The gut bacteria in people with generalized myasthenia gravis is often off balance. Curcumin, found in the golden-colored spice turmeric, has gut-related benefits. New research explores whether it could make a difference in myasthenia gravis. It’ll take more research to prove it helps humans, but when mice with myasthenia gravis were given this spice extract, their gut bacteria took a turn for the better and some of the cell processes that promote myasthenia gravis stopped. The finding could lead to new medicines containing the spice extract. In the meantime, it probably wouldn’t hurt to add a daily dash of it to your diet. Curry, anyone?

SOURCE: Cell

The next treatment for myasthenia gravis (MG) may be found in your morning joe. In people with MG, a brain chemical called acetylcholine—a substance that helps with muscle movements—doesn’t work as it should. Researchers already knew that caffeine could help to some degree with the acetylcholine problems seen in myasthenia gravis. Now scientists have boiled caffeine down to a few key byproducts that may be even more effective. These caffeine derivatives could one day be ingredients in MG drugs.

SOURCE: ACS Chemical Neuroscience

The gut bacteria in people with generalized myasthenia gravis is often off balance. Curcumin, found in the golden-colored spice turmeric, has gut-related benefits. New research explores whether it could make a difference in myasthenia gravis. It’ll take more research to prove it helps humans, but when mice with myasthenia gravis were given this spice extract, their gut bacteria took a turn for the better and some of the cell processes that promote myasthenia gravis stopped. The finding could lead to new medicines containing the spice extract. In the meantime, it probably wouldn’t hurt to add a daily dash of it to your diet. Curry, anyone?

SOURCE: Cell

IMMUNE CELLS RUN AMOK

As their name suggests, natural killer (NK) cells are born to kill. These immune cells obliterate infected or diseased cells like cancer cells. But they seem to go rogue in a number of immunological diseases, such as multiple sclerosis, Guillain-Barré syndrome, and generalized myasthenia gravis. New research teases out the unique havoc they wreak in each of these diseases. In myasthenia gravis, the study finds, rather than kill off disease-causing cells, NK cells activate the cells that promote myasthenia gravis flares. When scientists destroyed NK cells in animals with myasthenia gravis, it slowed the progress of the disease. This discovery could lead to new drugs that target NK cells directly.

SOURCE: Biomedicine and Pharmacotherapy
STATS & FACTS

By Sonya Collins
Reviewed by Brunilda Nazario, MD, WebMD Chief Physician Editor, Medical Affairs

>60
Ages when it’s most common for men to get myasthenia gravis (MG).

>70,000
Number of people in the U.S. who are diagnosed with myasthenia gravis.

1:1
Number of women compared to men who get MG after age 50.

up to 200
Number of people per million who have MG worldwide.

1 in 3
Number of people with MG who have depression or anxiety.

13%
Average amount of working hours employed people with MG miss. That’s a little over 1 in every 8 work days.

>70,000
Maximum number of months after diagnosis that it takes most people to get their symptoms down to a level that’s acceptable to them. Many people get symptom control sooner. For some it takes longer.

STATS & FACTS SOURCES: Myasthenia Gravis Foundation of America, Rare Disease Advisor, Brain and Behavior, Frontiers in Neurology, Muscle & Nerve
With generalized myasthenia gravis (gMG), your immune system attacks the cells that carry out communication between your nerves and your muscles. Your muscles feel weak, and it's difficult to move your eyes, mouth, arms, and legs.

Besides medical treatment, "There are several things you can do that may help reduce symptoms and flare-ups," says John Morren, MD, a neurologist in the Neuromuscular Center at Cleveland Clinic in Ohio.

**CONSERVE ENERGY**

With gMG, the more you move, the weaker your muscles get. Budget your energy. Plan to take frequent breaks throughout the day. Divide tasks into smaller activities that you can complete separately, and rest in between. Only do today what must be done today—and ask yourself if it really needs to be done.

Work with your health care team to develop an effective yet manageable exercise program. You might get a referral to a physical or occupational therapist or a trainer with expertise in myasthenia gravis. "A tailored exercise program with mostly mild to moderate aerobic activity, such as walking or swimming, can help maintain muscle strength and overall fitness," Morren says.

Aim for 7 to 8 hours of sleep a night. If you can't get to sleep or stay asleep, tell your doctor.

**Beware of New Medicines**

Some medicines and supplements can make gMG symptoms worse. Make sure that any health care provider who writes you a prescription knows that you have gMG so they prescribe safe medications.

"Before any new over-the-counter medication or supplement is started, discuss it first with your neurologist to get their clearance," Morren says.

Check the Myasthenia Gravis Foundation of America website for an up-to-date list, called "Cautionary Drugs," of medicines you should avoid or use with caution.

**Help for Your Eyes**

Some people with myasthenia gravis have double vision. An eye specialist can prescribe special corrective glasses, Morren says. "But even patching one eye can be a practical, simple and immediate way to alleviate double vision."

For droopy eyelids, Morren recommends tiny devices called "eye crutches," or ptosis crutches, that attach to your glasses and keep your eyelids lifted.

**You've Got This**

You may be overwhelmed by your symptoms now, but you can handle this.

"Integrating MG drug treatment with personalized lifestyle changes, one can navigate this condition with great success," Morren says.

"Leveraging tailored exercise, adequate rest, quality sleep, balanced nutrition, and social and psychological support, patients are able to not just live but thrive with MG."
Jaydeep M. Bhatt, MD, clinical professor in the department of neurology at NYU Grossman School of Medicine, answers common questions you may have about your myasthenia gravis diagnosis.

Q. What is myasthenia gravis?
Myasthenia gravis is a chronic autoimmune neuromuscular disorder that causes weakness in the eye and body muscles, which are responsible for clear vision, voluntary movements, and actions (those you make happen intentionally). Myasthenia gravis is not inherited, and it is not contagious. Autoimmune conditions happen when the body’s immune system mistakenly attacks healthy tissues. MG happens when communication between nerves and muscles is disrupted due to the presence of antibodies that block or destroy the receptors for the neurochemical acetylcholine.

Q. How will this disease affect my daily life?
Myasthenia gravis typically causes muscle weakness that worsens with activity and improves with rest. It commonly affects muscles that control eye movements, facial expressions, chewing, swallowing, and speaking. You can also have weakness in the arms, legs, and neck muscles. You should consult a neurologist if you have these symptoms. If you can’t get a quick appointment, set up a telehealth visit so you can discuss what’s going on and plan next steps.

Q. What are the most common symptoms?
Everyone with MG has their own unique combination of symptoms. The common ones are:

Eye problems: About half of all people with MG experience drooping eyelids or double vision. These symptoms occur because the muscles that control eye movement are weakened.
Your doctor can usually diagnose your disease based on symptoms, but may also:

+ **See how you respond to treatment.** If an anticholinesterase medicine improves your muscle weakness, it’s likely you have MG.

+ **Test your blood.** Your doctor can look for certain antibodies that can confirm an MG diagnosis.

+ **Perform a nerve conduction study.** Your doctor may give you a test called repetitive nerve stimulation to see how well your nerves are communicating with your muscles.

+ **Measure the electrical activity of your muscles.** An electromyogram (EMG) can detect abnormal electrical muscle activity to provide clues about an MG diagnosis.

**Speech and swallowing difficulties:** Some people with MG may have difficulty speaking clearly or swallowing food and liquids. This can lead to choking or aspiration pneumonia.

**Limb weakness:** Weakness in the arms and legs is also common in MG. This can make it difficult to perform daily activities such as lifting objects, climbing stairs, or getting up from a chair.

**Fatigue:** People with MG often feel tired or fatigued, especially after physical exertion.

**Q. What are my treatment options?**

MG does not have a cure, but there are several options to treat your symptoms. These treatments work on your immune system to decrease your autoimmune response and improve symptoms. These include oral medications, intravenous infusions, subcutaneous injections, hospital procedures, and chest surgeries for some people.

Not everyone with MG is eligible for every treatment option; your doctor will help guide you to the most appropriate option. It is important to tell your doctor about all of your symptoms during an office visit.

It’s key to also listen to your body and stop your activities and rest when you are tired. This will help to conserve energy until you can start to exert yourself without symptoms. There is no proven diet to clinically improve MG.

Due to the wide variety of treatment options, myasthenia gravis has a great prognosis for most patients who see treatment providers in the office ... or [patients who need to go to] the hospital if symptoms progress before an office visit can be arranged.
RYSTIGGO®
(rozanolixizumab-noli)
Injection For Subcutaneous Use
280 mg/2 mL vial

For adults with
GENERALIZED MYASTHENIA GRAVIS (gMG)

Discover what’s in reach with RYSTIGGO
The first FDA-approved treatment for both anti-AChR and anti-MuSK antibody-positive gMG

IMPORTANT SAFETY INFORMATION AND INDICATION

WHAT IS RYSTIGGO?

RYSTIGGO is a prescription medicine used to treat adults with a disease called generalized myasthenia gravis (gMG) who are acetylcholine receptor (anti-AChR) antibody positive or muscle-specific tyrosine kinase (anti-MuSK) antibody positive.

WHAT IS THE MOST IMPORTANT INFORMATION I SHOULD KNOW ABOUT RYSTIGGO (rozanolixizumab-noli)?

RYSTIGGO may cause serious side effects, including:

• Infection: RYSTIGGO may increase the risk of infection. In clinical studies, the most common infections were upper respiratory tract infections, COVID-19, urinary tract infections, and herpes simplex infections. Your healthcare provider should check you for infections before starting and during treatment with RYSTIGGO. Tell your healthcare provider about all the medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal supplements.

• Aseptic Meningitis: RYSTIGGO could cause aseptic meningitis. Tell your healthcare provider right away if you develop any signs or symptoms of meningitis during treatment with RYSTIGGO such as severe headache, neck stiffness, drowsiness, fever, sensitivity to light, painful eye movements, nausea, and vomiting.

• Hypersensitivity Reactions: RYSTIGGO can cause swelling and rash. Your healthcare provider should monitor you during and after treatment and discontinue RYSTIGGO if needed. Tell your healthcare provider immediately about any undesirable reactions you experience after administration.

Before taking RYSTIGGO, tell your healthcare provider about all of your medical conditions, including if you:

• Have a history of infection or think you have an active infection
• Have received or are scheduled to receive a vaccine (immunization). The use of vaccines during RYSTIGGO treatment has not been studied, and the safety with live or live-attenuated vaccines is unknown. Administration of live or live-attenuated vaccines is not recommended during treatment with RYSTIGGO. Completion of age-appropriate vaccines according to vaccination guidelines before starting a new treatment cycle with RYSTIGGO is recommended.

• Are pregnant or plan to become pregnant or are breastfeeding or plan to breastfeed.

Tell your healthcare provider about all the medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal supplements.

WHAT ARE THE POSSIBLE SIDE EFFECTS OF RYSTIGGO?

RYSTIGGO may cause serious side effects, including:

• See “What is the most important information I should know about RYSTIGGO?”

Please see the Consumer Brief Summary on the following pages and full Prescribing Information at www.RYSTIGGO.com, and talk to your healthcare provider about your condition or treatment. For more information, go to www.RYSTIGGO.com or call 1-844-599-CARE [2273].

AChR=acetylcholine receptor; MuSK=muscle-specific tyrosine kinase.

The most common side effects of RYSTIGGO include:

• headache
• infections
• diarrhea
• fever
• hypersensitivity reactions
• nausea

These are not all the possible side effects of RYSTIGGO. For more information, ask your healthcare provider or pharmacist. Tell your healthcare provider about any side effect that bothers you or that does not go away. Call your healthcare provider for medical advice about side effects.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch or call 1-800-FDA-1088. You may also report side effects to UCB, Inc. by calling 1-844-599-CARE [2273].

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Consumer Brief Summary

RYSTIGGO® (rozanolixizumab-noli)
Injection For Subcutaneous Use
280 mg/2 mL vial

Consumer Brief Summary

RYSTIGGO (rozanolixizumab-noli) injection, for subcutaneous use
RX Only
Brief Summary of Full Prescribing Information (See Package Insert for Full Prescribing Information)

This information does not take the place of talking to your healthcare provider about your medical condition or your treatment.

What is the most important information I should know about RYSTIGGO?

RYSTIGGO may cause serious side effects, including:

- **Infections.** RYSTIGGO may increase the risk of infection. In clinical studies, the most common infections (at least 5% frequency) were upper respiratory tract infections, COVID-19, urinary tract infections, and herpes simplex.
- Your healthcare provider should check you for infections before starting and during treatment with RYSTIGGO.
-Tell your healthcare provider if you have any history of infections.
-Tell your healthcare provider if you have any signs or symptoms of infection during treatment with RYSTIGGO, including fever, chills, frequent and/or painful urination, cough, runny nose, wheezing, shortness of breath, fatigue, sore throat, excess phlegm, nasal discharge, back pain, and/or chest pain.
- **Aseptic meningitis.** RYSTIGGO could cause aseptic meningitis.
- Tell your healthcare provider if you have any signs or symptoms of meningitis during treatment with RYSTIGGO including severe headache, neck stiffness, drowsiness, fever, sensitivity to light, painful eye movement, nausea, and vomiting.
- **Hypersensitivity reactions.** RYSTIGGO can cause hypersensitivity reactions (swelling and rash). Your healthcare provider should monitor you during treatment and after treatment.

Tell your healthcare provider about any side effect that bothers you or that does not go away. Call your healthcare provider for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

For more information, ask your healthcare provider or pharmacist. Tell your healthcare provider about any side effect that bothers you or that does not go away. Call your healthcare provider for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

How should I receive RYSTIGGO?

- **RYSTIGGO** is a subcutaneous infusion, administered by a healthcare professional using an infusion pump.
- Most people will receive RYSTIGGO at an infusion center or at their doctor's office.
- **RYSTIGGO** is available in 3 recommended doses, based on body weight. Preparation and infusion time may vary by patient dosage, infusion provider, and/or provider location.
- **RYSTIGGO** is administrated in the lower abdomen below the belly button. Do not receive RYSTIGGO in areas where the skin is tender, bruised, red, or hard.

You will be monitored while you receive RYSTIGGO, and for 15 minutes after your infusion is complete.

- **RYSTIGGO** is administrated once weekly in 6-week cycles.
- You will receive 6 doses of RYSTIGGO in total, spaced 1 week apart.
- Every 6-week cycle is followed by a break in your RYSTIGGO treatment.
- Most people may require repeated cycles of RYSTIGGO to manage their gMG symptoms. After you finish a treatment cycle it is important to:
  - Monitor your progress and track any symptoms.
  - Work with your healthcare provider to determine if or when another cycle is needed.

Ask your healthcare provider for more information about subcutaneous infusion and what to expect on infusion days.

What are the ingredients in RYSTIGGO?

**Active ingredients:** rozanolidixumab-noli
Each 2 mL single-dose vial contains 280 mg of rozanolidixumab-noli, histidine (2.10 mg), L-histidine hydrochloride monohydrate (9.74 mg), proline (57.56 mg), polysorbate 80 (0.60 mg), and water for injection, USP with a pH of 5.6.

For more information see the Patient Counseling Information section in the FDA-approved Full Prescribing Information at www.rystiggo.com or contact UCBCares at 1-844-599-CARE (2273).

Product manufactured by: UCB, Inc., Smyrna, GA 30080

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I was very athletic for most of my life. I played tennis and was in national tournaments. I also played baseball for 20 years and golfed. One day in July 2019, I was in a tennis tournament, and I noticed something was wrong.

A RARE DIAGNOSIS
While playing tennis, I noticed the ball coming over the net, but I just couldn’t react. My muscles wouldn’t cooperate. I shrugged it off and went on a work trip the next day. While traveling, I noticed an issue with my eye. My eyelid was pulling up. I called my doctor and he suggested I be seen right away. When the nurse saw my eye, she went to get the head doctor for the practice right away. He asked questions and ran tests to rule out Lyme disease, diabetes, and Bell’s palsy. I got an MRI and my doctor called me that same night. I was used to waiting a few days for these types of results. He told me all the things I did not have but said I’d have to wait for blood work. He suspected I had a rare condition called myasthenia gravis (MG). An appointment with a neurologist confirmed this.

LIFE WITH MG
As I was reeling from this new (and rare) diagnosis, I was scared. I didn’t know anyone with this. I’ve since learned that only about 80,000 people [as of 2021] have MG in the United States. For comparison, about 29 million people in the U.S. [as of 2021] have been diagnosed with diabetes.

Thankfully, I found some help and support from the Myasthenia Gravis Foundation of America. It was through that group that I found a neurologist who specialized in MG. That has made such a huge difference in my health.

MOVING FORWARD
A lot has changed in my life. I get tired and have to lie down. I had to resign from a job that I loved to focus on my health. I was getting brain fog and I just couldn’t do my job like I wanted to.
THOMAS’ TIPS

+ Be persistent. Because MG is rare, you may have to push for answers.

+ Be aware. Listen to your body. Rest when you need to.

+ Be flexible. Life may not look the same as before MG, but life can still be good.

Fortunately, I have been able to work as a writer and consultant from home. I’ve moved up the line in therapy from early treatment that wasn’t effective to an FDA-approved drug for MG. I read that only about 5% of rare diseases have an FDA-approved treatment, so I was lucky. Now, I’m getting infusions once a week for 4 weeks followed by a break for 4 weeks. So far, it’s going well. I have taken prednisone since my diagnosis in 2019 as well as medications for digestive issues. I’m happy to see more medications coming out for MG.

I also have made several lifestyle changes. I have to alter how I travel now—whether by car or plane. I’ve done my best to remove certain foods that are difficult to swallow due to my MG. I try to do an anti-inflammatory diet.

While I can’t play tennis or baseball anymore, I’m grateful that I can still play some golf. I might only be able to do a few holes, but it’s worth it to keep going.
As you live with and treat your generalized myasthenia gravis (gMG), there are small but significant ways you can improve your quality of life even as you navigate symptoms. Try these tips:

**REST, AND REST SOME MORE**
When you have gMG, it’s normal for your energy to come and go. It’s important to rest when you can so you store any extra energy you have for when you need it, says Alexis A. Lizarraga, MD, associate professor in the Department of Neurology at the University of Rochester School of Medicine & Dentistry in New York.

“The hallmark of gMG is fatigue that fluctuates during the day, sometimes minute to minute,” Lizarraga says. “Even with medication for muscle fatigue leading to weakness in gMG, people still report fatigue that interferes with their daily activities. Rest can help recharge the muscles.”

**BREAK UP BIG TASKS INTO SMALLER CHUNKS**
Instead of saving all your chores for the weekend, separate your tasks and do them in short spurts, or a little bit each day, with rests in between. And use your energy wisely as you go, says Charu P. Nagar, MBBS, a clinician at Northwestern University Feinberg School of Medicine in Chicago.

“Try to plan your day or routine to avoid unnecessarily repeating stuff that you’ve already done, like using a cart or a basket to carry cleaning supplies or groceries from one part of the house to another instead of repeatedly going back and forth from the car to your fridge,” Nagar says. Whenever possible, use a power tool or electrical device to do...
a task instead of manual muscle power.

**TREAT UNDERLYING CONDITIONS**

Do you also live with sleep apnea? Depression? Anxiety? Talk to your doctor and make sure these conditions are well-controlled so you’re not adding to your body’s toll.

**EXERCISE REGULARLY (AND WISELY)**

Exercise is important to you and your well-being, says Nagar, but with reduced energy and muscle weakness, it’s important to work out smartly.

“Take your prescribed medication before you exercise so your muscles are strongest,” Nagar says. Only exercise in cool weather or indoors with air conditioning, and when your muscles reach a point where they’re tired, stop.

“Don’t be embarrassed to conserve that energy,” Nagar says.

**BE STRESS SAVVY**

Stress is a well-known trigger for gMG symptoms, says Lizarraga, which is why it’s important to find ways to reduce your levels.

“Many patients living with gMG report worsening of symptoms in times of extreme stress, and stress can make us more susceptible to infections, which can also trigger gMG symptoms,” Lizarraga says.

Life will inevitably be stressful, but with regular stress-relief strategies, you can keep the effects at bay. Meditation, strategic naps, and gentle exercise such as yoga and tai chi, relaxing hobbies you enjoy, seeking support from family, friends, and others with gMG are all great ways to handle stress in a healthy way, Lizarraga says. And above all, give yourself grace.

“Be kind to yourself—you’re doing the best you can,” says Lizarraga.

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**SWALLOWING SAFETY**

Use these tips for easier eating.

+ Chop, mash, or puree your food before eating it.
+ Avoid dry foods.
+ Sip liquids often to aid swallowing.
+ Eat upright.
+ Plan meals for when you have the most energy.
Like almost all other autoimmune diseases, myasthenia gravis (MG) is a disease that “turns on” and “turns off” (remission). Treatment focuses on keeping the disease in its “off” position, says David Paul Richman, MD, distinguished professor in the Department of Neurology at UC Davis Health in Sacramento. “The No. 1 goal of treatment is to induce a remission and to maintain that remission,” Richman says. “And if you can’t do that, then you work on reducing the severity of the autoimmune attack.”

MEDICATIONS
Cholinesterase inhibitors are drugs that help boost the communication between muscles and nerves to improve your muscle strength and contractions. “They block the metabolism or the breakdown of the acetylcholine and allow more acetylcholine to hang around the remaining receptors,” Richman says.

Another effective line of MG defense is a high dose of a corticosteroid. “Around 80% of people go into remission after a couple of months [on it],” Richman says. However, these medications can come with significant side effects, such as bone thinning, weight gain, diabetes, and higher risk of infection and need to be closely monitored.

Immunosuppressants, a third drug option, work directly on your immune system. Your doctor may prescribe them alone or alongside corticosteroids. Richman says although these can be “steroid-sparing” treatments that can help get you off steroids sooner, they typically work very slowly, and they may not work at all for some people. “Biologics are a class of treatment made in a lab using living cells. Monoclonal antibodies, which are lab-made proteins a doctor gives you as infusions or injections under the skin, are one type. They help dampen an overactive immune system.”

IV THERAPY
Plasmapheresis is a process that filters your blood using an IV, like dialysis. “The idea is, if you have antibodies attacking your acetylcholine receptors, then let’s remove them from your body by removing plasma,” Richman says. This can work well to reduce symptoms, but effects typically only last a few weeks.

Intravenous immunoglobulin delivers “normal” antibodies into your blood through an IV to help change your faulty immune response. Its quick-acting nature makes it a good option for treating a myasthenic crisis, a life-threatening complication of MG that can cause respiratory failure. “Essentially, it’s the reverse of plasmapheresis,” Richman says. “Instead of removing plasma, you’re adding a whole bunch of normal antibodies from normal blood donors.”

SURGERY
For some people, MG is tied to a tumor in the thymus. A surgery where a surgeon removes your thymus (thymectomy) can improve symptoms. “It takes 5 years or so for the full effect [of the surgery], but it’s a very good, strategic, long-term treatment of myasthenia gravis and helps you get off these other immune-directed medications better and faster,” Richman says.