

CONQUER

News for our community

Myasthenia Gravis and Medication

On October 29, 40 MG patients and friends attended Conquer MG's seminar, "Myasthenia Gravis and Medication." Dr. Mitra Habibi, clinical pharmacist and clinical assistant professor from the College of Pharmacy, University of Illinois at Chicago, described many side effects and drug interactions that MG patients need to be aware of.

Dr. Habibi explained black box warnings, and identified those specifically directed at myasthenia gravis patients (fluoroquinolones like CIPRO, and Ketek). She discussed medications to avoid or use with caution, including antibiotics, Botox, magnesium, beta blockers, channel blockers, and some pain medications. Other topics were addressed as

well: side effects associated with steroids like prednisone, vaccines, statins, and drugs that are used for dental procedures and surgery.



Mitra Habibi,
PharmD

We are grateful to AxelaCare for sponsoring the videotaping of this



presentation. A recording of the presentation will be available on Conquer MG's YouTube channel in January. You also can find a summary on the Conquer MG website, www.myastheniagravis.org.

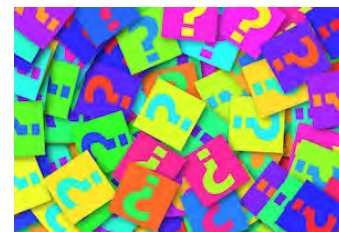


Join Us!

Trivia Night Event

Know the lyrics to Madonna songs? How about Emmy winners or odd facts about dogs? This is your time to shine! Such a good time was had at our Trivia Night fundraiser in Chicago, we decided to host our own event.

Join us Saturday, February 11, 2017, at the Elmhurst American Legion Post, 310 W. Butterfield Rd, Elmhurst, Illinois. Teams of two or more can sign up. Space is limited, so enlist your teammates, come up with a creative team name, and give us a call at 800-888-6208. Details inside!



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

FROM YOUR EXECUTIVE DIRECTOR

Season's Greetings!



The holiday season is upon us. It's easy to love the lights and get-togethers. The added stress and germs...not so much. Because stress affects the autoimmune system, we asked Dr. Julie Rowin, speaker at our Spring 2016 patient seminar, for a recap of her "destressing" yoga pose. See page 4 for instructions, and the science behind why this works.

Speaking of effective, did you know that your donations are helping the medical community understand MG? The two studies described in our August issue – one led by Dr. Betty Soliven, University of Chicago, and the other led by Henry Kaminski, George Washington University, were funded by Conquer MG donors – patients, family, and friends like you!

I invite you to do your part to support those who suffer with myasthenia gravis. It's easy to help Conquer MG provide support, information, awareness, and research funding. Contribute online at www.myastheniagravis.org, or donate through our Calendar Club or Bakers Square fundraisers (p. 3). Sign up your team for Trivia Night by calling 800-888-6208.

We'd like to wipe out MG. Are you with us?

Joan Wincentzen, Executive Director

Conquer MG Patient Assistance Program

This program will help cover the cost of medical bills, prescription drug costs, and durable medical equipment up to \$1,000 per person per year. The program paid out \$6,000 in benefits in 2015, and still has funds available for 2016.

You may be eligible if you are an MG patient; reside in Illinois, Indiana or Wisconsin; and can show that you have a financial hardship. Medical costs do not have to be MG-related. Contact the office at 800-888-6208 or info@myastheniagravis.org for the application.

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

► Thank You, Kelly!



On Sunday, September 4, Kelly Lozada and the Latin American Motorcycle Association (LAMA) – Chicago South hosted “Motorcycle Ride for Myasthenia Gravis.” The ride included over 70 attendees, 60 motorcycles, plus 10 sports cars from the Windy City Z Club. Conquer MG extends grateful thanks to Kelly and all participants for the awareness raising and the generous gift of \$2,000 in proceeds to support MG patients.

► MG Awareness at the Zoo



If you plan to attend Brookfield Zoo’s Holiday Magic 2016, be sure to look for Conquer MG’s tree, #389 decorated with the theme

“Myasthenia Gravis, the Snowflake Disease.” Thank you, Apex Management & Special Events, for your support, decorating skills, and donations!

Calendar Club Winners

September – Thomas Ehmann, George Green, Russell Laney, Ted Wienski

October – Fernando Calvarese, Bradley Chadwick, Deanne Scanlan, John Sturtevant

► Who Doesn’t Like Pie?



This season you can support those who struggle with MG, and enjoy mouthwatering holiday pies at the same time! Bakers Square Sweet Returns™ cards (just \$15 each) are again available from Conquer MG. The cards can be redeemed for any pie, have no expiration date, and make great gifts. Call 1-800-888-6208 or visit www.myastheniagravis.org to purchase.

► Calendar Club 2017

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. At year end, we pick a Grand Prize Winner (\$500!) and a 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!*

► Awareness Jewelry



Just in time for the holidays! Select sparkling awareness bracelets, pins, and necklaces from our website at

<http://www.myastheniagravis.org/gift-shop/>.

► Calling All Volunteers

The 2017 Strides Against MG Walk Planning Committee needs a hand! Call 1-800-888-6208 if you can find sponsors or raffle prizes, or pitch in the day of the walk.



Classic Yoga Pose for Reducing Stress

by Julie Rowin, MD, ABIHM

Dr. Rowin spoke at the Conquer MG Spring Seminar. This yoga pose is her personal favorite for stress reduction and immune system balance.



WE ALL HEAR ABOUT THE links between stress and disease. This technique practically guarantees a calm nervous system within 10-15 minutes. Let your own body's built-in reflexive responses aid you into relaxation. This traditional yoga posture is known to flip the switch from the sympathetic nervous system (fight or flight) to the parasympathetic nervous system (rest and digest).

Directions (see picture): Lie down on the floor in a quiet room (or with your favorite meditation music) with your legs up the wall and a bolster under your hips (or use 2 thick blankets folded at least six inches thick, about 10 inches wide to support your hips in entirety) placing it lengthwise against the baseboard. Sometimes it can be challenging to get into position. You may find it helpful to look

at the attached diagram. Settle your back on the floor aligning your spine perpendicular to the wall. Bring your hips as close and square to the wall as possible without causing discomfort. Make sure you are comfortable and warm and that you have a small blanket under your head so that your chin is slightly lower than your forehead. When you feel comfortable, close your eyes. Take some deep breaths while expanding your belly. Let your body have the sensation of sinking into the floor...the weight of the world falling away. When you have felt the shift (typically 10-15 minutes) slowly and gently bring your legs into your chest, rolling to your side, gently removing the bolster and rest for a few breaths in fetal position before slowly sitting up. Notice any sense of ease and renewal.

It is a great posture for the

transition from work to home or anytime you feel under stress. This traditional yoga posture (Viparita Karani) has been known for centuries to balance the nervous system. We know now that it works by shifting the hypothalamic-Pituitary-Adrenal (HPA) axis from "fight or flight" to "rest and digest". It does this by pooling blood in the upper chest region where there are blood pressure sensitive (barosensitive) receptors that are sensitive to the stretch of the blood vessels. These baroreceptors send a message to your brain to slow the heart rate and reduce blood pressure as well as activate the rest and digest response and restore body to a state of muscle relaxation and mental calm. This technique relaxes the physiology of the body which reflexively leads to relaxation and quieting of the mind.



ABOUT 85% TO 90% OF individuals who have MG can be diagnosed by a blood test that looks for antibodies to the acetylcholine receptor (AChR) or antibodies to muscle-specific tyrosine kinase (MuSK). However, some individuals have the clinical symptoms of MG but don't have either of these antibodies; they are considered "double-seronegative." Researchers in Spain have found antibodies against *cortactin* in blood samples of double-seronegative MG patients. Cortactin has a critical role in the development of the neuromuscular junction. In their study, double-seronegative patients with cortactin antibodies had an ocular or mild generalized form of MG. Including the detection of cortactin antibodies in the routine diagnosis of dSNMG may be helpful in ocular MG.

Source: JAMA Neurol. 2016;73(9):1099-1104.
doi:10.1001/jamaneurol.2016.2032



Advice On Living With MG

Question: I have MG, and my doctor recommended I get a colonoscopy. How will this affect my meds?

Answer: Don't walk in the day of your test and tell the nurse you have MG. Talk to your neurologist about your test. Work with your doctor to have plans for sedation and pain management. If you need to have Mestinon, it may be possible to administer it via IV. You may need to get the test in a hospital rather than an outpatient center. – **Mitra Habibi, PharmD**

Option Care is a proud sponsor of Conquer MG

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.

We are there to provide IVIG therapy to MG patients, in the comfort and privacy of home.

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



option
care™

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	2017 DATES	TIME	LOCATION
Chicago - Central			Discontinued
Chicago North Suburban	<i>Fri, Jan 27</i> <i>Sat, March 4</i> <i>Wed, May 5</i> <i>Wed, Aug 30</i> <i>Fri, Oct 20</i> <i>Wed, Dec 13</i>	9:30 am – 11:00 am 11:00 am - 12:30 pm	Glenbrook Hospital, 2100 Pfingston Road, Glenview, IL. 2nd floor conference rooms A1-A2 (Rooms C-D for August). Use main entrance and South (Blue) Parking. December meeting is in the John & Carol Walter Ambulatory Care Center, 2150 Pfingston Road, Rooms E-F, Glenview. Picnic, Rooms A1-A2.
Chicago - South Suburban	<i>Sunday</i> <i>Feb 12</i> 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.
Chicago - West Suburban	<i>Sundays</i> <i>Feb 19, May 21</i> <i>Aug 20, Nov 19</i>	1:00 pm – 3:00 pm	Central DuPage Hospital, Conference room 3, Women & Children's Pavillion, 25 N. Winfield Road, Winfield, IL. Use NW entrance, park in Visitor Lot 3 or use valet parking.
Rockford	<i>Saturdays</i> <i>Jan 14</i> Other dates tbd	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.
Springfield	<i>Sundays</i> <i>Jan 15, March 19,</i> <i>April 23, May 21,</i> <i>July 16, Aug 20,</i> <i>Sept 17, Oct 15,</i> <i>Nov 19</i>	3:00 pm – 5:00 pm	Parkway Christian Church, 2700 Lindbergh Blvd. in Springfield IL, just east of the Parkway Point Shopping Mall. Use office entrance and adjacent parking.
Northwest Indiana	<i>Saturdays</i> (dates to come)	10:00 am – 12:00 pm	Schererville Public Library, ask at desk for meeting room, 1001 W. Lincoln Highway, Schererville, IN. Adjacent parking.
Greater St. Louis, Missouri / Illinois	<i>Saturdays</i> <i>Jan 7, April 1,</i> <i>July 15, Oct 7</i>	1:00 pm - 3:00 pm	Glendale City Hall Auditorium, 424 N. Sappington Road, Glendale, MO. Use main entrance and adjacent parking.

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. Wondering about the nasal spray vaccine that MG patients should avoid? The CDC has recommended that the nasal spray vaccine not be used at all during the 2016-2017 flu season.

In Appreciation

SPECIAL THANKS to everyone who has helped Conquer MG fulfill its mission this year.

You are making a difference by improving the lives of those who struggle with this rare autoimmune disease. To pack this issue with as much useful MG information as possible, we're listing here only those gifts made in honor or in memory of loved ones, from August through October, 2016.

In Memory of Fred Arnold

Mrs. Fred Arnold
Loretta Fleming

In Memory of Patricia J. Fitzgerald

Bill Gwodz

In Memory of Dorothy Leoschke

Elaine and Ronald Lackie

In Memory of Alexander Niemczura

Darlene Niemczura

In Memory of Duane J. Seggerman

Cathy Jackson

In Memory of Don Simmons

Dot and Morton Goldenberg

In Memory of Laei Skeffington

Susan and Jim Heaton
Gerry and Carol Miller
Julian Orr
Charles Miller and Virginia Skeffington

In Honor of Laura Austin

Beverly Lodato

In Honor of Anne Breuker

Janice Arrott

In Honor of Carolyn Golz

Cathy Jackson

In Honor of Darlene Perrone

Beth Leese

In Honor of Mirianny Polanco

Wanda Taveras

In Honor of Nancy Van Laten

Arlene Sangmeister

Medical IDs

In the event of an emergency, medical IDs can alert emergency medical professionals to your critical health information. RoadID® (www.roadid.com, 1-800-345-6336) offers fitness-styled ID bracelets in silicone, leather and other materials, as well as dog tags. The bracelets have badges that can be imprinted with up to six lines of text, and have slide-buckles that adjust to your wrist size.

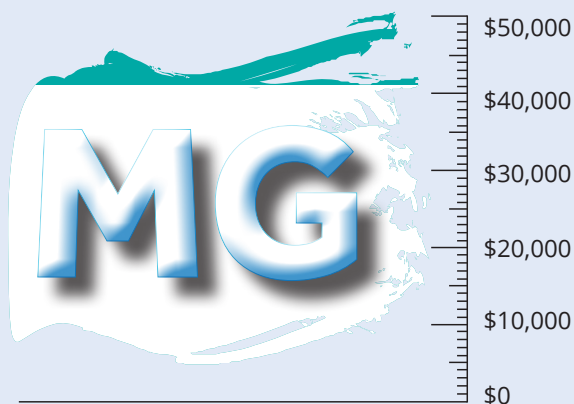
**“Gratitude makes sense of our past,
brings peace for today, and creates
a vision for tomorrow”**

-Melody Beattie

Can you help us meet our 2016 goal?

Your contributions support Conquer MG seminars, telephone response, newsletters, new patient information packets, support groups, and online resources like our website and YouTube channel. Let's wipe out MG!

2016 TARGET: \$50,000






Amount raised to date: \$42,400

The Myasthenia Gravis Foundation of Illinois, Inc.
275 N. York Street, Suite 401
Elmhurst, IL 60126

Non-Profit Organization
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Chicago, IL

CONNECT WITH US!

-  @ConquerMyastheniaGravis
-  @ConquerMG
-  @ConquerMG

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Raising MG Awareness at
Brookfield Zoo p.3!



Upcoming Events

FEBRUARY 11
Trivia Night Fundraiser

