



The Myasthenia Gravis Foundation
of Illinois, Inc.

Conquer

"Strength in Hope"

March 2015

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



Strides Against MG is turning 3! This June during MG Awareness Month, MGF of Illinois will host its 3rd Annual Strides Against MG Walk. This year we're bumping up the fun quotient for individuals and families alike. From bubbles to birthday cake, the event promises to be bigger (and more enjoyable) than ever.

Come on your own, bring a friend, or gather a whole team to join us on Sunday morning, June 7, at Berens Park in Elmhurst, Illinois. We'll start with the kids' dash, then everyone will be invited to walk, run, or just enjoy the music, free snacks and raffle. You can do a short turn or keep going for three miles or more at this untimed event.

Be part of the spirit of hope, as friends and family walk side by side with those affected by MG. **Your involvement raises vital awareness for myasthenia gravis. Use our online registration tool to share your own MG journey, through story and pictures.** All funds raised for the event go toward MGF of Illinois' work to provide patient support and education, raise awareness among the public, and directly fund vital medical research. *See the flyer insider for details.*

"Rise Above MG"

Have you wondered how to keep your fighting spirit when MG diminishes your strength? Some people do it well; they focus on goals, improve lifestyle, and hold fast to the things they love.

Join us Sunday, May 3, at Elmhurst Memorial Hospital in Elmhurst, Illinois for the presentation "Rise Above MG." At this MGF of Illinois Annual Business Meeting, we'll (re)introduce you to several speakers. Mark Grazman, founder of GH FitLab will share how his organization has successfully coached patients with MG and other challenging conditions through tailored programs of exercise and nutrition counseling. Mark will be joined by Dr. Robert Heller, who will talk about the psychological challenges and opportunities of taking control of your exercise and your health.

You'll also hear from two people who refused to let MG be the focus of their lives: Katie Jasmon, competitive college swimmer who is now an ER physician assistant, and Marie Smith, wife-mother-author-cellist. *See the flyer inside for details.*

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.

**The Myasthenia Gravis
Foundation of Illinois, Inc.**
275 N. York Street, Suite 401
Elmhurst, IL 60126-1530
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www.myastheniagravis.org

From Your Executive Director

“We become what we think about all day long.” - Ralph Waldo Emerson

So true, right? When my myasthenia gravis was active, I thought about it...a lot. Funny, though. The more I trained myself in MG caution (Can I lift that? Can I walk there? Should I ask for help?), the more I thought of myself as less-abled. With treatment, the MG symptoms gradually eased. But to my surprise, that thinking required recovery, too. That's why I'm excited about our "Rise Above MG" speakers. I think they'll help us understand how we can regain strength – both physical and mental – when living with a chronic illness.

I'm also excited about our 3rd Annual Strides Against MG Walk coming up June 7. There will be new games and give-aways. I sincerely hope you can join us. It's great to see individuals and teams expressing support for MG patients with signs and tutus and Uncle Sam hats. Feel free to be creative. Your support matters so much. Walk proceeds enable us to provide services to MG patients throughout the area and beyond. Come for the fun, and help with the cause!

All the best to you!

Joan Wincentzen
Executive Director

MARCH IS NATIONAL AUTOIMMUNE DISEASE AWARENESS MONTH

Patient Assistance Program

Launched in 2014, the MGF of Illinois Patient Assistance Program has been improved so it's easier for you to use the plan for prescription drug costs.

The program is for MG patients who are residents of Illinois or Indiana, and who struggle with the cost of medical care. The program will reimburse medical costs not covered by insurance, including prescription bills, up to \$1,000 per person per year*. Costs do not have to be MG-related.

You can submit an application for funds once you have more than \$200 in medical bills and paid pharmacy receipts. Contact us (800-888-6208 or info@myastheniagravis.org) for the application.

*To the extent funds are available

Activity Updates



Our New Website is Here!

Visit the new and improved www.myastheniagravis.org! (If your smartphone is handy, try it right now.) You'll find mobile-friendly MG information, easy-to-find news and events, FAQs about MG, and simplified donation steps.

Consider Board Service

Would you or a family member consider serving a term on the MGF of Illinois board? You can help MG patients and maybe even nudge the world closer to a cure. The board makes decisions about MGF of IL programs, outreach efforts, and fundraisers. (Our Medical Advisory Board helps us decide on research funding.) The commitment involves 5-6 board meetings a year in Elmhurst, IL.

Calendar Club Winners

November 2014 to January 2015

November 2014

Henrietta Harris
Glen Knudsen
Cecil Stuart
Anonymous

January 2015

Chuck Carlson
Eugene Deutsch
Janet Goldblatt
Heather Weber

December 2014

David Hofrichter
Ken Koss
Albert Paveza
John Sturtevant

2014 Year-End Runner-Up

John Davenport

2014 Grand Prize Winner

Laura Littner

Be a Walk Volunteer



Want to pitch in with the Strides Against MG Walk on June 7? Call the office at 1-800-888-6208 if you can direct parking, guide walkers, or help with set-up or clean-up.

Let us know if your business or employer could be a walk sponsor, or if you'd like to contribute a gift card for our raffle!

Kelly Lozada Raises MG Awareness

On July 11, 2015, MG advocate Kelly Lozada will host "Motorcycle Ride for MG Awareness." KSU (kick stands up) is 10a.m. at the Harley Davidson Shop, 9950 Joliet Road, Countryside, IL with the event ending in Oconomowoc, Wisconsin. To learn more, visit www.youcaring.com/nonprofits/motorcycle-ride-for-mg-awareness/246860. If you're available the morning of the ride, Kelly invites you to be part of the send-off and increase publicity for MG. MGF of IL is not a sponsor, but we wish Kelly and her group a safe, successful and fun event.

Jim Griffith - Trustee Emeritus

We'd like to thank Jim Griffith for 10 years of faithful service to MG patients through his terms on the MGF of IL board. Jim shows off his certificate of appreciation in the picture below.



MG Patient Wins Workers' Comp Case

In January 2015, the Alabama Supreme Court awarded workers' compensation benefits to a custodian of a private school in Huntsville, Alabama. The court found that Lisa Hanvey suffered a work-related injury from exposure to chemicals used for cleaning floors and stripping gym floor wax in 2011. The exposure aggravated an existing condition of myasthenia gravis. The court ruled that the chemical exposure led to her health crisis and disability, noting she had been able to perform her job - for about five years, according to court records - before the chemical exposure. The court took into account that the job is very physical and requires ongoing exposure to cleaning chemicals, and that Ms. Hanvey's circumstances make her unable to do other work. Chemicals mentioned in the case summary included urethane for the gym floors, Red Tornado wax stripper, and baseboard cleaner and stripper.

Source: <http://caselaw.findlaw.com/al-supreme-court/1691071.html>

The only way to have a friend is to be one. - Ralph Waldo Emerson

MG Triggers

Noticing and avoiding things that worsen your myasthenia gravis is one thing you can do to manage your disease. Below is a list of possible triggers. Keep in mind this varies from person to person, and not all patients will have a bad reaction to all of the things listed. Please note that this list does not cover every medication that can worsen MG. When taking a new medication, be sure to discuss with your doctor how it will affect your myasthenia gravis.

- | | |
|---|--|
| <ul style="list-style-type: none">• Beta blockers (atenolol, timolol maleate eye drops, propranolol)• Calcium channel blockers• Some antibiotics (including neomycin, Levaquin, ciprofloxacin, telithromycin, azithromycin)• Botulinum toxin (Botox)• Quinine or tonic water• Some chemicals, including some household cleaners, insecticides and pet flea sprays• Exposure to chemical lawn treatments | <ul style="list-style-type: none">• Fatigue, insufficient sleep• Overexertion, repetitive motion• Stress, anxiety, depression• Illness, pain• Extreme temperatures (hot or cold weather, hot showers or baths, sunbathing, saunas, hot tubs)• Hot foods or beverages (affects mouth and throat)• Alcoholic beverages• Low potassium levels or low thyroid levels• Magnesium salts, Epsom salts |
|---|--|

Infections and respiratory illnesses can produce increased weakness that lasts for a while after the illness is gone. The stress of surgery can make MG temporarily worse. The disease may intensify during certain times of a woman's menstrual cycle.

The first wealth is health. – Ralph Waldo Emerson

IATP – Illinois Assistive Technology Program

IATP is a nonprofit agency that helps Illinois residents with disabilities get assistive technology services and programs. IATP has a 5-week loan program for items like these that can help with vision, computer access and daily living:

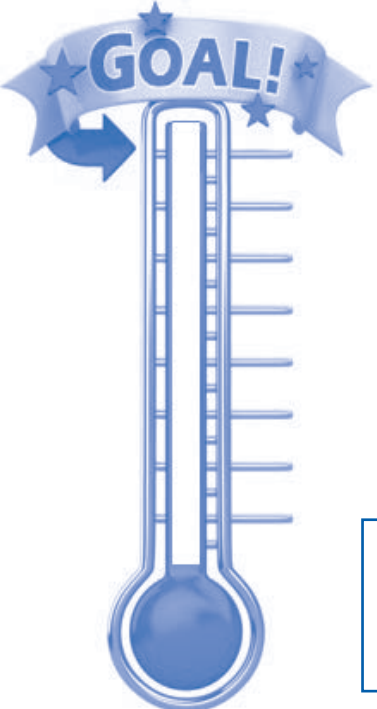
- Grips for pens and eating utensils, iPad stands, various clamps and grips that make daily tasks easier
- Ott-Lite bookstand light for clearer reading with less glare
- iZoom USB. When this flash drive is plugged into your (or any) computer, iZoom technology can enlarge everything on your screen, change colors, and read webpages using natural sounding voices.

The agency has a Demonstration Center in Springfield. If you can't visit the Center, arrangements can be made to have devices brought or shipped to you at no cost. Your only cost is for the return shipment. For more information, call 217-522-7985 or visit www.iltech.org.

Statin Use Rising in U.S.

The U.S. Centers for Disease Control and Prevention (CDC) has reported that in recent years there has been an increase in the number of adults taking drugs that combat high cholesterol, including statins. One CDC cardiologist explained that statins have been shown to lower the risk of heart attack, stroke, and premature death in men and women at risk for heart disease and stroke.

Does this raise any concerns for MG patients? Kourosh Rezania, MD, Department of Neurology, University of Chicago, responds: "There are a few reports (such as <http://www.ncbi.nlm.nih.gov/pubmed/18720508>) which suggest statins may cause worsening of myasthenia symptoms. I recommend statins be used with caution in patients who need it, and that they be aware of possible side effects such as increase in weakness."



2015 Target
\$50,000

Amount raised to date:
\$3,732

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.

Can you lend a hand? Your contribution will make a difference!

About Bob Rosecrans



We recently asked our newest board member, Bob Rosecrans, to tell us about himself. Here's what he shared:

“I work for NorthShore University HealthSystem in the Department of Pathology and Laboratory Medicine as a Clinical Laboratory Director. I have had teaching and research responsibilities, and have an academic appointment at the University of Chicago.

I have been married to my beautiful wife, Marlene, for 42 years and we live in Glen Ellyn. We have two children and two grandchildren. I've been involved with the Windy City Z (sports car) Club for over 30 years.”

What's your personal experience with MG? “I was diagnosed in 2002 but looking back, I had symptoms dating to 2000 and possibly earlier. My first symptoms were double vision and feeling tired. I wrote it off that I was working too much and figured I was getting older and my vision was changing. I saw an optometrist who prescribed glasses with a prism and sent me on my way. Later in 2002 during a trip to San Antonio I developed ptosis, or droopy eyelids, that rectified when I was in an air-conditioned room. My best friend, a rheumatologist, took me to one of his ophthalmologist colleagues who believed I had MG. This began the saga of neurologist appointments, Tensilon® test, Mestinon®, steroids, immunosuppressants, IVIg therapy, a crisis with hospitalization, more steroids, more Mestinon®, and finally a thymectomy. My MG has been stable for a number of years, and currently I'm only taking Cellcept®.”

How did MG affect you day-to-day? “At first I had to learn to pace myself at work and with family activities. The burden of Mestinon®, changing doses, the side effects were troubling. I still remember one of the first questions from my neurologist was not “How are you feeling?” but “How are you handling the bowel movements?” He knew the side effects of the drug. More troubling was the fact I was losing my speech and it affected my teaching ability. I began to think my career might be over. Fortunately with a good neurologist I was able to cross the many hurdles and continue to work and enjoy my family.”

What helped in dealing with the illness? “My wife Marlene was always there for me, understanding my physical and mental ups and downs. She was always loving and positive.”

Why did you join the board? “I have had the ups and downs of MG and so hope to help others with their struggles. Most physicians are unfamiliar with the disease and don't know how to treat it. MG is much more common than they realize and it's important that people find a physician knowledgeable about treating MG.”

For every minute you remain angry, you give up sixty seconds of peace of mind.

Ralph Waldo Emerson

A Phase II Trial of Rituximab in Myasthenia Gravis

In the last issue of Conquer, we reported on a Phase II trial of Rituximab in MG. Northwestern University's Department of Neurology in Chicago has just been added to the list of sites where the study is being conducted.

What is the purpose of this study?

The study purpose is to learn if rituximab is a safe and effective drug for people with myasthenia gravis who are on prednisone. The study will determine if rituximab will help people take less prednisone to manage their myasthenia gravis or possibly be able to discontinue prednisone.

What is a placebo-controlled clinical trial?

A placebo-controlled clinical trial means there will be two groups of people being enrolled in this study. Twenty-five people will receive the study medication (rituximab) and the other 25 people will receive a placebo (an inactive salt-water infusion).

What is Rituximab? How is it given? Rituximab is a type of medicine known as a monoclonal antibody (MAB). It works by reducing white blood cells called B cells. Rituximab is given through a needle inserted into a vein; this is called an infusion.

Where can I participate in the study in the Chicago area? Northwestern Medicine (previously known as Northwestern Memorial Hospital), 675 N. St.Clair, Galter 20-100, Chicago, Illinois. Other U.S. study locations are listed at www.clinicaltrials.gov (search on "NCT02110706").

What will happen if I choose to be in the study?

- Your first visit will include a review of the informed consent form. If you choose to be in the study, we will do various tests to make sure it is OK to include you in the study.
- You will get rituximab or placebo infusions weekly during the first four weeks of the study and during weeks 24 through 27 of your participation.
- You will come to regular study visits every 4 weeks. At these visits, you will have an MG-focused physical examination and complete questionnaires. Blood samples will also be drawn at each visit.

Who is eligible for the study?

- You must be 21 to 90 years old.
- You must have a diagnosis of generalized MG.
- You must already be taking a stable dose of steroids.
- The study coordinator will provide you a full list of requirements for participation.

To learn more about the study, visit www.clinicaltrials.gov or www.NeuroNEXT.org.

For more information regarding participation in this study please contact:

Sabeeha Mukit, Clinical Research Coordinator for Northwestern University Department of Neurology (s-mukit@northwestern.edu or 312-503-6868).

The reward of a thing well done is having done it. - Ralph Waldo Emerson

MG and Exercise

Excerpted from the “Practical Strategies for Living with MG” presentation by physical therapist Brittany White, October 2014, at Palos Community Hospital, Palos Heights, Illinois

Myasthenia gravis is often called the “snowflake disease” for good reason. Just as each snowflake is unique, MG presents in a unique way for each patient – in terms of which muscles are affected, the severity of weakness, and even how symptoms change from one day to the next. As a result, there’s no single approach to exercise.

Once your MG is stable and you have your doctor’s approval, consistent exercise will improve many aspects of your life. It won’t happen overnight, and you should take it slowly to avoid fatigue. But by progressing gradually and following some guidelines you can improve your strength. Keep in mind:

- **The dollar per day rule** says you should “budget” energy to accomplish daily activities. Avoid exhausting yourself in the morning by using 75 cents of your dollar with exercise.
- **Exercise at your best time of day.** For most MG patients this is in the morning after medications have kicked in.
- **Exercise when your medications are at peak dose.** For pyridostigmine, this is 1.5-2 hours after taking it.
- **Exercise the large, proximal muscles of the body.** These include upper arm and shoulder muscles, and thigh and hip muscles.
- Exercises should be **short in duration and never exceed moderate intensity.** Moderate exercise intensity is exercise that:
 - Raises your heart rate no more than 30 beats per minute from resting baseline
 - Does not cause shortness of breath at peak of exercise
 - Does not cause MG symptoms to become worse during the exercise (for example, drooping of the eyelids)
 - Doesn’t still leave you tired two hours after exercise
 - Should not cause severe muscle soreness the day(s) after exercise

How can you tell if you should or shouldn’t exercise? How long should you do an activity? What kind of exercise is best? For answers, you’ll want to pay careful attention to your body’s energy and strength, and be sure to check with your doctor.

You should avoid exercise if your MG is active - if your breathing is weak, or you struggle to swallow, for example, or if your symptoms are unstable or seem to be worsening. At this time it’s better to conserve energy to avoid falls and injury.

If you experience any of these things you are exercising at too high of an intensity!

Types of Exercises and Devices

Some exercise machines are more appropriate than others for MG patients. The upper body ergometer is useful for arm exercise. For lower extremities, the stationary bike or elliptical machine (with stationary arm supports) can help. These pieces of equipment provide self-paced activity that involves large muscle groups and are safe to use.



MG and Exercise (continued)



Walking is an excellent exercise. Be sure to walk on flat surfaces at a comfortable pace in a controlled environment; avoid extreme heat or stressful situations like busy streets. Indoor walking tracks are great!

Weight training also can be good, but always use light weights, no more than 10 to 12 repetitions and three sets per exercise. To avoid muscle fatigue, alternate between upper extremity and lower extremity exercises.

Things to Avoid

Because treadmills are not self-paced you run the risk of overexerting yourself.



Avoid the heat and increased temperatures as this can make symptoms worse. Swimming is an excellent exercise, but never swim in water that is above chest high to avoid too much fatigue. Some research suggests that whole body cooling suits, cold packs or cool showers and baths can ease muscle fatigue in patients with MG.



Avoid treadmills

If this is overwhelming don't panic! Ask your doctor for a prescription for physical therapy. A physical therapist can get you started on a program you can continue on your own.

Ms. White used these sources for her presentation:

1. Howard, James F. Jr., MD, ed. "Myasthenia Gravis A Manual for the Health Care Provider." *Myasthenia Gravis Foundation of America* (2008): 74-82. MGFA. Web.
2. Cass S. Myasthenia Gravis and Sports Participation. *Head Neck and Spine*. 2013; 12: 18-21
3. Kittiwatanapaisan W, Gauthier DK, Williams AM, Oh SJ. Fatigue in Myasthenia Gravis Patients. *Journal of Neuroscience Nursing*. 2003; 35.2: 87-106
4. Sheer BV, Valero-Burgos E, et al. Myasthenia Gravis and Endurance Exercise. *Am J Phys Med Rehabilitation*. 2012; 91.8: 725-727
5. Weeks B. Myasthenia Gravis Helping patients have better outcomes. *The Nurse Practitioner*. 2012; 37.9: 31-36
6. Merimier C, Schneider SM, et al. Preliminary Results: Effect of Whole Body Cooling in Patients with Myasthenia Gravis. *Medicine & Science in Sports Medicine*. 2006; 38.1:13-20

Common sense is genius dressed in its working clothes. - Ralph Waldo Emerson

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 starting in 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, March 5, April 2, May 7 future dates tbd	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, April 19, Saturday, July 18, Sunday, Nov. 15	1:00 pm – 2:30 pm	Glenbrook Hospital, Conference rooms B&C, 2100 Pfungsten Road, Glenview, IL. Use center entrance and adjacent parking.
Chicago - South Suburban	Sunday, April 19 future 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.
Chicago - West Suburban	Sundays, May 17, 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	Sunday, April 19	2:00 pm – 4:00 pm	Proctor Hospital Cafeteria, conference room in the cafeteria, 5409 N. Knoxville, Peoria, IL. Use the main entrance.
Rockford	Saturdays, April 11, July 11, 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, March 15, April 19, May 17, July 19, 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	Saturdays, March 28, May 30, Aug. 1, 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.

In Appreciation...

Special thanks to everyone listed who sent in a contribution from November 2014 through January 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.*

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Virginia Seggerman



The Myasthenia Gravis Foundation of Illinois, Inc.
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Join Us!
Rise Above MG - May 3
Strides Against MG Walk - June 7

Non-Profit Organization
U.S. POSTAGE PAID
Permit No. 3182
Chicago, IL

Conquer via Email reduces our expenses.

Member of:



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To keep our mailing list updated, we would appreciate your notifying us of any change in your contact information. Please fill out the following and mail it back to us. This will ensure you continue to receive Conquer. OR if you do not wish to receive Conquer, fill out the following and mark to be removed from our list.

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