

CONQUER

News for our community

One Man's Efforts to Raise MG Awareness



Ben Maravilla would laugh at the notion of "one man's efforts." He often is surrounded by family, friends, and anyone he can cajole into parade walking, boat paddling, or hosting a table at a community event.

Ben first came to the Conquer MG (then MGF of Illinois) office in 2012.

He and his fiancée (now wife) Vicky wanted to understand the disease that had garbled his speech, drooped his eyelids, and weakened his muscles. We shared pamphlets and the few Spanish-language articles we could find.

Ben was frustrated that he'd never heard of MG in his Spanish-speaking circles of family, church, and soccer. He made it his mission to bring information to those groups. He visited the Mexican Consulate in Chicago to explain MG, and hosted an MG table at the Latin American Health Fair. He talked to kids' soccer groups about being bullied because you look different with MG facial symptoms. He gathered his friends and family to walk in Aurora, Illinois parades – the Memorial Day Parade, 4th of July Parade, and Puerto Rican Heritage Parade.

Continued on page 3

Fall Patient Seminar



Among MG patients, concerns about activity vary as much as MG symptoms. How does MG affect

one's performance – at work, at the gym, or even in the bedroom?

Join us Sunday, October 22, at Advocate Lutheran General Hospital, Park Ridge, Illinois, for answers about **Exercise and MG**, and **Men's and Women's MG Issues**. We'll hear from NorthShore University Health System's neurologist Dr. David Randall (also Assistant Clinical Professor for the University of Chicago), and neurologic physical therapists Jennifer Ford and Angela Mackowiak.

See flyer inside for registration details.

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

Recover Your Spirit



No doubt about it, there's a mental part to coping with myasthenia gravis. I went from carrying a week's groceries up a flight of steps to wondering if I could lift a pickle jar out of the fridge. Over time, that leaves its mark. I began framing myself as someone who needed help. In recovering from MG weakness, I was surprised that I also needed to recover my "I'll just do it myself" spirit.

In this issue, you'll meet two people who have done just that. You can hear Linda Kelm's joy as she describes her exercise routine. You can hear Roger Collier's determination as he returns to activities he loves.

Do you need to recover your spirit? Doing something, no matter how small, can make a difference. I invite you to share your personal story for this newsletter, add some kind of exercise to your day, or even help someone else. Maybe you can host an MG support group!

Let's conquer MG together!

Joan Wincentzen, Executive Director

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) 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

► MG Vision Issues

On May 7, Thomas Mizen, MD, neuro-ophthalmologist from Rush University Medical Center, spoke to 70 Conquer MG Spring Patient Meeting attendees about vision issues related to MG. He explained that six muscles and three nerves control each eye. The coordination of eye movement (of these 12 muscles and six nerves) occurs in the brain so that we can see one image with two eyes. Double vision, or diplopia, results when the two eyes are not working together, even slightly.

You can see Dr. Mizen's full presentation at the Conquer MG YouTube channel <https://goo.gl/KNvPzw>. Thank you, Briova Rx, for funding this videorecording.



Calendar Club Winners

February 2017 – C. Carlson, S. Guzman-Holland, D. Kroll, G. Weber

March 2017 – B. Bosenbecker, J. Sturtevant, Anon (2)

April 2017 – T. Dammrich, D. Kroll, G. Volpe, Anon

May 2017 - Margaret Draths, Trudi O'Neill, Anon (2)

June 2017 - Thomas Dammrich, Cliff Zolna, Anon (2)

July 2017 - Carole Ostachowski, Carol Oswald, Anon (2)

► Our Website Gift Shop

Check out our MG awareness jewelry at <http://www.myastheniagravis.org/gift-shop/>



► Where There's Hope

The 5th Annual Strides Against MG Walk welcomed 230 participants on Sunday, June 4, at Berens Park in Elmhurst, Illinois. The walk raised \$26,000 for Conquer Myasthenia Gravis' patient services.

Individuals and teams gathered to walk the course, going anywhere from one half to three miles. The largest team for several years running, Janet Bauer's Family and Friends 2017 made their presence known with our favorite sign: "Where there's hope there's a way to Conquer MG."

► One Man's Efforts (from page 1)

And he convinced people to build an MG entry for the Fox Valley United Way Cardboard Boat Race. His mother, in particular, has been supportive with these activities, and this year's boat was dedicated to her. Paddlers Army Sgt. Jose Maya and Jose's brother-in-law Omar took 1st place in the nonprofit category!

Ben has had his MG ups and downs, which were aggravated by work stress. Now retired, he is doing much better. Thank you, Ben, for your dedication to raising MG awareness!

Linda Kelm

“I’m doing fantastic”

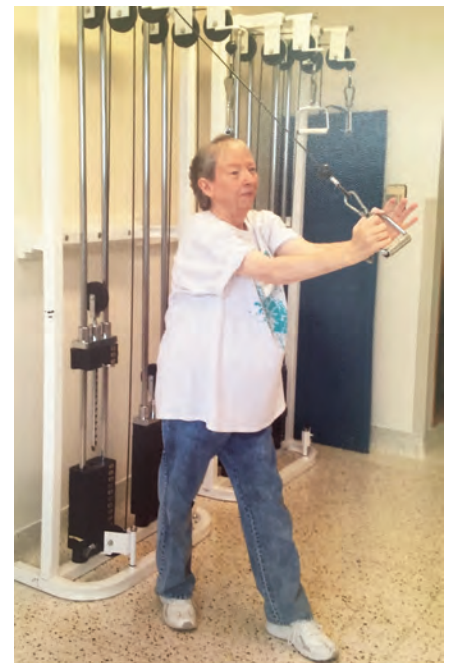


My name is Linda Kelm, I'm 66. In 2002, I had noticed that my arms were weak, I couldn't lift them over my head, speech was slurring, and my eyes drooped. I was terrified. What was happening to me? On June 11, 2002, I got the myasthenia gravis diagnosis. How was I going to take care of my family? Am I going to work again? Why me? Oh God, why me? My meds and treatments have included 1-3 day IViG treatments, prednisone, Mestinon, and Imuran. Now I'm on CellCept and 30mg Mestinon a day. At present, I've lost almost all of the 200 pounds that I gained while on prednisone.

Now I'm doing fantastic! I have a terrific neurologist who listens to me, and we work great together. I do 13 steps to my basement; I do my laundry, drive, grocery shop, cook/clean. I plan/organize small fundraisers for my auxiliary. Since January, I've crocheted six afghans for my family. I'm doing an exercise

program locally, spending two hours a day, three days a week there. I'm on the treadmill, or bike, Nustep, elliptical, arm crank, then I'm in the weight room. I work on weights, stretches, my balance, and started some mat exercises. I work with a personal trainer who helps me with everything. He knows about the MG; we both push me to my limits and beyond. He challenges me by adding a new exercise, or adding more reps to an old one, and I'm always asking for something new.

I'm having fun and loving the results!





Thanks to all our Walkers, Teams, Volunteers, & Fundraisers!



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MG Mimics

**By Kourosh Rezania, M.D., Associate Professor
Department of Neurology, University of Chicago**

MG is often mistaken for other diseases (that is, “MG mimics”), resulting in delay in the diagnosis and therefore lack of adequate treatment, which not only may adversely affect the patient’s wellbeing and quality of life but also may predispose the patient to life threatening situations. Following is list of more common MG mimics:

1. General fatigue and weakness due to systemic disease such as systemic cancer, anemia, malnutrition and hypothyroidism. In the elderly population, a droopy eyelid is common and often is attributed to sleepiness or fatigue; and shortness of breath is often attributed to cardiovascular and respiratory disease.
2. Cerebrovascular disease. This also is very common in the elderly, and is a common cause of double vision or bulbar [speech, swallowing, or smiling] symptoms. MG occasionally is overlooked because of presence of abnormal MRI sequences (it is therefore very important to correlate these abnormalities with the patient’s symptomatology).
3. Other central nervous system diseases such as demyelinating diseases (especially multiple sclerosis), brain tumors and infections (such as syphilis, Lyme disease). Therefore, appropriate diagnosis sometimes involves imaging studies such as brain and spinal cord MRI scans, as well as other testing on the blood and cerebrospinal fluid.
4. Guillain Barre syndrome (GBS), and particularly its Miller Fisher variant. These frequently are to be distinguished from acute MG in patients who present with sudden onset of weakness and/or double vision. Involvement of cranial nerves by diabetes also results in acute double vision, which is seldom mistaken for MG.
5. Mitochondrial myopathy, oculopharyngeal muscular dystrophy, and myopathy associated with thyrotoxicosis. These primarily muscle disorders sometimes are mistakenly diagnosed and treated as MG because of the presence of eyelid droopiness and weakness of the ocular and bulbar muscles in these conditions.
6. MG also has to be differentiated from congenital myasthenia and Lambert Eaton myasthenic syndrome (LEMS). LEMS presents with fatigable lower limb weakness and sometimes eyelid droopiness, but double vision is very rare. Botulism is also commonly mistaken for acute myasthenia gravis.
7. Amyotrophic lateral sclerosis (ALS) sometimes presents with bulbar symptoms, thus being mistaken with myasthenia; furthermore, titers to myasthenia-related acetylcholine receptor antibody could be mildly elevated in ALS, making the differentiation of the two diseases more complicated.
8. Psychogenic weakness and fatigue (somatoform disorder) remains a rather common differential diagnosis of MG; differentiating MG and somatoform disorder is sometimes very complicated as MG-related serology is negative in a significant proportion of MG patients and neurophysiological testing such as repetitive nerve stimulation and single fiber electromyography often yield falsely positive or inconclusive results.

Roger Collier

"I've lived a good life."

If anyone thinks myasthenia gravis can sidetrack Roger Collier of Lansing, Illinois, they need to think again. "I've had an interesting life," noted Roger, "and I'm still enjoying it."

Roger's life stories begin with jobs that paid for college - setting pins at the bowling alley, caddying, and doing ductwork for his father. He also financed his U of Illinois mechanical engineering degree by renting his then-new 1959 Oldsmobile convertible to college buddies - for 12-hour increments. From there his tales shift to industrial sales and real estate, acquiring a pilot's license, and flying to cover part of his 17-state work territory when he could. He bought a small Piper Cub plane, and gradually moved up to a Piper Cherokee Arrow with retractable landing gear and autopilot. In the meantime, he and his wife raised five daughters.

Roger notes his life included some investments that turned south,



and a chance visit to a lovely old Detroit church built in the 1920s that gave him renewed spiritual direction.

Roger's MG journey began after he had a bronchial infection and took a lot of antibiotics. It triggered weakness in his throat and eyes. Describing his situation, Roger said, "At one point I was just out of the hospital, heading across the parking lot to Bible Study. I dropped my Bible, and barely made it to the car. I had to drive over to get it."

But he tracked his symptoms and took his meds - pyridostigmine and methotrexate. He found that by resting in the evening he could reduce his dose of pyridostigmine bromide. When he asked his doctor if there was a way "to speed this along," his doctor suggested steroids. "I didn't want to do that," noted Roger. "And I think I was able to avoid a lot of problems that way."

Gradually he started feeling better. He slowly went back to exercise, first running in place, then doing a slow jog on his deck. Now he's on just a ½ pyridostigmine pill each day. Some days he doesn't need it at all. He's back to playing golf, and just recently was cleared by the FAA for a return to piloting. Aside from a bit of sciatica, he notes, "I'm getting closer to being fantastic!"

Thanks Gary!

After guiding the Springfield, Ill. MG support group for 10 years, Gary Nelsen is handing leadership to Gayle Burg, Kelly Aiken, and Dave Bettis. Thanks so much, Gary, for nurturing this group, and speaking on, writing about, and researching MG topics.

Medications known to interfere with the communication between nerves and muscles can worsen the muscle weakness of MG and should be used with caution (especially if used on an ongoing basis).

Beta blockers. Used to treat a variety of conditions including hypertension and headaches, this type of medication causes your heart to beat more slowly and with less force. Specific drugs include:

- Propranolol, atenolol, sotalol, nadolol, metoprolol
- Ophthalmic formulation: timolol, betaxolol (kerlone)

The effect on a person's MG depends on the dose. In some cases, beta blockers have produced MG symptoms in individuals who have no history of myasthenia gravis.

Propranolol is the most likely offender in causing fatigue for MG patients, while atenolol is least likely.

Calcium channel blockers are used to treat a variety of conditions, including high blood pressure.

- Specific drugs include felodipine, nifedipine, verapamil, and amlodipine.
- May produce symptoms of MG, such as general weakness, droopy eyelids, or difficulty swallowing.

Source: Oct. 2016 presentation by Mitra Habibi, PharmD, University of Illinois Chicago College of Pharmacy

Research Updates

In August, the European Commission (EC, counterpart to our FDA) approved Alexion Pharmaceuticals' medication Soliris® (eculizumab) to treat refractory generalized MG in patients who are anti-acetylcholine receptor (AChR) antibody-positive. Alexion also has filed for approval with the FDA.

Study results of MG patients using subcutaneous immunoglobulin (SCIg) (where patients self-administer immunoglobulin injections under the skin) were recently published. Researchers reported that among the 22 of 23 patients who completed the study, SCIg was well-tolerated and effective in treating mild to moderate MG exacerbations. Source: Neurology. 2017 Aug 16. doi: 10.1212/WNL.0000000000004365.

A multicenter, blinded, prospective review looked at 119 patients with anti-MuSK antibodies between 2005 and 2015, comparing those treated with rituximab and those not treated with rituximab. As reported in the online journal Neurology, "At last visit, 58% (14/24) of rituximab-treated patients reached the primary outcome (disease improvement and a reduction in prednisone dose) compared to 16% (5/31) of controls." The authors noted, "This study provides Class IV evidence that for patients with anti-MuSK MG, rituximab increased the probability of a favorable outcome." Source: <http://www.neurology.org/content/early/2017/08/11/WNL.0000000000004341.abstract>

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	REMAINING 2017 DATES	TIME	LOCATION
Chicago - North Suburban	<i>Friday</i> Oct 20, <i>Wednesday</i> 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 in the John & Carol Walter Ambulatory Care Center, 2150 Pfingston Road, Rooms E-F, Glenview.
Chicago - South Suburban	<i>Sunday</i> Nov 5	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>Sunday</i> Nov 19	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>Saturday</i> Oct 14	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> Sept 17, Oct 15, Nov 19	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.
Northwest Indiana	<i>Saturday</i> Oct 14	10:00 am - 12:00 pm	Schererville Public Library, ask at desk for meeting room, 1001 W. Lincoln Highway, Schererville, IN. Adjacent parking. Co-sponsors: MGA - Missouri & Kansas and Conquer MG.
Quad Cities Iowa / Illinois	<i>Saturday</i> Nov 11	10:00 am - 12:00 pm	UnityPoint Health Trinity Bettendorf Hospital Conference Room A/B (Garden level), 4480 Utica Ridge Road, Bettendorf, IA. Use main entrance & adjacent parking. Co-sponsors: Conquer MG and MGFA.

Partner with Us!

Would you like to help Conquer MG offer support, education, awareness, and research? You can ensure these services continue through a gift to Conquer MG in your will. Charitable bequests can be:

- A specific amount,
- A percentage of your estate, or
- A conditional gift made if your beneficiaries predecease you.



Any amount helps Conquer MG with its mission. You can feel confident in developing the best plan for yourself and your family while also supporting MG patients for years to come.

Conquer MG would be honored to share in your legacy.

In Appreciation

SPECIAL THANKS to everyone listed who supported our mission from February 2017 through July 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" section are not necessarily deaths due to MG.*

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Shirley Welna

For J. Holste's South
Suburban Walking Team
Nancy Van Laten

For MG Awareness Month
(June)
Nancy Van Laten

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In Memory of Fred Arnold
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Upcoming Event

- OCTOBER 22
- Fall Patient Seminar (Park Ridge)
- Exercise and MG
 - Men’s and Women’s MG Issues