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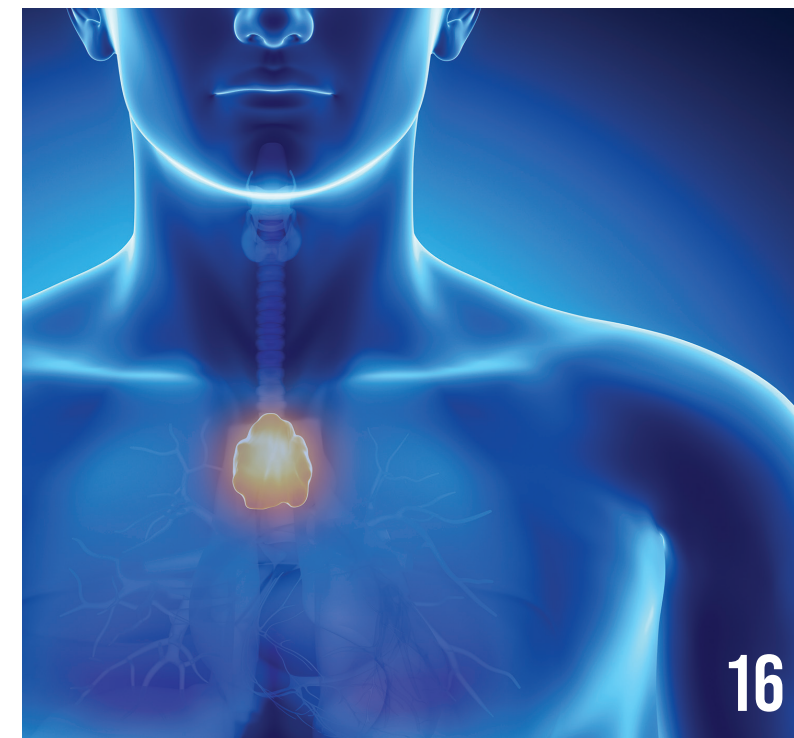
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Symptoms of generalized myasthenia gravis



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THE LATEST ON

GENERALIZED MYASTHENIA GRAVIS

BE PREPARED

With myasthenia gravis, you'll need to plan for the future so that you're ready if your condition changes. A new study of 1,859 people living with myasthenia gravis in nine countries might help you know what to expect. Compared with their peers in eight countries who did not have the condition, people with myasthenia gravis were 2.6 times more likely to have taken sick leave in the previous month. They were twice as likely to use medical care and four times as likely to need the help of a caregiver.

SOURCE: *Advances in Therapy*

1 in 5 Number of people with myasthenia gravis who have another autoimmune disease.

SOURCE: *Journal of Neurological Sciences*

1 in 8,064

Estimated number of people who have myasthenia gravis worldwide

SOURCE: *Journal of Translational Medicine*

MIND YOUR HEART HEALTH

Having an autoimmune disease, such as myasthenia gravis, may raise your risk for heart disease. Researchers compared nearly 500,000 people with 19 autoimmune diseases, including myasthenia gravis, to more than 2 million of their peers without these diseases. Those with any autoimmune disorder were up to 3.6 times more likely to develop heart disease over the 12 months that the researchers tracked them regardless of the presence of other risk factors, such as age, obesity, and diabetes. Because you might be at higher risk, make sure you stay on top of annual screenings like blood pressure and cholesterol checks.

SOURCE: *The Lancet*

AT-HOME PATIENT EXAM

With myasthenia gravis, you may have to see your doctor at least every 2 to 3 months—more often as your condition progresses and your treatment needs change. But you may not need to travel to a doctor's office for each of these appointments. Researchers have developed a patient exam that doctors can do via video chat. Recent studies show that the exam can accurately measure key metrics of disease, including muscle strength and eye motion. The researchers also noted that during video visits, doctors are able to focus more on the patient than on the logistics of a typical in-person visit.

SOURCE: *JMIR Neurotechnology*



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FREPIK.COM/GETTY IMAGES

STATS & FACTS

By Sonya Collins

Reviewed by Neha Pathak, MD, WebMD Lead Medical Editor



Estimated number of people who have myasthenia gravis in the U.S.



Most common age when women get a diagnosis of myasthenia gravis.



Most common age when men get a diagnosis of myasthenia gravis.



Approximate number of people with myasthenia gravis who have a myasthenic crisis—a weakening of the respiratory muscles that leads to temporary need for breathing assistance.



Number of years it may take to diagnose a person with myasthenia gravis.



3 in 100

Estimated number of people with myasthenia gravis who have a next-of-kin that also has the condition.



Number of people whose myasthenia gravis symptoms begin in their eyes that go on to develop generalized symptoms.

SOURCES: Myasthenia Gravis Foundation of America, National Institute of Neurological Disorders and Stroke, Medscape

SYMPTOMS OF GENERALIZED MYASTHENIA GRAVIS

HOW YOUR DISEASE MAY SHOW ITSELF

By Rachel Reiff Ellis

Reviewed by Neha Pathak, MD, WebMD Lead Medical Editor

Myasthenia gravis (MG) is a condition that causes muscle weakness in the muscles you control (voluntary muscles). Although this weakness shows up most frequently in certain parts of your body, it can affect any of your voluntary muscles.

“It’s an autoimmune disease where an antibody, or protein, gets in between the nerves and muscles, so signals sometimes get through and sometimes they don’t,” says David Saperstein, MD, director of the Center for Complex Neurology in Phoenix, AZ. “As a result, symptoms can be very variable.”

COMMON EFFECTS

Generalized myasthenia gravis is MG that causes muscle weakness in many different muscle groups, but more often than not, the eyes are involved.

“The key aspect to recognizing the disease is that it involves the ocular muscles,” says Henry Kaminski, MD, professor of neurology and rehabilitation medicine at The George Washington

University in Washington, DC. “At least half of patients at onset will have a droopy eyelid that comes and goes during the day, or double vision that fluctuates, or sometimes they have both.”

Because these symptoms come and go, it can make diagnosis tricky, Kaminski says. You may wake up with a droopy eyelid and by the time you get to the doctor, it’s gone.

“The key is the identification of the eye muscle problems, either alone or in concert with generalized weakness such as slurred speech or difficulty chewing and swallowing.”

Your muscle weakness might make you choke easily, or you might find that liquids you try to swallow come out your nose, for example. You may also have problems with facial expressions like smiling.

If your neck and limbs are weak, it may feel harder than usual to hold up your head, and walking can become more difficult.



WHEN TO CALL YOUR DOCTOR

Your condition may need attention if you have new or worsening problems with:

- + Breathing
- + Seeing
- + Swallowing
- + Chewing
- + Walking
- + Using your arms or hands
- + Holding up your head

GOODBOY PICTURE COMPANY/VIA GETTY IMAGES

SEVERITY AND COMPLICATIONS

Just like the muscles involved, the intensity of your symptoms and how often they occur varies from person to person.

“Some of the time these symptoms occur, and then they resolve, and then they come back,” Kaminski says. “For some people, symptoms come on very quickly over a few weeks to a month.”

Typically, the severity of weakness comes and goes during the day. Usually it’s mildest in the morning and gets worse as the day goes on, especially if you’ve been using your muscles for a while.

It’s possible for the muscles you use to breathe to become affected to the point where your breaths become shallow and you can’t get enough oxygen to your lungs. This is a complication called a myasthenia crisis. This can happen because of a respiratory infection, stress, or surgery.

“In this case, you may need to be placed on a ventilator and treated with potent immunomodulatory treatments or immune treatments,” Kaminski says.

WHAT CAN WORSEN SYMPTOMS?

These factors can affect your muscle weakness:

- | | |
|----------------------------|--|
| + Stress | + Hot foods and beverages |
| + Lack of sleep | + Illness |
| + Pain | + Certain medications such as beta-blockers and muscle relaxants |
| + Extreme emotions | + Anesthesia |
| + Sunlight or bright light | |

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to learn more



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 if you have any history of infections. Tell your healthcare provider right away if you have signs or symptoms of an infection during treatment with RYSTIGGO. Some of the signs and symptoms

may include 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 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?"

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].

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 1-844-599-2273.

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



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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 if you are experiencing any undesirable reactions after administration.

Call your healthcare provider right away if you have any serious side effects listed above.

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.

Before starting RYSTIGGO, tell your healthcare provider if you:

- Have a history of infection or have an active infection.
- Have received or are scheduled to receive a vaccine (immunization). Administration of live or live-attenuated vaccines is not recommended during treatment with RYSTIGGO.
- Are pregnant or plan to become pregnant or are breastfeeding or plan to breastfeed.

Tell your healthcare provider about all the medications 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?”

The most common side effects (reported in at least 10% of patients treated with 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 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 administered 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 administered 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: rozanolixizumab-noli

Each 2 mL single-dose vial contains 280 mg of rozanolixizumab-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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QUALITY OF LIFE WITH MYASTHENIA GRAVIS

HOW YOUR DISEASE MAY IMPACT YOU

By Rachel Reiff Ellis

Reviewed by Neha Pathak, MD, WebMD Lead Medical Editor

Myasthenia gravis (MG) looks different in every person who has it, so it can be hard to know what your life will be like as you navigate the condition. The good news is that it's very treatable.

YOUR EXPERIENCE MAY VARY

Even though it's a lifelong condition, you can manage MG with intentional care and prescribed treatments from your doctor—which are more effective than ever, says George Small, MD, a neurologist at Allegheny Health Network in Pittsburgh, PA.

“The landscape of myasthenia gravis treatment has exploded in the last 5 years,” he says. “It may seem like an odd thing to say, but there's never been a better time to have myasthenia gravis than now.”

For most people, living with MG means adopting new habits and protocols while continuing to live life mostly as you did before, Small says.

“Around 80% of people can be treated with simple therapy; take a pill, see their doctor every once in a while, and live a normal life,” Small says. “They may not feel like they did before diagnosis, but they can do daily activities, just with an awareness that they have a problem.”

The other 20%, he says, live with their MG symptoms more on display.

“They may go through bouts where they can't walk, or they choke on their food, or in some cases, require mechanical ventilation,” he says. A very small percentage go on to need chronic breathing assistance.

SOCIAL AND MENTAL EFFECTS

While the physical symptoms of your MG may be at the forefront of your mind, it's important to consider how the chronic condition can play a part in mood and social life, too.



Hani Kushlaf, MD, director of neuromuscular research at the University of Cincinnati, says it's common to feel withdrawn because of your symptoms.

“For example, if you have trouble chewing, swallowing, or you cannot carry on a long conversation before your speech becomes garbled, you may be less willing to go out to a restaurant and eat with friends or even family and instead just stay at home,” he says.

Similarly, you may pass on outings because you struggle with walking long distances. You may lose the ability to enjoy outdoor activities and be with friends and family when you want to. Double vision may mean you can no longer drive. For some people with

MG, this puts their jobs at risk.

“We have patients who have lost their job just because they cannot work anymore, especially if their job requires frequent eye focus,” Kushlaf says.

The combination of these mental effects with the physical symptoms raises your risk of anxiety and depression. And studies show the more severe your symptoms, the higher the risk of these mood disorders.

IMPORTANCE OF SUPPORT

Whether you deal with occasional disruptions or daily focused care because of your MG symptoms, connecting with MG organizations and others who live with the condition can help you feel less alone.

“The Myasthenia Gravis Foundation of America has a lot of information for patients, including their MyMG app, which helps you track your symptoms, and offers webinars, brochures, research information, events, blog posts, and MG assistance and guidance,” Kushlaf says.

You can also find both online and in-person support groups through their website where you can meet others to talk about treatments and experiences.

“It helps put you at ease, especially if you're newly diagnosed and don't know what's going to happen in the future,” Kushlaf says. “Meeting someone who's had myasthenia gravis for 20 years and doing well just gives you an idea where things are going to go. It gives you hope.”

KEEP TABS

George Small, MD, lists ways to manage your life with MG.

- + **Pay attention to any breathing or swallowing problems** and tell your doctor.
- + **Wear a medical alert badge** so others know you have a rare condition.
- + **See your doctor regularly** and report changing symptoms.

MY LIFE WITH

GENERALIZED MYASTHENIA GRAVIS

FROM DIAGNOSIS TO TREATMENT, HERE'S WHY I FEEL PRETTY GOOD

By Howard Brickman

Reviewed by Neha Pathak, MD, WebMD Lead Medical Editor



I started noticing symptoms 12 years ago when I was 57. For a year, I didn't do anything about it. When you have myasthenia gravis, it affects your vision. Your walking changes. Your arms get weak. One of my eyes started to droop. It's hard to breathe sometimes. Your head will drop because you can't hold it up. Even lifting a cup is hard. It's like having a whole new body.

I had symptoms, but I had never heard of myasthenia gravis before. Then a family member who is a doctor came to visit us in New York. After dinner one night, he said, 'Howard, are you worried something is wrong with

you?' He told me I had all the signs of myasthenia gravis and needed a blood test. That's how I found out.

STARTING TREATMENT

I got started on a drug regimen. With myasthenia gravis, if you are not diagnosed when the signs first show up, it takes longer for your body to come back if it does at all. And I had waited a year to do anything about it. Despite that, I decided I was going to fight and push to get my body back.

Some of the drugs you take for myasthenia gravis are like an express route to the restroom, especially at first. It's hard to leave the house if you

are not careful. But things start to settle down after 6 months or a year. I started going to support group meetings and made a lot of friends. This disease is extremely frustrating, but it gets easier over time.

GETTING STRONGER

My treatment is working. My legs have gotten stronger. My arms are stronger. I'm not going to be as I was before all of this started, but I can do tasks such as hanging up laundry whenever I want. If I get tired, I stop for 15 minutes and then start again. If I'm out and get tired, I sit in the car for 10 minutes.

One thing to keep in mind is that myasthenia gravis is a snowflake disease. We're all different. People may say that you look normal, but there are still difficulties in what you can do in your daily life. If you overdo it, it may take a couple of days for your muscles to come back. After a while, you'll get better at remembering that you have myasthenia gravis. You'll learn how to listen to yourself better and do household chores or other activities at times of day when you feel stronger.

GAINING TRUST

In the beginning, I was very embarrassed about having myasthenia gravis.

Little by little, I started trusting people. Now I don't mind explaining what I have and educating people. When I go to the dentist, for example, I let them know what's going on. You have to be your own advocate and keep talking about it.

I just keep going. I realize I'm getting older, but I'm still very active. I still beat my wife and kids up the block. I've been able to give back by supporting people who are newly diagnosed through the Myasthenia Gravis Foundation of America. I help out in my own neighborhood. My family is behind me. I've been lucky, and I feel pretty good.



HOWARD'S TIPS

- + Listen to what your body is telling you.
- + When you're feeling tired or weak, stop what you're doing for a few minutes and then start again.
- + If you need help, ask for it. You'll find people you can trust.



TREATMENT OPTIONS

WAYS TO MANAGE YOUR DISEASE AND ITS SYMPTOMS

By Kendall K. Morgan

Reviewed by Neha Pathak, MD, WebMD Lead Medical Editor

Myasthenia gravis is a chronic disease of your immune system that causes muscle weakness. When you have it, your body makes antibodies that block or destroy proteins that you need for your nerves to tell your muscles to move. This breakdown in communication between your nerves and muscles makes it harder to move and you may tire quickly. It tends to affect some muscles more than others, such as those you use to open your eyes, swallow, or talk.

“Myasthenia gravis is an autoimmune disorder,” says Min Kang, MD, a neurologist at UCSF Health’s Myasthenia Gravis Clinic in San Francisco. “This is a broad category of disease in which the immune system is attacking against yourself, [in this case] at the neuromuscular junction. Your muscles and nerves talk to each other all the time.”

While there’s no cure, you will have many treatment options to help keep your symptoms at bay. Your doctor will help you decide the best treatment or combination of treatments for you depending on your age, symptoms, and goals.

GIVE YOUR NERVE MESSAGES A BOOST

Cholinesterase inhibitors are one class of medicines you can take for your myasthenia gravis. They work by blocking an enzyme that normally breaks down a chemical called acetylcholine. Acetylcholine plays a major role in signaling your muscles to move. By blocking the enzyme, the amount of acetylcholine will go up, which helps to improve communication between your nerves and muscles.

“These medicines are used as a temporary patch,” Kang says. They don’t fix the underlying autoimmune problem,

she says. But they are effective and work right away.

SUPPRESS YOUR IMMUNE SYSTEM

You’ll likely take a second drug to calm your immune system down. You may take steroids for this reason, but only for a short time. That’s because steroids have a lot of side effects if you keep taking them.

There are many other options for immunosuppressant drugs you can take for myasthenia gravis. They don’t work fast, but you can take them longer. Doctors can now also use monoclonal antibodies to target specific parts of your immune system and lower the amount of attacking antibodies you have. Ask your doctor which treatment they recommend for you.

MORE OPTIONS

In an emergency, you will have still more ways to quickly lower the attacking antibodies. One called plasmapheresis filters antibodies out of your blood. Another is an IV infusion of healthy antibodies, which can change your immune response. Along with medicines, Kang recommends people with myasthenia gravis under age 65 consider surgery to remove their thymus gland. She expects even more treatment options in the future and possibly even a cure.

“The future is very bright for patients with myasthenia gravis,” she says.