful that I happened to live in a city where there was a specialist who knew about the disease and was able to diagnose her. I have talked to several people who have been misdiagnosed and went years with issues before they were properly diagnosed. I am stepping up by getting involved to help raise awareness. I feel it is extremely important to share my story with other people because even if it helps one person, that is one more person who can receive proper care.

*Note: MGF of Illinois is grateful to have Tiffany Rivera as its newest board member.*

# Consider Rx Costs for Medical Plan

*(Continued from page 1)*

Take an extra step and ask if the medication is covered for MG. A number of medications used to treat MG are considered “off-label” by the FDA (<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3002545/>) and off-label uses may not be covered by your plan. “Off-label” means the drug has not been approved by the FDA for that specific use through an approved series of clinic trials (although it may have passed rigorous testing for other uses). For example, you might say, “I have the autoimmune disease myasthenia gravis. My doctor has prescribed CellCept (mycophenolate mofetil). I understand that treatment of MG is an off-label use of CellCept. Is this medication covered by your plan in this situation?” It may be useful to note that CellCept is classified as an orphan drug to treat MG (<http://www.medscape.com/viewarticle/521133>). If the plan does not cover the medication, Cathy Bajkowski, owner of CB Health Insurance, notes your physician can apply for an exception, and if necessary follow this up with an appeal.

## Diabetes and Myasthenia Gravis

Compared to the general population, MG patients are more likely to have more than one chronic disease. And in many cases that disease is diabetes. The following Q&A was first posted 9/17/2001 on [www.Netwellness.com](http://www.Netwellness.com). The author is Robert M. Cohen, MD, Professor of Clinical Medicine, College of Medicine at the University of Cincinnati; his response continues to be relevant today.

“Q: If a person has diabetes and myasthenia gravis, is there any way you can treat the myasthenia gravis without affecting the diabetes?”

A: I would like to respond to this question primarily with some general principles but with a few specifics added in. Myasthenia gravis is a muscle disease caused by abnormalities in the immune system, a so-called ‘autoimmune disease.’ The immune system forms an antibody which acts on the surface of the muscle cell to block a signaling molecule called acetylcholine that usually transmits instructions for muscle action. Therefore, most treatment for myasthenia gravis is directed either towards replacing the acetylcholine or suppressing the immune response. Drugs which block acetylcholine breakdown are used. Immunosuppression is attempted either with immunosuppressant drugs; the use of an operation to remove the thymus, a major source of the aberrant immune response; or some other newer approaches.

Of these therapies, one in particular, corticosteroid drugs, most commonly prednisone or prednisolone, is likely to have a substantial negative impact on blood sugar control. It may bring out underlying diabetes that was not apparent before or it may worsen blood sugar control in a person already known to have diabetes. The decisions about choices of therapy for the myasthenia need to consider all the potential benefits and risks in a given individual. In some, the decision will be that the benefit of the prednisone on the myasthenia can’t be achieved as well or as safely with other means and it becomes necessary to accept worsening of the blood sugar control as a condition of treatment. As a diabetes specialist, I frequently take the approach of accepting that choice and making plans to make the diabetes treatment more aggressive to protect against the glucose raising effects of the treatment.

In a broader sense, control of blood sugar depends on exercising large muscles that help to dispose of carbohydrate in the diet. Some muscle disease, particularly that affecting respiratory muscles, will reduce the amount of exercise and impair the ability of other muscles to respond appropriately to a carbohydrate load. In that sense, there is a relationship between the myasthenia and diabetes itself rather than between the myasthenia drugs and diabetes and that can be hard to get around.

The bottom line is that the decisions need to be made taking the whole person into account, including other seemingly unrelated diseases and the person’s ability to take advantage of compensatory measures that may help to reduce the effect either of the disease or of its treatment.”

Source: <http://www.netwellness.org/question.cfm/22291.htm>, retrieved 11/12/2015

# MGF of Illinois Support Groups 2016



Our 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

## SUPPORT GROUPS

AREA	2016 DATES	TIME	LOCATION
<b>Chicago - Central</b>	Planned for the first Thursday of the month	1:00 pm - 2:00 pm	Rush University Medical Center Professional Building; tentative location is Conference room 1119 (11th floor), 1725 W. Harrison St., Chicago IL. Parking garage is at SE corner of Harrison and Paulina. Information Desks can direct you to Elevator 1. Parking vouchers available for attendees. You're welcome whether or not you're a Rush patient. Call Eve Escalante, MSW, LCSW, 312-942-8175 to confirm meeting details.
<b>Chicago North Suburban</b>			Large and small groups meet at Glenbrook Hospital, 2100 Pfingsten Road, Glenview, IL.
<b>Large Group</b>	Sundays, March 5, Sept. 17	1:00 pm – 2:30 pm	Conference Rooms B&C; use center entrance and South (Blue) parking off Hospital Drive.
<b>Small Group Breakfast Chats</b>	Mon. 1/18, Mon. 2/15, Tues. 5/17, Sat. 7/16, Tues. 8/16, Sat. 11/12, Tues. 12/13*	9:30 am – 11:00 am	Atrium Café; use the entrance for the hospital's John & Carol Walter Ambulatory Care Center, turn right at the piano for the café. Park in the West (Green) lot.  *December is holiday gathering
<b>Chicago - South Suburban</b>	Sunday, Feb. 21, other dates tba	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. 21, May 15, Aug. 21, Nov. 20	1:00 pm – 3:00 pm	Central DuPage Hospital, Conference room 3, Women & Children's Pavilion; 25 N. Winfield Rd., Winfield IL. Use NW entrance, park in Visitor Lot 3 or use valet parking.
<b>Rockford</b>	Saturdays, Jan. 9, April 9, July 9, Oct. 8	1:00 pm – 3:00 pm	St. Anthony Medical Center, St. Francis Room; 5666 E. State St., Rockford IL 61108. Use main entrance and adjacent parking.
<b>Springfield</b>	Sundays, Jan 17, March 20, April 17, May 15, July 17, Aug. 21, Sept. 18, Oct. 16, Nov. 20	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 26, May 28, July 30, Oct. 1	10:00 am – 12:00 pm	Schererville Public Library, ask at desk for meeting room; 1001 W. Lincoln Hwy, Schererville IN. Adjacent parking.

### 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](mailto:info@myastheniagravis.org)) for the application.

\*To the extent funds are available.

# In Appreciation...

*Special thanks* to everyone listed who sent in a contribution from August 2015 through October 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.*

## Contributors

Edwin Aitken  
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**We're Almost There!**

Can you help us with our mission to improve the lives of MG patients? Your dollars support our telephone responses, seminars, 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: \$42,812

## It's Flu Season

The Center for Disease Control (CDC) recommends a yearly flu vaccine, especially for those who have chronic neurological disorders and those who are taking immune suppressant medications (like prednisone, Imuran™, CellCept™, and tacrolimus). The CDC recommends that these groups avoid the nasal spray vaccine because it is made with a live virus.

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Happy Holidays!

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