

CONQUER

News for our community

Let's Conquer MG Together



Dress like a Viking and join us for the 6th Annual Strides Against MG Run/Walk on Sunday, June 3, in Elmhurst, Illinois. New for 2018: a 5K fun run has been added for our fitness warriors! Our ever-popular walk (your choice of one to three miles) and kids' dash will follow. Whether you run or walk, be sure to strike your favorite Viking pose as you cross the finish line. Or just enjoy the music as you tend the hearth back at the tent! Note the run is untimed. The Strides Against MG Run/Walk fundraiser helps our organization support those with myasthenia. And it's a wonderful opportunity for folks with MG to be uplifted by friends and family who care.

See flyer inside for registration details.



Making Treatment Decisions with MG



Who can help with treatment decisions when

you're ill? What if you disagree with your doctor? Can you opt out of care? Rev. Clint Moore will address these issues at the Conquer MG Spring Meeting on Sunday, April 22, at Elmhurst Memorial Hospital, Ill.

Moore is the Director of The Center for Clinical Ethics at Advocate Lutheran General Hospital. An engaging presenter with unique credentials, he's spoken to community groups and medical professionals about the ethical choices involved in health care. He has discussed difficult topics with countless patients, including those with myasthenia gravis. Don't miss it! *See flyer inside for 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

Welcome to our First “Women’s Issue”



We’re interested – and thought you might be, too – in the connection between MG and issues unique to a woman’s physical and mental health. (Spoiler alert: Watch for the “Men’s Issue” in September!) This newsletter addresses how MG is impacted by and can impact menstrual cycle and bone density loss. On page 6, we direct you to our YouTube channel for information related to pregnancy and breastfeeding.

But MG also affects women in roles as breadwinner, wife/partner, mother, and friend. So we profile Mallory, p. 4, who is a young mother of three, and Lisa, p. 7, an entrepreneur who recently started a new business.

Many people dealing with chronic disease are not as connected as Mallory and Lisa. We’d like to hear from you, to understand your challenges and special ways you cope with MG.

Wishing you well,

Joan Wincentsen, Executive Director

— “ —

With the new day
comes new strength and
new thoughts.

- Eleanor Roosevelt

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 \$12,500 in benefits in 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

► Trivia Night



On February 24, Jim White of J.S. White and Associates, LLC (shown here at last year's event) will host our 2nd Annual Trivia Night for Conquer MG at the Elmhurst American Legion. We look forward to reporting on this Battle of the Einsteins!

Calendar Club Winners

\$500 Grand Prize – Charles O'Neal

\$100 Runner Up – Ted Wienski

December – Mr. & Mrs. J Begale, Dorothy Mykisen, Joel Schohn, Anonymous

January – Patrick Considine, Robert Nunziata, Cliff Zolna, Anonymous

► Lend a Hand!

The 2018 Strides Against MG Walk Committee needs you! Call 1-800-888-6208 if you can find sponsors or raffle prizes, or can pitch in the day of the walk.

Can you or a family member serve for two years on the Conquer MG board? We're looking for two to three people with a strong desire to serve MG patients. Appreciated: skills in planning, budgeting, fundraising support, and/or social media; plus attendance at 5-6 meetings a year in Elmhurst, Illinois.



► Keep a "How Can I Help?" list

When someone asks, have ideas!

- Pick up items at the grocery store
- Provide a ride to the doctor or dentist or hairdresser
- Chauffeur the kids to an activity
- Walk the dog
- Shovel the sidewalk
- Wash the inside car windows
- Drop off library books
- Rake leaves, water plants, pull weeds, or mow the lawn
- Help rearrange the kitchen so often-used items are within reach
- Bring dinner on Wednesday night
- Stop by and chat

► Assistance Fund Offers Copay for MG Patients

The Assistance Fund, an independent charitable patient assistance foundation that helps patients and families facing high medical out-of-pocket costs, announced in 2017 that it will offer a program to provide financial support to patients with myasthenia gravis. The new fund will assist individuals with out-of-pocket medical expenses associated with their condition and treatment, including premiums, deductibles, copays, coinsurance and incidental medical expenses. To learn more or determine eligibility for financial support, individuals should visit www.tafcares.org or call (855) 845-7608 to speak with a patient advocate.

Mallory Hermanson

Young Mom of 3

Mallory was diagnosed with myasthenia gravis at age 29. She was juggling a physically demanding life with two toddlers and a baby. When Mallory first contacted Conquer MG, carrying the baby up and down the stairs had become unmanageable.



I'm a mom of three (ages 3, 5, and 6), which takes most of my energy. I'm grateful that at the moment we have got my illness to a more stable point. I still have symptoms daily, but not as debilitating as they were the first year. I have weakness in my neck, mouth, tongue and smile. I also have weakness in my arms and legs.

Even though it's been two years, I feel like we're still figuring out what works. Currently I'm on prednisone. I was at 60 mg when I first got diagnosed, then down to 20 mg for a good year and currently at 4mg a day - woohoooo! I also receive IVIg every 2 weeks. This is what truly makes it possible for me to live as close to my new "normal."

Every day is different. I listen to my body and change things on

the fly. If I'm feeling good I go out and do things; if not, I "rest" as much as I can with a 3-year-old at home. My schedule is a mix of go times and rest times. I nap each day in the afternoon with my BiPAP*, and need a full eight hours minimum of sleep each night to recharge. With little ones it's hard as a parent to find time for yourself but it is essential to be able to take care of my family.

What has helped? Finding a great doctor who listens and works with you to find the right treatment plan has been one of the best things. My husband has been so amazing in helping with everything at home. My parents and friends have made dinners, and watched kiddos. In the beginning it was super hard to ask for help, but letting go and accepting help has been a godsend. Going to the gym helps,

too. I can't do even close to what most are, but water aerobics or walking the track helps me both physically and mentally. Also, with prednisone weight gain, I've developed sleep apnea and the BiPAP has helped so much!

**A Bilevel Positive Airway Pressure (BiPAP) machine is sometimes used by MG patients to help diaphragm muscles with breathing.*





Bone health in Myasthenia Gravis (MG)



By Rabia Malik, M.D., Department of Neurological Sciences, and
Sandford Baim, MD, Rheumatology, Rush University Medical Center

Women with myasthenia gravis (MG) face unique challenges. In this article we will discuss how female patients are at an increased risk of developing bone loss, which can increase their chance of developing fractures. This risk is even greater in postmenopausal women. However, steps can be taken to preserve bone health and reduce the risk of broken bones.

Bone mass tends to be lower in women compared to men of the same age and weight. As we age, bone density naturally decreases, but postmenopausal women experience particularly accelerated bone loss. This occurs because the bone repair process by which old bone is replaced by new elements have been altered by low estrogen resulting in less new normal bone. There are numerous additional risk factors for bone loss and increased fracture risk that include family history of osteoporosis and fractures, prior history of fractures, low weight, race and ethnicity, smoking, excessive alcohol, diabetes mellitus and many other diseases,

and numerous medical therapies such as steroids (prednisone-like drugs).

Most myasthenics require life-long treatment with steroids. Since most young patients (below the age of 40) diagnosed with MG are women, they typically are exposed to years of treatment that may span over decades. Steroids have been linked to an increased risk of fractures at even relatively low dosages. Patients with hip weakness have difficulty arising from chairs, climbing stairs and frequently lose balance placing them at risk of frequent falls that often result in fractures.



To reduce bone loss and risk of fractures:

1. Your neurologist will attempt to control your disease by keeping you on the **lowest possible steroid dosage**, possibly by addition of other immunomodulatory medications such as mycophenolate mofetil, azathioprine, IV immunoglobulin and plasmapheresis. However, this may not be always possible.
2. Increase your intake of **calcium and vitamin D-containing foods** in your diet to avoid lack of sufficient calcium in bone and vitamin D deficiency (see National Osteoporosis Foundation web site for recommended types and doses at NOF.org)
3. Perform **weight bearing exercises** such as walking, with adaptive devices if required, to prevent falls.

(Continued on page 10)



Women's Health and MG

Highlights from the October 2017 presentation by Dr. David Randall



How does MG affect the menstrual cycle, pregnancy, labor and delivery, the newborn child, and breastfeeding? Dr. David Randall, neurologist from NorthShore University Health System and Assistant Clinical Professor for the University of Chicago, recently addressed these issues for a Conquer MG audience. View his full presentation on our YouTube channel at <https://goo.gl/a1w9yA>.

MG Incidence in Women. When considering how myasthenia gravis affects men compared to women,

- Women are over represented; they make up over 60% of MG patients.
- Women are more often affected at a younger age.
- The highest incidence for women is in the 20s and 30s.
- Genetic studies correlate early-onset myasthenia gravis, which affects women of childbearing age, and the HLA-DR3 and B8 gene-alleles. Other genes also affect susceptibility to autoimmune disorders.

MG Exacerbation. Periods of exacerbation – when MG symptoms get significantly worse – can be triggered in both men and women. Triggers include infection, anesthesia, thyroid changes, medications, emotional stress, and physical stress (such as illness, trauma, or surgery). MG symptoms in women also can be affected by menses, pregnancy, and postpartum changes in hormones.

Regarding MG and menstrual periods:

- Small studies and case reports have demonstrated a frequent exacerbation of myasthenia gravis during the menstrual period.
- In one study, 42 premenopausal women with generalized disease were evaluated. Twenty eight (67%) of the patients reported exacerbation of their myasthenic symptoms two to three days prior to the menstrual period.
- This exacerbation persisted in 22 study participants to the third day of the menstrual period. In nine of the women this clinical worsening necessitated an increased intake of medications during the days prior to menstruation.
- Menstrual exacerbations occur in both seronegative and seropositive patients. These exacerbations may frequently necessitate therapeutic changes.
- Anecdotal benefits of long acting birth control pills have been reported.
- Improvement of these exacerbations tends to occur after menopause.



Make a Plan for Pregnancy. If you're a woman with MG, it's important to discuss your pregnancy plans in advance with your neurologist whenever possible, so you can work as a team for the best outcomes. You'll want to discuss how pregnancy can affect your MG, and how MG can affect your pregnancy. Together you can discuss if pregnancy is an option, medications that need to be changed, and risks to the fetus and newborn. You'll want any pregnancies to be closely monitored.

Lisa Guerrero

Reinventing Yourself with MG

Lisa recently opened Lake Street Bean, a coffee shop in Grayslake, Ill. She (R) and co-owner Darlene Placko (L) are dedicated to serving commuters with their first sip of coffee each morning.



It's been quite a journey living with MG. It has taken me through some very frustrating moments and extremely low points in my 23 year struggle with this unpredictable disease. After being diagnosed in 1995 (at the age of 23) and quickly undergoing a thymectomy, I had to learn to live my new "normal." Those of you who have MG or know someone living with it, understand this isn't easy.

My low points included: intubation while giving birth, being lifted off of the toilet, driven home from work when I've been too weak to drive myself and often being carried up the stairs by my stepsons. Additionally, the inability to be active with my daughter when she was little. I couldn't bike with her, play much in the park, jump rope, skip, swim, etc. I had difficulty holding

her, changing her and feeding her at times. I felt inadequate as a mother.

I've worked parttime, fulltime and been on short term disability. I missed celebrations, weddings and get-togethers. Life has certainly been a roller coaster but I take each day as it comes.

I recently quit my job of 16 years as a teacher assistant and opened up a coffee shop with a friend in our local train station. We are only open in the morning which allows me to get the most out of my day when I am well-rested and strong. Being able to do this has reminded me that MG doesn't have to stop you from living, you just have to find what works for you.

MG is unpredictable, so being patient is key. I can be paralyzed one minute and mobile in the next if I just wait it out. I rest when my body tells me and I ask for help when I need it. I have a great doctor and I am my own advocate. Lastly, my faith has been an important part of managing this disease. I trust God's plan is bigger than I can even understand.





Better breathing through safe swallowing

By Sally O'Meara, RN

Special lecturer in the Oakland University School of Nursing

Named 2017 Nurse of the Year by the Myasthenia Gravis Foundation of America

Many patients with myasthenia gravis (both men and women) have weakness of muscles that control swallowing. This can lead to difficulty swallowing, a problem known as dysphagia. Impaired swallowing can lead to inhalation of food, fluids and saliva into the airways, called aspiration. Chronic aspiration can lead to pneumonia, which can in turn lead to myasthenic crisis. Patients with dysphagia can take precautions to help ensure that food and fluids go down to the stomach rather than the airways.



Aspiration:
inhalation of food,
fluids and saliva
into the airways

Patients with dysphagia should tuck their chins down to their chests when swallowing. This movement closes off the airway and helps ensure that food goes down to the stomach. Patients should take care never to tilt the head back when swallowing food, fluids or pills as this greatly increases the chance of aspiration. Small amounts of food or fluids should be taken at one time, and the throat should be cleared with a gentle cough after every few bites or sips. Patients should avoid talking when eating or drinking in order to focus on swallowing and avoid accidental aspiration.

One of the hallmarks of myasthenia gravis is fatigable muscle weakness. The muscles become weaker as they are used. Patients should try to avoid large meals whenever possible and have smaller frequent meals instead. Rest periods may also be taken during meals to let weakened mouth muscles regain their strength. Dry, tough, stringy foods should be avoided in favor of soft foods that can be mashed with a fork. Meats should be chopped as needed for easy chewing. This will prevent tiring of the mouth muscles and promote safe swallowing. Acidic or spicy foods should also be avoided as they are more likely to cause pneumonia if aspirated.

Patients should be sure to sit completely upright when eating and for 30-45 minutes afterward. Drinking fluids with a straw causes the liquid to be introduced to the back of the mouth where it can easily be aspirated. Liquids should be taken by cup or spoon only. Liquids may be thickened to a nectar- or honey-thick consistency using commercially available thickeners such as Thick & Easy®, Thick-It®, ThickenUp®, Simply Thick® and Thik & Clear®. Patients may wish to swallow twice after each sip or bite in order to ensure that the food has left the mouth safely and is on the way to the stomach.

Symptoms:
choking, difficulty
breathing, or
coughing after
swallowing

Mixed-consistency foods such as chicken noodle soup, ice chips and cold cereal with milk increase the risk of aspiration as the muscles must manage liquids and solids in the mouth at the same time. Creamy soups and hot cereals are recommended instead. Mestinon may be crushed and mixed with applesauce or pudding for easier swallowing.

Better breathing through safe swallowing

(Continued from page 8)

Time-release mestinon must not be crushed however, as it can lead to overdose and increased muscle weakness.

Patients with dysphagia should be aware of the signs and symptoms of aspiration. These include choking, difficulty breathing, or coughing after swallowing. Patients may feel like they have food stuck in the throat and may have a wet, gurgly voice after swallowing. Silent aspiration occurs when patients do not have any symptoms of inhaled food or fluids. Occasionally, watery eyes may be a sign of silent aspiration.

Myasthenic patients with weak throat and mouth muscles should take these simple steps to help prevent inhaling food and fluids at mealtimes. This can help maintain breathing status and prevent aspiration pneumonia.



A woman is like a tea bag. You can't tell how strong she is until you put her in hot water.

- Eleanor Roosevelt

Research Updates

Vitamin D levels in MG patients were significantly lower than those in healthy individuals, in a study reported February 2018 in the Journal of Clinical Neuroscience. Researchers noted vitamin D levels can affect muscles and the autoimmune response, and should be monitored in MG patients. Source: DOI: <https://doi.org/10.1016/j.jocn.2018.01.047>

Researchers in Sweden have found a marker in the blood that might reflect the severity of a person's MG illness. Anna Rostedt Punga and Tanel Punga have identified **circulating microRNAs**, small pieces of RNA found in blood, which could help physicians monitor the disease and determine an appropriate drug therapy. DOI: [10.1111/nyas.13510](https://doi.org/10.1111/nyas.13510)

A recent study published in the Journal of Neurology, Neurosurgery & Psychiatry, conducted by researchers at multiple sites in Japan, suggests that a low dose of steroids combined with early combination of other treatment options may ensure earlier achievement of the treatment target in generalised MG and may be **preferable to a high dose steroid treatment**. <http://jnnp.bmj.com/content/early/2017/11/19/jnnp-2017-316625>

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, March 27, Tuesday, April 24 Tuesday, August 21 Tuesday, October 9 Thursday, Dec 13 Saturday, June 16	9:30 AM - 11:00 AM 11:00 AM - 1:00 PM	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. Potluck indoor picnic, Rooms A1-A2.
Chicago - South Suburban	Sunday March 11 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	Sundays May 20, Aug 19, 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	Saturdays April 14, July 14, 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 March 18, April 15, May 20, July 15, Aug 19, Sept 16, 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	Saturdays Mar 3, May 26, July 21, 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 April 14 Other dates TBD	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.

Bone health in MG (Continued from page 5)

1. **DXA scans** are obtained annually. Bone mineral density (BMD) is a measure of the bone mineral content at selected sites (hip, spine, forearm), that is measured by an imaging study called Dual Energy X-ray Absorptiometry (DXA). This is a very low radiation X ray study whereby a score called the T-score is determined. The difference between normal score for a healthy 30 year old with a patient's number is measured in standard deviations (SD). One SD difference in bone density is equivalent to 1 T-score. A T-score of -1 and above is normal, between -1.1 SD and -2.5 SD is defined as "osteopenia" and T-score of lower than -2.5 SD (more negative) is categorized as "osteoporosis".
2. **Medications for osteoporosis may be prescribed.** There are numerous medical therapies for the prevention and treatment of osteoporosis. The types of medications and further discussion of their benefits and potential risks can be found at NOF.org.

In Appreciation

SPECIAL THANKS to everyone listed who supported our mission from December 2017 through February 15, 2018. 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" deaths are not necessarily related to MG.

Peggy and Willard Anderson
Vicky Benyr
Robert and Ruth Brown
Lorraine Carella
Howard Caywood
Neal Chadwick
Robert Crane
Peggy DeLaurentis
Marilyn Fitch
Anne Flanz
Mike Friedland
Richard Galitz
Edward Gittelsohn
Warren Hanssen
Jean Johnson
Dianne Kaufman
Ward Keever
David Kelly
Carol Lampres
Steve and Dorothy Litwitz
Dr. William Markey
Adele Merkel
John Morris
Dorothy Mykisen
Gail Olley
Bob Ratzel
Ed Rickert
Robert Rosecrans
Art and Eileen Roth
Sharon Ruddy
Joanne Schroeder

Robert Schwab
Sherry Sherfy
Dwain Sims
Ruth Smith
Debbie Stumpf
John Sturtevant
Angela Vasandani
Katherine Vennetti
Geraldine Volpe
John and Martha Ward
Joan Wincentsen

In Honor of Shirley Jordan
Donald and Joyce Franklin

In Honor of Sione LaPointe
Howard and Evelyn LaPointe

In Honor of Cherly Meltzer
Ann and Bob Neuman

In Honor of Michael P. Merchut, MD
Stuart M. Weis

In Honor of Joan Wincentsen
Nancy and Jim Bulger

In Memory of Fred Arnold
Loretta Fleming

In Memory of Michael J. Jamen
Ida L. Jamen and Family

In Memory of Robert W. Mool
Kathy Amundson
Vicki Ehlers
Becky Herald
Kristin Martin
Leonard Neisler
Carl Radebaugh

In Memory of Helen Bull Neuhaus
Cindy Loomis

In Memory of David Nixon
Ashley Hogewood

In Memory of Charles Dwane Noble
Deborah Noble

In Memory of Leonard Okon
Elena Okon

In Memory of Dennis Riedel
Judie Riedel

In Memory of Ethyl Rogers
Maureen McGrath

In Memory of her mother
Gwendolyn Thompson

In Memory of Mark Weinberg
Pamela Weinberg

In Memory of Sam Widran
Betterose Widran

With your help, we met our 2017 donation goal of \$55K. Your contributions support Conquer MG seminars, telephone response, newsletters, new patient information packets, support groups, and online resources like our website and videos on our YouTube channel. Let's wipe out MG!




2017 TARGET: \$60,000



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Upcoming Events

- APRIL 22
Spring Patient Meeting
- JUNE 3
Strides Against MG Fun Run/
Walk