

CONQUER

News for our community

Conquer MG Like a Viking!



Bring your warrior helmets and horns, beards and braids, and join us for this year's Viking 5K Fun Run/Walk Fundraiser on Sunday, June 2, at Danada Forest Preserve in Wheaton, Illinois. There's a 5K scenic trail run for fitness warriors, a 1-3 mile walk around the bridal path circle for non-warriors, plus the kids dash! And you can strike your favorite Viking pose as you cross the finish line. This event is untimed.

The Viking 5K fundraiser helps our organization support those with myasthenia. It's also a wonderful opportunity for folks with MG to be uplifted by friends and family who care.

Look inside for registration details.



Spring Patient Seminar

IVIg and plasmapheresis are often used to provide important relief when an individual's MG weakness doesn't respond to first line medications. One therapy involves an infusion of normal antibodies, while the other "cleans" offending antibodies from one's system.

Join us Sunday, April 28, at Elmhurst Memorial Hospital in Elmhurst, Illinois, for Conquer MG's **Spring Patient Seminar** to learn more. A physician from Rush University will explain the patient experience, when each approach is prescribed, and how they compare to new drug therapies.

See flyer inside for details.

We've Moved!

...Down a couple floors to Suite 201. Our new address is:
275 N. York Street, Ste 201
Elmhurst, IL 60126



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

Developing MG as a Teen



At what age did you or a loved one get a diagnosis of myasthenia? I hope you can relate to Sajad and Kelsea, who developed MG as teens, and who share parts of their stories in this issue. I think if I was a teen with MG, like them I would deny my symptoms as long as possible – until problems became too big to ignore. I would be embarrassed when my body wasn't working. I might need, yet struggle with my parents. They both have given me insight, too, on how much getting a serious illness when you're young can affect your mental health and shape your self-image.

Speaking of self-images (or selfie opportunities!), we invite you, your family, and friends to *act like Vikings* and help conquer MG! Put on your beards and braids, helmets and horns, and join us for our Viking 5K Fun Run/Walk on June 2 in Wheaton, Illinois. Danada Forest Preserve is our new location, even more scenic than in the past. *Your support is essential. Are you with us?*

Wishing you 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. We are accepting applications for 2019.

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 201, 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

► Chicken Dinner - 2x Winner!



For the second year in a row, the team “Chicken Dinner” took home the trophy and cash prize from Conquer MG’s Trivia Night fundraiser. We gratefully acknowledge the mind-bending questions, emcee skills, and 2nd prize donation of steak knives by Jim White, of J.S. White and Associates, LLC.

► Lend a Hand!

The Viking 5K 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.



**March is National
Autoimmune Disease
Awareness Month**

► Introducing New Leaders!

We welcome Claudia Cox, leader of the Illinois/Iowa Quad Cities group, and Victor Yipp, who will head up the Chicago Near West Suburban group in Oak Park, Illinois. Claudia and Victor received plenty of ideas and tips from four veteran Conquer MG leaders in January. Thanks, Joyce, SeAnn, Kelly, and Joan! Note the Quad Cities April 13 meeting is from 12 noon to 2 p.m. (new time). And the Oak Park group next meets May 19 at 1:00 p.m. (new date).

► Newsletters Via Mail or Email?



One of Conquer MG’s biggest expenses (over \$11,000 last year) is newsletter printing and mailing. If you’d like to receive this newsletter via email (and save us a few dollars), please contact us at info@myastheniagravis.org.

We understand you have giving priorities, and we’re sure you understand we have expenses. So please keep in mind we periodically remove nondonors from our print mailing list. If you tell us you are financially unable to make a donation, we’ll make an exception.

Calendar Club Winners

2018 \$500 Grand Prize – Deb Volpe

2018 \$100 Runner Up – Margaret Draths

December - Glen Knudsen, Steve Kuhnhofer,
Alberta Steinhoff, Anonymous (1)

January – Claudia Cox, Robert Nunziata, Milos
Sekulic, Bonnie Zivich



Better Breathing Through Technology

From Conquer MG's Fall Patient Seminar presentation by Sally O'Meara, RN



Myasthenia gravis can sometimes weaken diaphragm muscles and affect a person's ability to breathe; in November, 2018, Sally O'Meara, RN and nurse educator, described how technology can help one cope. See her full presentation on Conquer MG's YouTube channel at <https://tinyurl.com/ycp58uwb>.

Read the signs

When MG affects respiratory muscles, it can cause **acute respiratory failure** (or an "MG crisis"). You also might have an ongoing problem with breathing (or **chronic respiratory failure**). If you can't swallow easily, food and liquids can go down your airway and get in the lungs, leading to **aspiration pneumonia**. And breathing issues related to **sleep disorders** (sleep apnea) are not unusual with MG patients.

These signs indicate MG is affecting your breathing:

- Shortness of breath with activity or rest
- Inability to breathe when laying flat
- Pausing to take a breath after every few words
- Single breath count less than 25
 - Take a deep breath in, count out loud as quickly as you can – saying each syllable of each number - while you exhale. (A healthy person can count to about 50)
 - Failure to count to 25 is a sign to seek immediate medical attention or call your neurologist
- Slurred speech with nasal, wet voice
- Waking during the night feeling short of breath
- Morning headaches & unexplained sleepiness

Technology to the Rescue

Several devices can help relieve MG-related breathing difficulties. Many have heard of C-PAP (continuous positive airway pressure) machines that are used to treat sleep apnea. C-PAPs are not recommended to help with MG breathing issues. Instead, a BiPAP (bi-level positive airway pressure) helps with breathing in two ("bi") ways. It delivers high pressure for inhaling and low pressure for exhaling. A BiPAP reduces the work of breathing.



A Bi-PAP works like a ventilator, without a tube down the throat. A tight mask is worn over the mouth/ or nose to regulate breathing. It can be used at home during the night to correct shallow breathing during sleep, and during the day to relieve shortness of breath.

A BiPAP can be used to avoid intubation when breathing assistance is needed during myasthenic crisis. To be able to use a BiPAP, a patient:

- Must be able to swallow, and
- Must be cooperative and alert.

(Continued on p. 5)

Infusion Q & A



By Samantha Masmar, RN
Home infusion nurse, Kabafusion

Q: Is Immunoglobulin (Ig) a blood product?

A: Yes, it is. But it is very safe. Human Immunoglobulin (Ig) is pooled from tens of thousands of blood donors to make a batch of IVIG medicine. Once the Ig is collected, manufacturers filter it to remove all the viruses and bacteria that can be transfused to the patient.

Q: What are the side effects of IVIG? How can they be minimized?

A: Most common side effects are headaches, nausea, rash, back pain, leg pain, high blood pressure and chills. Hydration is the best way to minimize side effects. Patients should be drinking plenty of water days prior to infusion, during infusion, and after infusion. Patients should avoid drinking caffeinated drinks because they can cause dehydration. Pre-medications such as Tylenol and Benadryl can also help with side effects.

Q: What should I expect during an IVIG infusion?

A: Whether done in a medical facility or at home, a nurse will monitor a patient's vital signs and side effects before, during, and after the infusion. The average IVIG infusion takes approximately 4-6 hours and is given over 2-5 days every 3-4 weeks. The nurse will start an IV to infuse the medication and will remove it when the infusion cycle is completed.

Q: What can I expect after an IVIG infusion?

A: Some patients complain of fatigue for a few days after their infusion cycle is completed. I recommend to my patients that they should not schedule anything stimulating for a few days after completion of the infusion cycle. This will give their bodies time to absorb the Ig and hopefully start to resolve any of their symptoms. Some patients notice relief after the first day of infusion while for others it could take weeks. Also, continue to drink plenty of fluids to help with absorption.

In the spring, I have counted 136 different kinds of weather inside of 24 hours.
- Mark Twain

(Continued from p. 4)

Using a BiPAP machine at home can help you maintain a healthy oxygen level and improve daily living. It can promote your comfort, support ventilation, maintain oxygenation, and prevent hospitalization.

BiPAP criteria for MG

BiPAP machines can be obtained through Medicare & most insurance plans. You can qualify for a BiPAP without doing a sleep study if you have an MG diagnosis from a medical professional and one of the following:

- Pulse oximeter reading of less than 88% for more than 5 minutes during sleep
- Awake ABG (arterial blood gas) reading $\text{PaCO}_2 > 45$ mm Hg (you have a high level of carbon dioxide in your blood)
- FVC Forced vital capacity (FVC) (the amount of air you can force out of your lungs) $< 50\%$ of predicted level
- NIF (or MIP) reading (the strength to inhale) < 60 cm H₂O; normal reading is 90 to 100.

A BiPAP machine with a program called AVAPS is best for MG patients with chronic respiratory failure. This program adjusts to fluctuating muscle weakness and poor breathing during sleep.

Sajad Husain

Learning through Rebellion

Sajad grew up in the western suburbs of Chicago. He notes, "Because of what I went through, I don't worry about the stuff that others worry about; it's allowed me to find my own way".

Photo of Sajad as a teen.



Sajad Husain, age 42, vividly recalls when he was diagnosed with myasthenia gravis. "I was 17. I was bussing tables, and suddenly I couldn't walk up two small steps in the restaurant where I worked. Although I'd hidden it from my parents, I hadn't been able to eat or drink for five days."

The next day his 4'9" mother somehow "got me in the car; on the way to the hospital, I told her there were trees in the road – I thought I was seeing things, but it was double vision from the MG."

Because of his age, the ER doctor thought Sajad had taken hallucinogenic drugs. "My symptoms just got worse, to where I couldn't cough to clear my lungs." Sajad remembers when a new doctor arrived. "It was 11:55pm. He was in a tuxedo. (He had just come from a benefit dinner.) He gave me something called Tensilon and suddenly I could swallow again. 'I think I

know what you have,' he told me, and diagnosed myasthenia."

Sajad spent two weeks in the ICU, did plasma exchange for four months, and had a thymectomy. He was in a wheelchair for eight months. "One person I met then is now my closest friend. We raced in the halls, and delivered pizza to folks."

Unfortunately, one doctor's words stayed with him: "You have three to 10 years to live



Still a kid at heart!

before this will happen again." Sajad explains, "That messed me up." Sajad responded like the teenager he was – with rebellion. "I was successful – I graduated from DePaul University, got a law degree, and started a tech company. But I figured I wasn't going to live long, so I did a lot of drugs and alcohol." In retrospect, Sajad notes, "My friends and family pushed me to be normal, but I think young people need help to deal with the anxiety and depression of being seriously ill. If I had advice for parents, it would be to think about their children's mental health as well as the physical stuff."

Sajad goes on to say, "When I was 33, I realized I'd lived six years past that prediction, and decided to turn things around. Now, I occasionally have MG symptoms. I also have better ways to manage my health. I have a dog and a house that's paid off, and I publish my own poetry. I'm proud of the work I do. I'm happy."

Writing about Life's Challenges



Writing can give you a way to talk about difficult stuff. It can help you view things from a

new perspective. Sometimes it allows you to step back and say, "Yes, I went through that." Or, "There, it's recorded; now I don't have to relive it in my head so often."

Kelsea Major has been through a lot in the last few years, and a family member suggested she write down her experiences. She began with a declaration, "I'm 18 years old and I have myasthenia gravis." She writes because "I'm still new to my situation and I feel like no one understands but my

doctor. Don't get me wrong, my family is supportive. I just need and want to hear others like me."

She describes her first symptoms this way:

"I was 12 years old when I started to notice something was really wrong. One morning I was walking to my bus stop and I had to go up a hill. When I was close to the bus I fell right in front of it and couldn't get up. The embarrassment I felt was the start of the struggle. I thought to myself it's probably a small problem – because I was an excellent athlete."

Kelsea had to move frequently in her teens, and it took a while to find a neurologist who understood her health issues. Now, she is preparing for a thymectomy and notes, "I still have to deal with getting my

body to the place I want it to be. But the love of my life and the love of my family are always by my side."

If you have a moment, consider writing answers to these questions

- What were your first MG symptoms?
- What do you wish people understood about your illness?
- What has been your biggest challenge with MG so far?
- How do you introduce yourself to others?
- What are you most afraid of?
- What's the most helpful advice you've received?
- Where would you like to see yourself in five years?

Research Notes:

- A number of clinical trials related to myasthenia gravis are in the recruitment phase. At www.clinicaltrials.gov, studies are listed as "recruiting" for various drugs and biologicals – some for generalized MG and other for MuSK-antibody MG. One study aims to gather definitive data on the effectiveness of existing treatments mycophenolate mofetil (CellCept®) compared to azathioprine (Imuran®). Another study is looking into an external magnetic device that could help with MG drooping eyelids. Studies are being conducted at a number of locations across the U.S.
- In a three-year study of 117 patients receiving eculizumab (Soliris®) patients continued to see improvements with activities of daily living, muscle strength, functional ability, and quality of life measures. Reported in *Muscle & Nerve*, February 14, 2019. <https://doi.org/10.1002/mus.26447>
- A study published in the February 19, 2019 issue of the *Journal of Clinical Apheresis* reported that a majority of patients with MG respond to treatment with plasmapheresis, and half experienced "complete response." Of the 58 participant, men were more likely to have a complete response, while the women were more likely to require maintenance therapy. Those with late onset MG were also more likely to have a successful response to plasma exchange treatment. Source: <https://doi.org/10.1002/jca.21694>



Pick Your Battles

*In the process of moving the Conquer MG office to a new suite, we came across a favorite resource published in 2000: **Hoping, Coping & Moping – Handling Life When Illness Makes It Tough**, by Ronna Jevne, PhD. Here is an excerpt.*

"The dishes are in the sink. The peanut butter is always on the counter, never in the cupboard. The doctor hasn't phoned back. The neighbor's dog barks incessantly. Your physical therapist isn't very encouraging. Your aunt sends you religious poems with hints that if you were a believer you would be cured. The back door sticks. You are paying the youngster down the street to cut your lawn, but it looks like a buzz saw ran away with it.

Sound familiar? Researchers have found that daily hassles affect people's lives as much as, if not more than, major life events. Whenever you don't feel well, you have only so much energy. Where do you want to use it? Do you want to spend it being annoyed? If you could be annoyed with only three things, what would they be?"

Conquer MG's Patient Assistance Program Challenges

Since 2014, Conquer MG has offered a Patient Assistance Program to myasthenia patients in financial need who live in Illinois, Indiana, and Wisconsin. We have helped individuals with the cost of medications and treatments, hospital and office visit co-pays, and durable medical equipment – up to \$1,000 per person per year.

In 2018, we helped 22 people, exceeding our budgeted amount of \$15,000. Some recipients are older and living on a fixed income. Some were forced to take early retirement because of MG. One person developed MG while undergoing chemotherapy for cancer. Here are comments they've shared:

- "I'm paying off my medical deductible at \$300 a month... I'm currently having to do home modifications and will be using retirement money for that."
- "I have extensive medical bills due to costs associated with MG, including IVIg infusions. I am a recent college graduate and I have high student loan expenses. My family is unable to financially help me due to my father's and sister's medical bills."
- "Our family has low wages - with only my wife able to work."
- "In the past 2 years I have lost all my furniture and belongings due to catastrophic storm damage, requiring an unplanned move, followed by car repairs needed after my car sat while I was hospitalized and in rehab after an MG crisis."

If you'd like to support Conquer MG, we welcome your help. If you want your gift to specifically go toward Conquer MG's Patient Assistance Program, please explain that in a note to us – either with your mailed gift, or as part of your online contribution.



Be a Viking and Help Conquer MG!

Bring your warrior helmets and horns, and join us for this year's Viking 5K Fun Run/Walk. You can give hope to those struggling with the rare autoimmune disease myasthenia.

- NEW Location: Danada Forest Preserve, Wheaton, Illinois
- Viking theme! Beards, braids, and shields welcome! Team signs!
- NEW: MG patients pay just \$20!
- NEW: Early discount until midnight March 31!
- Untimed 5K Fun Run for fitness warriors, through woods and meadows
- Leisurely walk (any distance) around the bridal path circle
- Kids Dash with prizes for every participant
- Amazing raffle prizes!

Visit <https://runsignup.com/Race/IN/Wheaton/Viking5KRunWalkOnline> registration for:

Online registration - More user-friendly than last year!

Donations and Fundraising – asking your friends and family to support your cause – is a huge way you can help Conquer MG help others. Set up your own fundraising page, so that your friends' donations can be attributed to you or your team. Just go to the page shown above, then click the "Donate" button to get started.

PRICING – Grab the early discount!

MG Patients: \$20 (including reg. fee)

Kids 13 and under: \$15 (including reg. fee)

Everyone else

- **Early – through March 31:** \$30 + \$2.50 registration fee
- **Regular – March 31 to May 7:** \$35 + \$2.50 registration fee
- **Late – May 8 to 4pm May 31:** \$37 + \$2.50 registration fee
- **Race Day – June 2:** \$40 including registration fee

Sign up by May 7 to ensure you get a t-shirt and that it's the right size!

WHERE

Danada Forest Preserve
35580 Naperville Rd, Wheaton, IL 60189

SCHEDULE

7:15 a.m. Event check-in opens
8:00 a.m. Welcome
8:15 a.m. Fun Run
8:30 a.m. Walk starts
9:30 a.m. Kids' Dash

For details and (if you prefer) a downloadable registration form, visit www.myastheniagravis.org



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	2019 DATES	TIME	LOCATION
Chicago - North Suburban	Tuesday, Apr 9 Tuesday, Aug 13 Friday, Oct 25 Tuesday, Dec 10 Saturday, June 8	9:30 AM - 11:00 AM 11:30 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
Chicago - South Suburban	Sunday, May 19 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.
NEW! Chicago - Oak Park	Sundays May 19 August 11 November 10	1:00 PM - 2:30 PM	West Suburban Medical Center, 3 Erie Court, Oak Park IL, lower level conference room A-B. Use main entrance or enter via parking garage lower level. Near CTA Green Line, Austin Station
Chicago - West Suburban	Sunday May 19	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. Join us for a celebratory last meeting.
Rockford	Saturdays April 13 July 13 October 12	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 Mar 17, May 19, July 21, Aug 18, Sept 15, Oct 20, Nov 17	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 23, May 25 July 27, Oct 26	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	Saturdays Apr 13, Aug 10, Nov 9	12:00 PM - 2:00 PM for Apr 13 meeting	Davenport Public Library - Eastern Avenue Branch, Room A, 6000 Eastern Avenue, Davenport, IA. Note: Future meeting times may change.

**“March is a month of expectation.”
- Emily Dickinson**

In Appreciation

SPECIAL THANKS to everyone listed who supported our mission from December 2018 to January 2019. Your continuing financial support keeps our organization going! We also thank those who asked not to be listed but support Conquer MG work.

Marilyn Bill
Bright Funds
Jeffrey and Kathleen
Brown
Robert and Ruth Brown
Chip Chapdelaine
Eddie Colvin
Herbert Drower
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Sharon Ruddy
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Dwain Sims
John Skarbek Jr.
Ruth Smith
Alberta Steinhoff
Katherine Vennetti
Andrew Virkler

In Honor of Kellie Ann
Bracioner
Robert and Patricia
Sweeney

In Honor of Shirley
Jordan
Donald and Joyce
Franklin

In Honor of Dr. Michael
P. Merchut
Stuart Weis

In Honor of Jan
Slomiany
Elizabeth Aasen

In Memory of Beatrice
Feinstein
Fred Feinstein

In Memory of Kathleen
Hanneman
Thursday Grant Park
Women's Golf Club

In Memory of Robert
Newman
Joyce Holste

In Memory of Bonita L.
Ostarello
John Ostarello

In Memory of Carolynn
E. Unzicker
Elaine and Ronald
Lackie




In Memory of Donald R.
Weir
Phyllis Weir

If You're Over the Age of 70^{1/2} and Have an IRA

If that "if" describes you, then you know you are required to withdraw a certain amount of money from your individual retirement account (IRA) each year. And that amount is taxed as ordinary income. If you'd like to make a tax-effective donation to Conquer MG (meaning you also end up paying less to Uncle Sam for the year), you can designate all or part of your required minimum distribution as a qualified charitable distribution (QCD). Your QCD won't count toward your taxable income, but still counts toward your required minimum distribution for the year. A tax advisor can help you figure out the details.

**IRA
QCD**

CONNECT WITH US!

-  @ConquerMyastheniaGravis
-  @ConquerMG
-  @ConquerMG

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2nd Place Trivia Team
Shows off their “Prizes”

Upcoming Events

- APRIL 28
Spring Patient Seminar
- JANUARY - DECEMBER
Support Group Meetings
- JUNE 2
Conquer MG 5K Fun Run/Walk
Registration Discounts!

