

CONQUER

News for our community

COVID-19 Vaccines and MG



Vaccines for COVID-19 will be available in the coming weeks and months. Conquer MG will share guidance issued by the Centers for Disease Control (CDC) when it becomes available. Because individuals who have myasthenia gravis may be at increased risk for severe COVID-19 illness, Conquer MG's Medical Advisory Board offers these general guidelines.

Please keep in mind this is not intended to be a substitute for professional medical advice. Be sure to consult with your physician to decide what's appropriate for your specific situation.

- Most MG patients should get vaccinated. Generally, we anticipate that the risks associated with the COVID-19 vaccine will be relatively small compared to the risk of contracting the disease itself.
- More than one vaccine is being developed for COVID-19. There is not yet enough information to say which vaccine will be better for the MG population. As of early December 2020, two cases of transverse myelitis have been associated with the AstraZeneca vaccine (with adenovirus vector), so this specific vaccine may not be best for someone with autoimmune disease.

(continued on page 5)

Webinars in 2021

Conquer MG will continue to offer support and education online in 2021. Virtual support group offerings are listed on page 3. Join us for these hot-topic webinars in the next couple months:

Eating to Combat Prednisone Weight Gain

Thursday, February 18, 2pm Central
Speaker: Danka Lekovic, Personal Trainer and Nutrition Coach

MG: Navigating the Disability Benefits Maze

Thursday, March 18, 2pm Central
Speaker: Mark DeBofsky, Attorney

See page 8 for registration and the full 2021 webinar schedule.

2021
happy new year

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 201
Elmhurst, IL 60126-2752
800.888.6208
www.myastheniagravis.org

FROM YOUR EXECUTIVE DIRECTOR

Our Commitment to Serve



Whew, that was one heck of a year. The coronavirus shaped social and political changes along with our decision whether or not to walk into a grocery store. Our school, work, and health care environments changed on a dime, and we did, too.

At Conquer MG, *you are still our primary focus*. Guided by our four pillars of support, education, awareness, and research, we're here to serve *you*. In 2020, that meant providing up-to-the minute COVID-19 information, plus guidance for staying well via calls, emails, webinars, and Zoom meetings. The Patient Assistance Program paid \$14,000 in MG patient medical expenses. And as explained on page 7, we supported innovative research that could improve clinical trials for MG treatments.

To be honest, you kept us going. You joined virtual meetings, took up the Virtual Viking 5K, and asked difficult questions.

Whether 2020 was relatively calm or took the wind out of your sails, know that Conquer MG is committed to supporting you. We're in this – this mix of myasthenia and COVID-19 and clinical trials and how-do-I-get-through-the-day stuff – together.

By now you've received plenty of COVID-19 information. If you're looking for MG-specific information about COVID-19, call us or visit the Conquer MG website home page.

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 2021.

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.

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

GROUP	2021 DATES	TIME (Central)	LOCATION
Anywhere MG Group	Wednesdays Jan 13, Feb 10, Mar 10, Apr 14, May 12, June 9, July 14, Aug 11, Sept 8, Oct 13, Nov 10, Dec 8	2:00 PM - 3:30 PM Central Time	Meets virtually*, second Wednesday of the month
Chicago - North / North Suburban	Wednesdays Mar 3, June 2, Sept 1, Dec 1	10:00 AM - 11:30 AM	For now, meets virtually.* Usually @ Glenbrook Hospital, Glenview
Chicago - South & West / South & West Suburban	Sundays Feb 21, May 16, Aug 8, Nov 14	1:00 PM - 2:30 PM	For now, meets virtually.* Usually @ Alsip (South) and Oak Park (West)

We invite members of other Conquer MG support groups - Northwest Indiana, Rockford, Springfield, and Quad Cities - to attend the Anywhere MG Support Group online until face-to-face meetings can resume.

*Contact us at info@myastheniagravis.org (or call 800-888-6208) to receive the link and phone number to join these groups. Be sure to say which group(s) you want. At the meeting time, join via computer, tablet, or telephone.



Trivia Night for MG Awareness

We had a great time kicking off Myasthenia Gravis Awareness Month last June - with Trivia Night! Congrats to David and Julie Roberts who took home bragging rights with the top score. Thanks so much to our host, Jaime Rowe (top left), for her entertaining trivia topics!



Calendar Club Winners

2020 \$500 Grand Prize – Cathryn Madsen
2020 \$100 Runner Up – Anonymous (1)

December – Amy Booker, Cheryl Heldt, Jane Horan, Ashwin Patel
November – Cathy Jackson, Maria Kunca, Gail Olley, Carole Ostachowski
October – Jim Begale, Jim Griffith, Cathy Jackson, Julie McCracken
September – Kathy Bingley, Claudia Cox, Maria Kunca, Trudi O'Neill
August – Kaleb Thomas, Joan Cook, Ardith Wiley, Anonymous (1)
July – Marita Janzen, Carol Oswald, Julie Szacko, Ardith Wiley
June – Mike Ondek, Joe Garrity, Steve Malinovich, Arlene Sangmeister
May – Dave DeFries, Jr., Julie McCracken, Marvin Savage, Anonymous (1)
April – Thomas Dammrich, Carol Oswald, Anne Smith, Geri Weber
March – T. Cawley, Pat Considine, Warren Hanssen, Natalie Striegl
February – Claudia Cox, Glen Knudsen, Irene Olney, Anonymous (1)
January – Dave DeFries, Jr., James Gaba, Sr., Mark Hoffmann, Anonymous (1)

Wellness Matters

Julie Rowin, MD
Maria Zepeda, NBC-HwC

Now more than ever we need to take care of ourselves. The payoff is huge; we're more prepared mentally and physically to handle stress and illness.



In a May 2020 webinar, Julie Rowin, MD (left), and Maria D. Zepeda, NBC-HwC (right), discussed why self-care during the pandemic is so important for those who have myasthenia. Here are excerpts, edited for space.

How is your immune health part of wellness?

Rowin: Wellness strategies affect all aspects of your health, including your immune health. During the pandemic, things that we know to be disease-causing are becoming the norm, and therefore are posing an even bigger threat to our health: prolonged stress, social isolation, lack of physical activity, and poor dietary habits.

Does the pandemic pose a bigger threat to those who have myasthenia?

Rowin: Yes, but I think there are some misconceptions. Having an autoimmune disease doesn't put you at higher risk for COVID by itself as far as we know. However, issues arise if your MG

is not well-managed and you have respiratory weakness or swallowing problems. In this case you could have trouble fighting off an infection or pneumonia. So stay on your medications, and keep your disease under control as much as possible.

Immune-suppressants may put you at higher risk for a serious or more prolonged infection. If you're on prednisone (at higher doses), azathioprine, CellCept, or rituximab, for instance, you may have trouble getting over a viral illness. We don't have clear data at this time. Often people who have MG have other illnesses that complicate things, too. Some of the MG medication side effects worsen weight gain, type 2 diabetes, and hypertension. These can add to your degree of risk, but I want to stress that there are steps you can take to ease or even reverse these side effects.

Loneliness

Rowin: Some social distancing is increasing loneliness. Loneliness

may be an even stronger risk factor for heart disease than obesity. I'm trying to get creative about staying in close contact with those who are uplifting, with those who support me in my decisions.

Zepeda: The key element is to reach out to others.

Effects of pandemic stress

Rowin: Several years ago in JAMA (Journal of American Medical Association), there was an article that linked autoimmune disease to prolonged stress. I believe stress exacerbates autoimmune disease. It's a difficult time for many people, with the prolonged stress causing elevated cortisol levels.

Zepeda: People think stress will go away. But there's always stress. Depending on your lifestyle and personal preferences, you can minimize it. Use meditation, journal writing, or walking. Even for people who have myasthenia, it may be possible to exercise at some level.

Rowin: I often get resistance when I talk about self-care with patients. "I'm not worth it. I don't have time." It can just start with 5-10 min a day. It's not time wasted.

Zepeda: I would add this: It's important to accept that we are stressed. Just accepting it is a way of destressing.

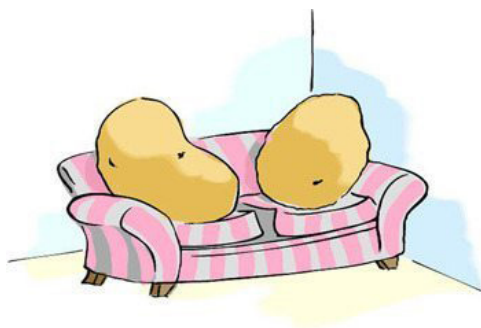
Overeating

Rowin: There's a huge connection between what we eat and our immune system. Our gut cultivates bacteria depending on what we're eating. The more junk food or sugar you eat, the more bad bacteria you get. The result is that your gut bacteria tells your brain: "Send down more junk food!" It's an addicting cycle.

Most Americans have a big

nutrient gap, not getting enough vegetables, fiber, and omega 3s, and have low Vitamin D levels. These are necessary for normal immune function. So eat the rainbow, all the colors of the vegetables, get good omega 3s, and get vitamin D (more sun exposure, or take a supplement.) Food is medicine. And #2, food is mood. There is a huge association between what we eat and our mood.

Zepeda: Water consumption is important, too. Sometimes we mistake being hungry for being thirsty. Give your brain enough time to understand that it's not hungry anymore. Once you start eating healthier foods, your body will respond.



Not being active

Zepeda: Not being able to go places doesn't mean you can't do anything. With MG, I thought

I couldn't be active because it would wear me out easily. Honestly, I used it as an excuse. I started doing as little as possible. Now, I understand movement is important; it has healing properties in our bodies.

It's confusing that MG patients need to boost their immune systems when they are on immune-suppressants. It sounds counter-intuitive.

Rowin: I think we throw around these terms: strong immune system, weak immune system, boost the immune system...and it's not really how it works. What we really want is a smarter and more balanced immune system. We want to be able to turn on the inflammatory response when we need it to fight a virus. But we don't want it on all the time, causing inflammation and attacking our neuromuscular junctions. Your immune system needs to have the right nutrients – the right food and activity – to perform optimally, with the proper balance.

— “ —

“Junk food creates a lot of inflammation in your body long term. Inflammation is your immune system trying to rid your body of those chemicals. When it's chronic, symptoms of illness develop. That's why you want to avoid eating those foods.”

-Maria Zepeda

COVID-19 Vaccines, continued from front cover:

- If a person is taking immunosuppressant medication (such as prednisone, azathioprine, mycophenolate mofetil, or others), this may reduce the effectiveness of the vaccination. However, the person still should get the vaccine.
- Persons receiving monoclonal antibody therapy (such as rituximab or Soliris®) for myasthenia should discuss with their doctors how to time the COVID-19 vaccine so the vaccine is most effective. For rituximab, it's suggested individuals get the first vaccine dose 6 weeks before rituximab treatment, and the second vaccine dose 4 weeks before another treatment.
- Vaccinated individuals should continue to follow masking, handwashing and social distancing recommendations to further reduce risk, especially if they are on immunosuppressant medications that may affect their response to the vaccine.



MG United is a new digital platform for the MG community, dedicated to providing clear, credible information about myasthenia gravis, plus advice on the many ways MG affects you, your family and your life.

CHECK OUT ALL WE'RE DOING AT [MG-UNITED.COM](https://mg-united.com)

MG United

Helpful. Hopeful. Real.



Conquer MG Research Funding in 2020

In 2019, Conquer MG joined the Myasthenia Gravis Rare Disease Network (MGNet) – a consortium of academia, patient advocacy, and pharma organizations – to spend its research dollars more effectively. This network is supported by a \$7.8 million award from the National Institutes of Health (NIH). Led by Henry Kaminski, MD, George Washington University, and other MG experts at Duke University and Yale University, the network is supporting several lines of research to better understand biomarkers and subtypes of MG, improve clinical measurement tools, and support new researchers in the field. The Chair of Conquer MG's Medical Advisory Board, Betty Soliven, MD, University of Chicago, serves on the MGNet review team.



1 Carolina Barnett-Tapia,
MD, PhD - MGNet 2020
Pilot Award Recipient

The MGNet has awarded the 2020 MGNet Pilot Award to Carolina Barnett-Tapia, MD, PhD, Assistant Professor, Department of Medicine (Neurology) and Institute of Health Policy, Management and Evaluation, University of Toronto. Dr. Barnett-Tapia specializes in patient-centered outcomes in

neuromuscular disorders, researching patients' perspectives on their symptoms and treatments.

Dr. Barnett-Tapia's project, "Patient Preferences Regarding Symptoms and Side Effects from Treatments in Myasthenia Gravis: A Discrete Choice Experiment," aims to explore the perspectives of myasthenia gravis patients regarding symptoms and side effects from treatment, focusing on the differences between physician and patient preferences. The project also will explore and demonstrate how using patient-centered preferences affects clinical trial design and drug development.

Conquer MG is funding the MGNet Pilot Award equally with the National Institute for Health (NIH) and the Myasthenia Gravis Foundation of America (MGFA). Dr. Barnett-Tapia will receive up to \$75,000 support for her work.

MyRealWorld MG

On November 12, 2020, Conquer MG hosted a webinar addressing an MG research study sponsored by the biotechnology company argenx. Kathy Perez, Head, Global Patient Advocacy and Policy for argenx, shared information about *MyRealWorld MG*, and MG patient Lisa Guererro provided a user's perspective.

MyRealWorld MG is an international two-year study that looks at the impact of myasthenia gravis on patients' lives. The study offers a way for individuals to share their myasthenia gravis journey to help researchers understand the impact and burden of MG on patients and their families. Patients provide their data via smartphone through the use of the MyRealWorld mobile app.



The study sponsor, argenx, is working with patient organizations from nine countries (US, Japan, Germany, UK, France, Italy, Spain, Canada, Belgium). To learn more about the study, visit <https://myrealworld.com/uk/en/myasthenia-gravis/>

Please note: Conquer MG is pleased to provide information about current MG research to the MG community. Conquer MG does not endorse this or any other study.



Research is creating
new knowledge.

-Astronaut
Neil Armstrong

Conquer MG Presents: 2021 Webinar Series

Just because we can't meet in person doesn't mean Conquer MG stops delivering relevant, timely education! Six webinars are scheduled for the year - practical topics, and outstanding content - so mark your calendars NOW! Register for any of our scheduled webinars at www.myastheniagravis.org

Eating to Combat Prednisone Weight Gain **Thursday, February 18, 2pm Central**

One thing leads to another: Prednisone can trigger increased appetite that causes weight gain that leads to less activity. Danka Lekovic will explain nutritional strategies to stop the train and improve your health.

- Speaker: Danka Lekovic, Personal Trainer and Nutrition Coach

Navigating the Disability Benefits Maze **Thursday, March 18, 2pm Central**

You've received a diagnosis of MG. Now, questions about work and disability benefits may be looming. Mark DeBofsky will discuss workplace accommodations and the process of applying for disability benefits.

- Speaker: Mark DeBofsky, Attorney
- Presenting Sponsor: Catalyst Pharmaceuticals

Nutrition topic #2 **Thursday, May 20, 2pm Central**

Topic will be determined with input from MG community

- Speaker: Danka Lekovic, Personal Trainer and Nutrition Coach

Tell Me about Autoimmunity **Thursday, July 15, 2pm Central**

- Speaker: Ryan Jacobson, MD, Rush University Medical Center
- Presenting Sponsor: argenx

Nutrition topic #3 **Thursday, September 16, 2pm Central**

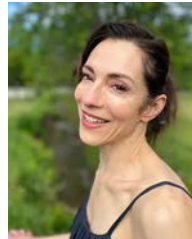
Topic will be determined with input from MG community

- Speaker: Danka Lekovic, Personal Trainer and Nutrition Coach

MG Subtypes **Thursday, November 18, 2pm Central**

- Speaker: David Randall, DO, Advocate Lutheran General

February 18 Presenter



Danka Lekovic is a NASM Certified Personal Trainer and exercise and nutrition enthusiast who enjoys motivating and supporting individuals on their path toward better health. Her passion is learning about the effects of food on our health and the environment and putting what she learns into everyday practice. She has managed a women's health medical office and is raising four children, three of whom have special needs. It excites Danka to help individuals, including those with neurological and neuromuscular disorders, navigate all stages and aspects of wellness.

March 18 Presenter



Mr. DeBofsky is a partner with DeBofsky Sherman Casciari Reynolds P.C., as well as an adjunct professor of law at University of Illinois-Chicago John Marshall Law School. In addition to his legal practice, which is focused on representing disabled individuals seeking disability insurance and other benefits, he is a regular columnist for both Law360 and the Chicago Daily Law Bulletin, an annual contributor to the ERISA Survey of Federal Circuits published by the ABA, and served for many years as a senior editor of Employee Benefits Law published by Bloomberg.



Conquer MG 2020 Webinar Recap

Couldn't attend these webinars last year? Highlights and video are still available! Visit Conquer MG's YouTube channel (<https://www.youtube.com/c/MyastheniagravisOrgIllinois/videos>) for these presentations offered in 2020. Links to the highlights are at <https://www.myastheniagravis.org/popular-mg-topics/>



Wellness Now: Own Your Health in a COVID-19 World May 2020

Julie Rowin, MD (left), and Maria D. Zepeda, National Board Certified Health and Wellness Coach (right), discuss ways to combat pandemic stressors of loneliness, overeating, too much time indoors, and cleaning product exposure. (See page 4 for excerpts). *Presenting sponsor: argenx*



MG Wellness: Myasthenia Gravis and Exercise June 2020

"If your MG has stabilized, exercise can be part of your recovery," notes Julie Rowin, MD (left). She and Julie Hossack, Certified Fitness Instructor (right), explain how to gradually resume exercise if you're deconditioned from illness. (See page 10 for excerpts) *Presenting sponsor: argenx*



Meditative Breathing July 2020

Jill Crockett, instructor and owner of Molcintah Yoga Studio (left), and Julie Rowin, MD, discuss health benefits that occur when you set aside time to focus on the rhythm of breathing. Includes a guided demonstration to use this always available, always affordable tool of breath. *Presenting sponsor: argenx; Participating sponsor: Soleo Health*



Myasthenia Gravis and Telemedicine, December 2020

Rabia Malik, MD (left), Rush University Medical Center, explains how to make the most of your telemedicine visit if you have MG – how to position your phone/camera, having a support person if you need one, and what parts of the neurological exam work well. *Presenting sponsor: argenx; Participating sponsors: Immunovant, Soleo Health*

Thanks to our 2020 Webinar Sponsors





Movement and MG

**Julie Rowin, MD and
Julie Hossack, Personal Trainer**

*People who have MG want to get moving again.
But there is fear that exercise will make the weakness
and fatigue worse.*



In a June 2020 webinar, Julie Rowin, MD, and Julie Hossack discussed the power and possibility of exercise for those who have myasthenia gravis. Dr. Rowin is board certified in neurology, neuromuscular medicine, integrative medicine, and acupuncture. Ms. Hossack is an A.C.E Certified Personal Trainer, ISSN Certified Nutrition Coach and Peak Pilates certified Pilates Instructor.

For links to their complete conversation and the exercise demonstration, visit <https://www.myastheniagravis.org/mg-wellness-exercise/>

Please keep in mind this is not intended to be a substitute for professional medical advice. If you're having shortness of breath or swallowing difficulties with any exertion, now is not the time to start an exercise routine. In this case, contact your neurologist.

Rowin: It's exciting for the MG community that we're starting to talk about exercise. For a long time the message was to conserve energy, to avoid exacerbating your weakness or fatigue.

We've come to recognize that exercise can benefit those who have myasthenia. It's good for the immune system, it combats fatigue. Exercise helps gut health, mental clarity, sleep, and mood. It can help to counteract side effects if you're on prednisone; for instance, exercise can help with weight control, as well as blood pressure and blood sugar management.

However, it's been my experience that many people who have myasthenia become stable with treatment. Although there are normal fluctuations with MG and every day is different, if your MG is stable, then exercise can be part of your recovery process.

Biggest Concern

Rowin: People who have MG

— “ —
I learned a lot and I have really been afraid to exercise since my diagnosis years ago. As a result I have lost muscle mass, gained weight and lost strength. I'm going to work towards changing all of that now.

– Wanda Jewett

want to get moving again. But there is fear that exercise will make the weakness and fatigue worse.

Hossack: You may not think of it this way, but movement that you do in your everyday life is exercise. Every time you sit up to get out of bed you are working your abs. Every time you stand up to get out of a chair you're using your quads. If you put some planning around those movements, you can slowly progress.

Rowin: You're saying exercise doesn't have to be something that leaves you exhausted. You can think of it as building on what you do every day.

Hossack: Yes. I'll add that it should be structured with a purpose. To get started, you can use this 15-minute routine (page 11). It's intended for someone new to exercise, or coming back to exercise after a break or an illness. (See demonstration at <https://www.youtube.com/watch?v=fl13GH812j0>)

continued, p.13

Start Your Exercise Routine

with Julie Hossack,
Certified Personal Trainer

Purpose Demonstrate basic exercises to improve flexibility, balance and strength.

Audience Video is intended for those of you that may be new to exercise or be out of condition from illness.

Length This is a 15-20 min program that can be completed every day, in segments or in full.

Equipment You won't need any special equipment, just somewhere to stand, sit and lay down.

► How to Proceed

1. Be honest. Start with the body. Be forgiving of your body if you need to. But also don't let yourself off the hook. If you can do more, do more!
2. Be accountable. In your job you are expected to show up and do your work. Yes, you get periodic holidays and flexibility in today's world. But in the end you are expected to complete a task. Create a schedule! Include the number of times you will exercise each week and pencil in an appointment.
3. Set a goal. It's the only way to make progress. See where you find yourself with our workout today. Write down what you were able to do and number of reps. Set a goal to reach more reps by the end of this week. By the end of this month.
4. Find your reason. Why is it important for YOU to exercise? Is it to be able to do fun activities with your kids or grandkids? To reduce pain in your daily life? To have stamina to be able to garden? Now find a picture of that reason and use it as your phone screen saver or print it out and put it on your bathroom mirror.

► Beginner Exercise Routine Frequency

Month 1

- Week 1: 3 days 10 repetitions each exercise
- Week 2: 4 days 10 reps each exercise, balance 45 sec
- Week 3: 5 days 10 reps each exercise, balance 1 min
- Week 4: 6 days 10 reps each exercise, balance 1 min but add skiing arm movement

Month 2

- Increase reps to 12-15; balance 1 min move arms by rotation, circling

Month 3

- Increase reps to 15-20, balance 1 min on uneven surface

► Beginner Exercise Routine Sequence

Warmup (repeat 1-3 times)

- March in place
- Arms up
- Hinge
- Repeat 2 times

Standing

- 10 reps Pushups to the wall
- Balance one leg 30 sec each side
- 10 reps Hinge, Row, Stand. Drive elbows to the ceiling and squeeze the space between your shoulder blades
- 10 reps Wall slides. Stand with your feet 6-8 inches from the wall. Rest your back on the wall. Bring your arms to 90 degrees. Try to get your forearms to the wall then slide your arms overhead.

Seated

- Seated in chair, nod head yes 2 times and no 2 times)
- Bring your right ear to your right shoulder. Repeat on the left
- 10 each direction Hold arms out to sides, do arm circles then stretch arms
- 10 reps Chair sit to stand
- 10 reps Seated leg extensions (kick each foot up 10x)
- Figure 4 stretch (cross your legs and lean forward)

Laying down

- 10 reps each leg Single leg marching while laying on back
- 10 reps Bridges (Lay on your back. Bend your knees. Lift hips.)
- Knee hugs Roll to side to finish

8th Annual Viking Run/Walk Goes Virtual

In June, many of you walked and ran and biked on your own schedule, in your own neighborhood. And you donated and fundraised to the tune of nearly \$20,000. **Thank you!**



Special Thanks to Our 2020 Sponsors

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Event Sponsors Richards Graphic Communications, Inc. Optum Specialty Pharmacy; CVS Specialty Infusion

continued from page 10

Some parts of the exercise video might be too challenging, while some might not be challenging enough. Try to stick with it from being to end. Track how many repetitions you can do.

Rowin: I noticed you gave a lot of modifications. That's really helpful so a person can take it up or down a notch.

How do I know what's enough? What's too much?

Hossack: Make sure you start with what feels pretty easy today. Follow along with the video, and write down how many of each exercise you can do. Write it on a calendar or date it in a notebook. Tomorrow try to do same thing. Pay attention to how your body

felt, and write that down, also. Once you get to doing about 10 repetitions, it's time to move on.

How do I know whether I'm experiencing muscle soreness from the workout, or fatigue from MG?

Hossack: That's a little tougher to answer. It is very normal to have muscle soreness. It almost feels like having a bruise in your muscle up to one or two days after doing an exercise. That's normal. Keep track of that feeling to see whether it subsides over time as you get more conditioned; this will help you know whether you've set your goals appropriately.

Rowin: If you're weak the day after exercise, and it's not muscle

soreness but power loss, then you need to take it down a notch. I'm asked, "How do I know before I get to that point?" Just start by doing what you know is ok. There is plenty of time to add repetitions or make the exercise more difficult.

Will exercise increase my energy levels?

Rowin: Fatigue is a major issue with myasthenia, and this is one reason why exercise is so important. It often happens with MG that you get treated and improve, and your strength is better. But the fatigue lingers and just doesn't improve. Your doctor may look for other causes. One of the biggest culprits is being sedentary. Deconditioning leads to fatigue. Moving will increase your energy levels.

(Sponsored Content)



Clinical Support for Patients with Myasthenia Gravis (MG)

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- Skilled Pharmacists and Infusion Nurses
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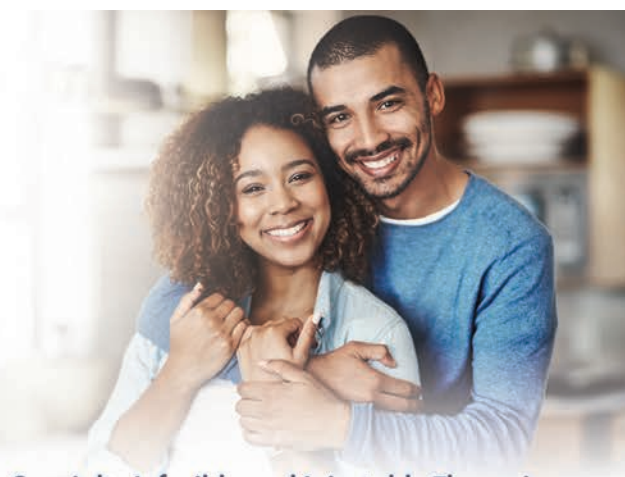
Meet Our MG Patient Advocate



Natalie McGill, BSW is our patient advocate. As our MG patient advocate, Natalie is here to help answer any questions you may have, share her experience, and provide you with the support you need to make the best decision for you, your treatment plan and your lifestyle.

To speak with Natalie, please call or email:

Phone: 208.866.9695 | Email: nmcgill@soleohealth.com



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www.soleohealth.com



Nancy Van Laten, 1949 - 2020

By Joyce Holste

I met Nancy Van Laten at my first South Suburban Myasthenia Gravis Support Group meeting in Blue Island, Illinois, at St. Francis Hospital in October 1993. I had just been diagnosed with MG. I was so sick and was scheduled to go to University of Chicago for a week of plasmapheresis treatments before getting a thymectomy. Nancy took me under her wing, giving me advice about plasmapheresis and surgery. I improved some, and returned to the meetings. Nancy encouraged me to join her on the board of the Myasthenia Gravis Foundation of Illinois (now called Conquer MG). She served on the MGFI Board in several roles from 1994 to 2006, including Chair and Vice Chair. Despite health issues, she worked tirelessly on the MG Board. Well versed on MG, she always was willing to help a patient or pitch in for the Executive Director. She donated her time and money passionately to help find a cure.

Nancy was very close to her twin sister, Nora, who passed away in 2011. Nancy was diagnosed with MG in her teen years and Nora was, too, a year or so later. Their mother was diagnosed with MG also a couple of years before she died. They always wondered what about their genes made them susceptible to MG.

Over the years we became good friends. We attended many theater performances together, dined out and enjoyed visiting. I admired a quilted wall hanging in her condo that she won from an MGFI raffle. The design symbolized MG, and I know she cherished it very much.

Nancy, I feel you are enjoying life in the Kingdom of Heaven with your family and friends now. I truly miss you each and every day.

Supporting Those Who Have MG

You can get valuable information and support in the hands of myasthenia gravis patients by supporting the work of Conquer MG.

Donate online at www.myastheniagravis.org

Or Send your check to:

Conquer MG
275 N. York Street, Suite 201
Elmhurst, IL 60126

Your Legacy

You can make a lasting difference in helping those who have myasthenia gravis by including Conquer MG in your will. Whether you bequeath a specific dollar amount or a percentage of your estate, your legacy will be dedicated to helping future generations fight MG. A qualified financial planner can guide your decision and help you consider tax consequences.

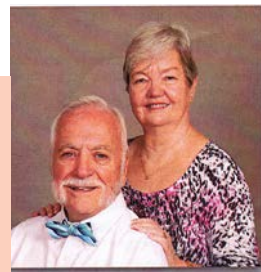
Matching Gifts

Many companies support employee philanthropy by offering matching gift programs. This way you can maximize the value of your gift at no additional cost. If your employer needs information about Conquer MG's 501(c)(3) tax status, contact info@myastheniagravis.org.

Donor Advised Funds

Donor Advised funds (DAFs) allow you to combine the most favorable tax benefits with the flexibility to support your preferred causes. You can support meaningful MG patient assistance and research by recommending a grant to conquer MG directly from your DAF. Examples of DAFs are the Fidelity Investments Charitable Gift Fund, Schwab Fund for Charitable Giving, and Vanguard Charitable Endowment Program.

Fred and Sharon Grabenhofer passed away in September, due to COVID-19. Fred supported and sometimes filled in to lead the Chicago South Suburban MG Support Group. They were always ready with a story or a laugh, and we'll miss them.



In Appreciation

WE ARE GRATEFUL to everyone who supported Conquer MG's mission this year. To provide you with additional content in this issue, we are only listing those who donated in memory or honor of a loved one. Your continuing financial support keeps our organization going.

In honor of Anne Breuker
Janice Arrott

In honor of Peggy
Cashman
Michael & Sally Pope

In honor of her sister
Ghena Al Hajeri

In honor of Katie Jasmon
Sue & Pat Landgrebe

In honor of Mary Ann
Kania
Charlene Nass

In honor of Don Kurtzman
Betty Ann Fineman

In honor of Sione LaPointe
Howard and Evelyn
LaPointe

In honor of Scott James
LeGrave
Dotty Kinnard

In honor of Joanna
Hamilton Sherrod
Marcella Holt

In honor of Jan Slomiany
Elizabeth Aasen

In honor of Joan
Wincentzen
Nancy & Jim Bulger
Bill Hargreaves

In honor of Iris Yipp
Katherine and Bradley
Stephens

In honor of Victor Yipp

Katherine and Bradley
Stephens

In memory of Nicholas
Albers
Carolyn & Edward Albers

In memory of Elizabeth
Alexander
Joyce Holste

In memory of Paul Berman
Pat Berman

In memory of Marie J. Cifra
Peggy O'Brien

In memory of Debra
Clyden
David Clyden

In memory of Jane Ferrill
Julie McGarry

In memory of Charles
Garcia
Chad Gordon

In memory of Elizabeth
Garrett
Sean Newell

In memory of Denise
Gordon
Mary Kraegel
Scott and Julie Vowinkel
Paul and Nancy Pitaro
Pat Warter, LJ and
Maloney
Richard and Michelle
Raclawski
Mary Kraegel

In memory of Fred &
Sharon Grabenhofer

Joyce Holste

In memory of Dr. Ray
Kubisch
Gerald and Janice Foltz

In memory of Louis and
Louise Mroz
Jack and Judy Trevillian

In memory of Alexander
Niemczura
Darlene Niemczura

In memory of Dwane
Noble
Deborah Noble

In memory of David
O'Bryant
William Moore
Teresa Simons

In memory of Ethyl Rogers
Maureen McGrath

In memory of Krishan
Gopal Saini
Rita Saini

In memory of Lorraine
Schohn
Joel Schohn

In memory of Duane and
Dorothy Seggerman
Donald Seggerman

In memory of Darrin Layne
Tucker
Eddie and Yolie Chapa

In memory of Nancy Van
Laten
Arlene Sangmeister
Joyce Holste

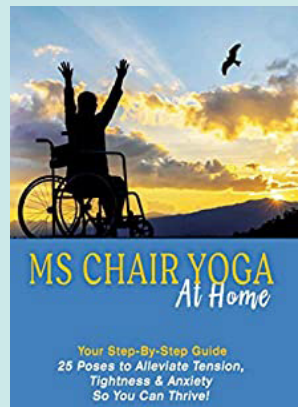
In memory of Judge
Clifford Weckstein
Joseph Weisman

In memory of Susan
Weston Weinstock
Heather Binn

In memory of David
Wiseman
Pennie J. Robinson

Chair Yoga




Paula Strupeck Gardner has taught yoga for over 20 years to women who have multiple sclerosis. She encourages people to gently push the limits of their bodies, and regain confidence and mobility in the process. Her book, MS Chair Yoga At Home - Your Step-By-Step Guide, is available on [amazon.com](https://www.amazon.com). For anyone who has limited mobility or strength.



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Trainer Julie Hossack
demonstrates exercise



Upcoming Events

- FEBRUARY 18**
Eating to Combat Prednisone Weight Gain
- MARCH 18**
Navigating the Disability Benefits Maze
- 3RD WEDNESDAY OF THE MONTH**
Anywhere Virtual Support Group Meeting
- JUNE 30 - SAVE THE DATE!**
Conquer MG 5K Fun Run/Walk