

CONQUER

News for our community

Better Breathing through Technology



If myasthenia gravis affects your breathing, do you call your doctor? Or just try to wait it out?

Join us Sunday, November 4, at Advocate Lutheran General Hospital's Auditorium in Park Ridge, Illinois for Conquer MG's Fall Patient Meeting. Sally O'Meara, RN and nurse educator from the Detroit, Michigan area (pictured, center), will discuss ways MG patients can assess their respiratory status and determine when breathing support is needed. She'll review supportive devices including BiPAP machines, portable suction units, cough assist devices, and Trilogy home ventilators.

We'll also hear from MG patient Sara Hasemeyer. Before MG, Sara was a dancer with a professional dance troupe in Chicago. She'll explain how she has revised priorities to continue living her best life possible.



A Guy's Take on Chronic Illness



Jay Armstrong is one of the few writers to explore how men cope with chronic illness. In 2013 he was found to have cerebellar atrophy; a part of his brain had permanently wasted away. Eventually doctors diagnosed the autoimmune disease sarcoidosis.

While doctors could explain his symptoms, he writes, "No doctor warned me about the shame I feel every time my children ask me to ride bikes with them or my friends invite me to play basketball or the light bulb burns out in the hallway and I have to ask my wife to climb a ladder and to change it.

(continued on p. 7)

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

Welcome to the "Men's Issue"



Our last newsletter addressed issues that arise specifically for women who have myasthenia gravis. For balance, this issue covers issues more often encountered by men.

What are those concerns? Strength, loss of it, and surprisingly – shame at losing it. How medications affect testosterone. A Facebook source to get your questions answered. And because of its higher prevalence among men, we have Dr. Kourosh Rezaian discussing late onset MG (that is, beginning after age 50).

Thank you, Garry Morehouse and Victor Yipp, for sharing your own experiences that reflect how MG affects the work, play, and even mental tasks of active men.

Wishing all our readers well,

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 still has funds available for 2018.

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

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Address _____

City _____ State _____ Zip _____

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- ☐ Please note the above change in my contact information.
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- ☐ Please send **Conquer** via e-mail instead.

Events & Activities

► Making Treatment Decisions with MG



Speaker Clint Moore (standing) with Bob Rosecrans, Anne Flanz, and Ed Rickert

On April 22, Rev. Clint Moore, medical ethicist, spoke to 45 people at the Conquer MG spring patient seminar held at the Elmhurst Memorial Hospital conference center. He explored some tough issues and ethical choices involved in health care. Find a summary at www.myastheniagravis.org.

Moore invites us to ask, "What should be done [for ourselves or a loved one who is ill]?" instead of "What can be done?" We can ask ourselves, "What is in the patient's best interest – that aligns with his or her desires?"

For guidance, Moore recommended downloadable materials developed by Five Wishes (<https://fivewishes.org/>). Conquer MG has a small supply; contact us if you'd like a copy.

You can see excerpts from Reverend Moore's talk on the Conquer MG YouTube channel at <https://bit.ly/2x7SrxE>

► Facebook Group for Guys



Facebook is full of groups for individuals with myasthenia gravis. (Just visit [Facebook.com](https://www.facebook.com) and search on "myasthenia gravis.") "Myasthenia Gravis support group - Just For Men" is a place for guys to ask questions they wouldn't feel comfortable putting forth in an open forum.

► Raising MG Awareness



Ben Maravilla continues to tell the public about MG in Aurora, Illinois. With Ben's help, Conquer MG was present in Aurora's parades for Memorial Day, Mexican Independence, and the 4th of July. Great job!

Calendar Club Winners

February – Sheila Mitchell, Lorraine Muntean, Anonymous (2)

March – Carol Hofrichter, Christina Menchaca, Rosemary Sprague, Anonymous

April – Patrick Considine, Lorraine Muntean, Anonymous (2)

May – Sharon Adamscheck, Donna Kroll, Charles Lobodzinski, Laurel Manthey

June – Kathleen Brown, Mary Hoffmann, Dwayne Lucy, Christina Menchaca

July – Randy Holste, Barbara Lehotan, Bruno Czernoch, Danielle Lehman

August – Sharon Adamscheck, Margaret Draths, Carol Hofrichter, Tracy Loland-Knotek

Garry Morehouse

Back in the Game

"Getting well is as much about who you surround yourself with, your attitude, and your exercise, as it is about your medication."



Last November some terrifying things started to happen to me. My usual active, healthy, 72-year-old self suddenly had to wear a patch over one eye to prevent double vision, use a walker and a neck brace for weak muscles, and wear a bike helmet in case I fell. I couldn't hang up my bathrobe on a hook or sign my name. I had difficulty chewing and had to wear a bib as water or milk spewed from my mouth because my lip muscles were limp. A fall outdoors sent me by ambulance to the hospital. Following a two-week period of many blood tests, a head MRI, a CT scan, a chest x-ray, and a nerve test, I was diagnosed with myasthenia gravis (MG), a rare nerve immune disorder characterized by muscle weakness.

I come from Midland, Ontario and was very impressed by the quick diagnosis by a neurologist and the turnaround of the symptoms. Mestinon, the drug of choice for MG, allowed me to regain, almost overnight, 80% of my muscle strength; it corrected my double vision and eating problems.

The next level of treatment for me has been IVIG. Following five consecutive days of IVIG infusions, I got most of my muscle strength back.

I learned from a presentation by a Dr. Nicolle, a neurologist who specializes in MG, that IVIG infusions are like having an army of good antibodies working for you. I don't know how they know this, but how they work is threefold: 1) They swarm the bad antibodies and dilute them, 2) They suppress

the production of the bad antibodies, and 3) They bind to the bad antibodies and take them out of action.

[Since resuming] daily exercises to improve my coordination, I have my full muscle strength back and my stamina has improved. I am playing pickleball several times a week. ***I got my life back. I am back in the game.***





Late Onset Myasthenia Gravis

By Kourosh Rezania, M.D.

Associate Professor

Department of Neurology, University of Chicago

Although myasthenia gravis (MG) was initially thought to predominantly affect younger females, its frequent occurrence in middle-aged and older individuals was established in the 1990s. The incidence of MG is increasing, and the increase is mainly attributed to newly diagnosed patients in the middle to older ages. For example, in a large Danish study, there was an almost fivefold increase in the incidence of late onset MG from 1970 to 1999 (1).

Late onset MG (if defined by age >50) is slightly more prevalent in the men, i.e., male to female ratio of 1.1:1 in late onset compared to 1:3 in young onset cases (2). One of the likely reasons for underdiagnosing MG in older individuals is rather high incidence of comorbidities that make the MG diagnosis more challenging. For example, droopy eyelids (ptosis), a common manifestation of MG, is often mistaken for age-related eyelid laxity; blurry vision can be attributed to cataracts and macular degeneration, MG related diplopia could be related to cerebrovascular disease (as incidental brain white matter

disease is rather common), fatigue and shortness of breath are also common in the older people with underlying cardiopulmonary disease. Head-drop, which is especially common in older men with MG, is also rather frequently encountered in Parkinsonism or spinal osteoarthritis, which are more prevalent than MG in the elderly.

Although MG crisis is not more common in late onset MG patients, there is increased risk of mortality in hospitalized older MG patients (4), likely the result of increased prevalence of medical comorbidities in that age group. On the other hand, late onset MG cases often run a mild and treatment-responsive course (5).

Management of MG in general, and of older patients in particular, should be tailored to individual patients. Use of corticosteroids is more likely to cause adverse effects because of increased prevalence of osteoporosis, diabetes, cataracts, glaucoma, peripheral edema and hypertension, and complex drug-drug interactions

should always be considered when using immunosuppressant medications in older patients (6,7). It should also be noted that there is increased risk of complications from plasma exchange or intravenous immunoglobulins, treatments that are commonly used in patients with MG crisis, in older individuals.

References

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Victor Yipp

Not the Garden Variety MG

"Do men have special health concerns with MG? I don't know, but men generally are not as proactive as women in addressing health. Maybe it's the idea that men are the "breadwinners," that we have to hold in our feelings."



If you had told me that I'd be spending a month in the hospital suffering from a chronic disease I never heard of, I would have said, "You're crazy!"

I have been a very healthy person for seventy-plus years. But from November 5 through December 7 of last year (32 days, I counted each and every one), I found myself confined in hospital, suffering from anti-MuSK myasthenia gravis. Not the garden variety MG, that strikes about 30 out of 100,000, people, but a special version of this disease (probably no more than twenty percent of all MG cases), in which you have "auto antibodies to muscle-specific tyrosine kinase."

With the expertise of my neurologist, Dr. Wayne Rubinstein, and many fine staff

at Lutheran General, I was able to reach an almost symptom free stage. Only my hoarse Godfather-like voice and fatigue remain.

I feel lucky that I was retired when MG decided to enter my life. I really admire those with MG who have to make a living, which takes so much energy out of you.

My own symptoms started with trouble swallowing. I lost a lot of weight, got the droopy eyelids and double vision, etc. By November 5, I couldn't even swallow water, so I went straight to the hospital. IVIg did nothing for me. Plasma exchange finally addressed my symptoms. Now I am on Rituxan infusions every six months, which keep me symptom free (cross my fingers). Rituxan looks like the go-to drug for my version of MG.

I would love to resume the activities I enjoyed before the onset of MG; however, hot and cold weather can exhaust me. I was quite happy that by the end of this past ski season, I was able to ski a little, on the bunny hills in Wisconsin.

I am a fiction writer and I still can't get to the mental energy level I had before MG. It's the fatigue, overtiredness that poops me out, but I am hopeful that as my endurance increases and I taper off some of the more powerful meds (prednisone), I can recapture my creative sensibilities.

Finally, hope and a positive attitude have always been a force in my life and will remain so as I continue navigating my way through MG.

A Guy's Take on Chronic Illness

(continued from page 1)

In his blog post, "What You Need to Know About Men Who Have a Chronic Illness and the Shame They Feel," Armstrong goes on to explain, "Men would rather be labeled a loner than a loser. Because men define themselves by their ability to do impressive things. Things that require strength and stamina. ...So when we are suddenly dependent, when we lose our physical abilities, our capacity to do impressive things—we lose ourselves."

And then he notes, "Research has shown that "normalizing" is a crucial step. Normalizing means a willingness to adapt to a new life of chronic illness. It's having the integrity to be more resourceful and find or invent ways to minimize the impact the chronic illness has on daily life. It also requires letting go of the past, letting go of dreams and aspirations and placing a greater value on the present."

Armstrong's posts are short and honest. For more, visit <https://mystudentvoices.com/@writeonfighton>

- The Day I Learned I Could No Longer Jump
- Accepting Uncertainty: The Most Important Question A Chronic Illness Patient Can Ask
- The Scary Work of Redefining Yourself
- How I Finally Kicked Prednisone



Trustee emeritus Peggy Cashman gratefully accepts Glen Ost diek's \$1,000 sponsorship gift to support the work of Conquer MG.

NIF Meters

By Sally O'Meara, RN



NIF meters measure an individual's respiratory muscle strength to inhale. The NIF is used to help determine eligibility for BiPAP and need for respiratory support with a ventilator. (The NIF may also be referred to as the MIP.) Patients can use NIF meters at home to assess their breathing status and determine when to call the neurologist or go to the ER.

NIF meters generally are not available for sale to individuals. However, if you'd like to purchase one (\$20), you can order it through Sally O'Meara, payable to the omeara@oakland.edu PayPal account. Thanks to donations from generous MG angels, patients who need a NIF meter but cannot afford them should email Sally at omeara@oakland.edu to receive one at no charge.

Conquer MG Note: In the mailing, O'Meara includes an explanation for using a NIF meter. You may want to review this with your doctor as part of your MG treatment plan.



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Special Thanks!

Janet Bauer, Lisa Bychowski,
Anna Stargardt, Joyce Hummel





Six Years Strong

The 6th Annual Strides Against MG Walk welcomed over 200 participants on Sunday, June 3, at Berens Park in Elmhurst, Illinois. On a sparkling sunny day, Conquer MG hosted its first-time-ever 5K run for fitness warriors, and lots of folks came dressed as Viking conquerors ready to do battle with MG.

We gratefully acknowledge the outpouring of support from (and for) individuals who struggle with myasthenia. Special thanks go to these folks who went the extra mile to involve family and friends with Conquer MG's mission!

Top Fundraisers	Raised
Janet Bauer	\$4,685
Sara Hasemeyer	\$2,676
Joanna Sherrod	\$1,997
Peggy Cashman	\$1,970
Michael Brady	\$1,800
Bob Rosecrans	\$1,240
Bob Ratzel	\$1,078
Darlene Perrone	\$905
Danielle Woodward	\$800
South Suburban MG Support Group	\$785

Research Update

Pain, Headache, and Other Non-motor Symptoms in Myasthenia Gravis. A paper published May 3, 2018, online in the journal *Current Pain and Headache Reports* reviews data on symptoms the medical community typically does not associate with myasthenia: bodily pain, headache, sleep disturbances, and abnormalities in the ability to smell, taste, and hear, and in autonomic function. The authors note that "our understanding of the immunologic basis of this disease is expanding. The classic view of MG as a purely motor disorder may be incomplete." <https://doi.org/10.1007/s11916-018-0687-3>

MG and Men

Excerpt from October 2017 presentation by Dr. David Randall

For men, MG generally is not a direct cause of infertility, erectile dysfunction, or loss of libido. However, low testosterone may be correlated with myasthenia gravis in terms of MG medications and with factors not associated with medications.

Low testosterone is known to cause:

- Loss of muscle mass and strength
- Fat distribution
- Bone density
- Hair Loss
- Mood
- Fatigue
- Decreased sex drive
- Erectile dysfunction

Other factors related to a chronic illness like myasthenia can play a part in male sexual dysfunction. Individuals who have MG are at higher risk for general fatigue, depression, thyroid disease, and diabetes. These other symptoms and diseases and their treatments may cause male sexual dysfunction.

If you have these issues, discuss them with your neurologist. Your medications should be reviewed, and other underlying causes such as depression or diabetes should be considered and treated. Your doctor can check hormone levels, and treat low testosterone.

"With me, the ego really took a hit with MG. I got this when I was in my mid-50s. I was very upset. I was teaching people how to drive and I couldn't do it. It took me a year to ask for help. Here's what I learned: find a good neurologist, a support group, and someone to talk to."

— Howard Brickman

In Appreciation

SPECIAL THANKS to everyone listed who supported our mission from February 16 through July 31, 2018. Due to space constraints we are listing those who donated \$50 or more. Your continuing financial support keeps our organization going! We also thank those who asked not to be listed but support Conquer MG work.

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In Honor of Peggy Cashman
 Bob and Jeanne Pitra
 Michael and Sally Pope

In Honor of Joyce Holste
 Nancy Van Laten

In Honor of Joyce Holste's
South Suburban Walking
Team
 Nancy Van Laten

In Honor of Darlene Perrone
 Elizabeth Kroll

In Honor of Bob Rosecrans
 Clyde Partner

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 2018 DATES	TIME	LOCATION
Chicago - North Suburban	Tuesday, Oct 9 Thursday, 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 a holiday party.
Chicago - South Suburban	Sunday Oct 7	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	Sunday Nov 18	1:00 PM - 2:30 PM	Central DuPage Hospital, Conference room 3, Women & Children's Pavilion, 25 N. Winfield Road, Winfield, IL. Use NW entrance, park in Visitor Lot 3 or use valet parking.
Rockford	Saturday Oct 13	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	Sundays Oct 21 Nov 18	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	Saturday Oct 6	10:00 AM - 12:00 PM	Schererville Public Library, ask at desk for meeting room, 1001 W. Lincoln Highway, Schererville, IN. Adjacent parking.
Quad Cities Iowa / Illinois	Saturday Oct 13 Speaker: Dr. Jesse Walden	10:00 AM - 12:00 PM	Davenport Public Library - Eastern Avenue Branch, Room A, 6000 Eastern Avenue, Davenport, IA. Use main entrance and adjacent parking. Co-sponsor: Conquer MG and MGFA.

In Memory / In Honor

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Vancil

Bill Vancil




In Memory of My Late Husband and In Honor of My Daughter

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Upcoming Events

- NOVEMBER 4
Fall Patient Meeting
- OCTOBER - DECEMBER
Support Group Meetings -
Chicago South, North, and
West, Rockford, Springfield,
NW Indiana, Quad Cities

