

CONQUER

News for our community

Conquer MG Ambassadors Advocate for Change During Rare Disease Week in Washington, DC.

An estimated 30 million people in the United States live with a rare disease—many of which are serious, life-threatening and often go undiagnosed or untreated due to limited treatment options and high costs.

Every year, during the last week of February, advocates representing dozens of rare diseases take time from their often medically complex lives to travel to Washington, D.C., to raise awareness of the needs of the rare disease community. The multi-day event, hosted by the Rare Disease Legislative Advocates, a program of the EveryLife Foundation for Rare Diseases, brings together advocates from across the country to make their voices heard and effect change.

This year, Conquer MG was thrilled to see three of its dedicated organization ambassadors travel to Washington, D.C. to engage in advocacy work on behalf of those living with rare diseases. Each of them described the experience as truly unique.

"To be in the company of hundreds of individuals living with or caring for someone with a rare disease was breathtaking," said Gary Jackson, co-leader of the Conquer MG Men's Support Group. While he described the week as an emotional roller



Kelly Aiken, Gary Jackson and Tammy Carter in Washington.

coaster filled with conversations, stories, smiles and occasional tears, he noted that everyone was united by a common mission: advocating for those affected by rare diseases.

Jackson knows all too well that myasthenia gravis, like many other rare diseases, does not discriminate. The three-day conference reinforced this reality. "It was energizing to be with so many people who came armed with strength, determination and a shared commitment to improving the lives of those affected," he said.

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About MG

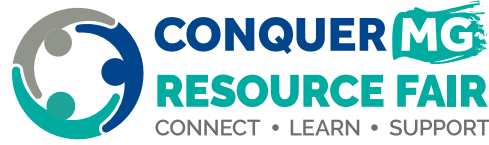
It strikes at any time and any age. Any income. Any ethnic background.

Myasthenia gravis (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
4055 W. Peterson Ave., Ste. 105
Chicago, IL 60646
800.888.6208
www.myastheniagravis.org



LIFE WITH MG

Don't miss this opportunity to learn, connect and empower yourself. Bring your support network of family and friends to learn with you.

Engage in small groups and one-on-one discussions with experts who can help you live your best life.

Meet and connect with others who share your journey with MG.

Gain valuable knowledge on managing your condition effectively.



Register Today!

Thank you to our sponsors

argenx

ALEXION
AstraZeneca Rare Disease

AMGEN

ucb Inspired by patients.
Driven by science.

Sunday, April 27

2:30–5:30 PM

Lombard Community Building
433 East St. Charles Rd.
Lombard, IL

Financial Assistance Programs



Conquer MG's **Patient Assistance Program** helps qualifying patients defray the cost of medical bills, prescription drugs, and durable medical equipment up to \$1,000 per person, per year. Eligible patients are those who live in Illinois, Indiana, or Wisconsin and can demonstrate financial hardship. You may

request the 2025 application by emailing info@myastheniagravis.org or find it on our website, www.myastheniagravis.org.

Our website lists other organizations that offer financial support for MG patients. Each organization has its own rules, and application periods vary. Pharmaceutical companies that manufacture specific medications may help with the cost of their medications. Check the individual company websites for details.



Upcoming MG Support Group Meetings

Whether you have myasthenia gravis or care for someone with MG, you're encouraged to join the conversation. Sign up for a Support Group at myastheniagravis.org.

VIRTUAL GROUPS	2025 MEETING DATES	TIME	GROUP LEADER(S)
Thursday Monthly Anywhere MG Support Group (via Zoom)	Meets Monthly, 2nd Thursday Jan. 9, Feb. 13, Mar. 13, Apr. 10, May 8, June 12, July 10, Aug. 14, Sept. 11, Oct. 9, Nov. 13, Dec. 11	2:00 PM CT	Kelly Aiken
Men's MG Support Group (via Zoom)	Meets Quarterly, Thursdays Mar. 20, June 19, Sept. 18, Nov. 20	6:00 PM CT	Gary Jackson and Dr. David Randall
Chicago South and West MG Support Group (via Zoom)	Meets Quarterly, Sundays Feb. 16, May 18, Aug. 10, Nov. 9	1:00 PM CT	Joyce Holste and Victor Yipp
NEW! Women's MG Support Group (via Zoom)	Meets Quarterly, Thursdays Feb. 27, May 29, Aug. 28, Nov. 6	6:00 PM CT	Tammy Carter

IN-PERSON GROUPS	2025 MEETING DATES	TIME	LOCATION GROUP LEADER(S)
Springfield, IL MG Support Group	Meets Monthly, Sundays Virtual: Jan. 19 and Feb. 16 Please email info@myastheniagravis.org for Zoom link In-person: Mar. 16, May 18, July 20, Aug. 17, Sept. 21, Oct. 19, Nov. 16 No Meeting in April, June and December	2:00 PM	Parkway Christian Church 2700 Lindbergh Blvd. Springfield, IL Kelly Aiken
Chicago North MG Support Group	Meets Saturdays Feb. 8, April 5, June 14, Aug. 2, Oct. 4, Dec. 6	10:00 AM	Levy Center 300 Dodge Ave. Evanston Library Room Evanston, IL Linda Loland
Northwest Indiana Support Group	Meets on Saturdays March 15, May 17, August 2, October 11	10:00 AM	Schererville-Dyer Library 1001 W. Lincoln Hwy. Schererville, IN SeAndrea Ferguson
NEW! MG Strong Together Support Group	Meets Saturdays March 15, July 12, November 15	10:00 AM	Ascension Alexian Brothers 800 Biesterfield Road Room: Kennedy 4 Elk Grove Village, IL Please use entrance #7 to enter the hospital. (All other entrances are closed on the weekend, parking is free) Janet Bauer

Questions about joining a support group? Reach us at info@myastheniagravis.org or call (800) 888-6208.

Myasthenia Gravis Activities of Daily Living Chart

With a disease like myasthenia gravis, in which symptoms can vary greatly from day to day, it becomes important to track your MG symptoms so that you can have productive conversations with your medical providers and caregivers. Use this chart to track your daily and weekly symptoms and bring it with you to your next doctor appointment so that you can reflect on and recall how you've been feeling.

Score yourself (from 0= normal to 3=most severe) for each of the daily activities listed below.

	0	1	2	3	Your Score
Talking	Normal	Intermittent slurring or nasal speech	Constant slurring or nasal, but can be understood	Difficult to understand speech	
Chewing	Normal	Fatigue with solid food	Fatigue with soft food	Gastric tube	
Swallowing	Normal	Rare episode of choking	Frequent choking necessitating changes in diet	Gastric tube	
Breathing	Normal	Shortness of breath with exertion	Shortness of breath at rest	Ventilator dependence	
Impairment of ability to brush teeth or comb hair	None	Extra effort, but no rest periods needed	Rest periods needed	Cannot do one of these functions	
Impairment of ability to rise from a chair	None	Mild, sometimes uses arms	Moderate, always uses arms	Severe, requires assistance	
Double vision	None	Occurs, but not daily	Daily, but not constant	Constant	
Eyelid droop	None	Occurs, but not daily	Daily, but not constant	Constant	
Total Score (add items 1-8) = Max 24 points					



Continued from page 1

Though groups represented different conditions, the atmosphere was one of collective purpose, and advocacy speakers energized the room with empathy and urgency.

Kelly Aiken, who leads two of Conquer MG's monthly support group meetings and plays a significant role in the annual Viking Challenge for MG and its Resource Fairs, shared her experience. "I was with four other remarkable people and quickly got to know what brought them to Rare Disease Week. For most, it was their own disease, but for one, it was his son's syndrome."

Between meetings, the time spent with others was just as meaningful as the meetings themselves. "We learned about each other's lived experiences, talked politics, our diseases and what motivates us to advocate," Aiken said, reflecting on the intensity of the week. "During our meetings with elected officials and their staff, we were united in our purpose as we shared our stories with the hope of making a connection with someone who holds the power to enact change."

One question came up repeatedly: What is one thing you wish more people knew about rare diseases? For Aiken and those in her group, the answer was clear. "While a single rare disease provides a small voice, grouping 10,000 rare diseases gives us a mighty voice."



Gary Jackson and Tammy Carter arrive for Rare Disease Week in Washington, D.C.

Tammy Carter, Conquer MG Board of Trustee, Chair of Education and Events, and leader of the Women's Support Group, also reflected on her experience. "I felt so honored and excited to attend Rare Disease Week. When I saw the conference room full with supporters who wanted to be heard and bring awareness to the rare disease world, I knew that I was in the right place at the right time. I never imagined that it would be so invigorating."

One particularly memorable moment for Carter was meeting Sen. Amy Klobuchar, D-Minn., co-chairwoman of the Rare Disease Caucus. "She is dedicated to ensuring that millions of Americans with rare diseases have access to resources."

Carter emphasized, "We all have a voice that needs to be heard, so please raise awareness by sharing your story."

Conquer MG thanks the EveryLife Foundation for supporting the participation of our organization's ambassadors. The EveryLife Foundation is a nonprofit, nonpartisan organization dedicated to empowering the rare disease patient community to advocate for impactful, science-driven legislation and policy that advances the equitable development of and access to lifesaving diagnoses, treatments and cures.



Above from left to right: Shonda Berry, Kelly Aiken, Rep. Bill Foster and Jamie Aranda.



EXPLORE THE POSSIBILITIES

Ask your doctor about VYVGART Hytrulo (efgartigamod alfa and hyaluronidase-qvfc) and VYVGART (efgartigamod alfa-fcab)

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hyaluronidase-qvfc)

Subcutaneous Injection
180 mg/mL and 2000 U/mL vial

VYVGART®
(efgartigimod alfa-fcab)
Injection for Intravenous Use
400 mg/20 mL vial



Scan the QR code or visit
[VYVGART.com](https://www.vyvgart.com) to learn more

Questions? Call 1-833-VYVGART (1-833-898-4278)

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Do Not Let Your Health Condition Take Your Voice

Written by: Alicia J. Peconio, Conquer MG Vice Chair and Chair of Communications and Marketing Committee

As individuals with a rare disease, we are living in stressful and unpredictable times. Decisions made at the highest levels of government are impacting the daily lives of everyone in the United States. For those of us who live with chronic illnesses, this stress is amplified by the news of the funding freeze for medical research—research that aims to one day find a cure for myasthenia gravis.

Taking action can reduce stress! Consider writing a patient advocacy letter to your elected officials stating the importance of this medical funding. Your story lets them know how these decisions affect your financial, emotional and physical health.

A great resource to help you get started is in the Conquer MG Advocacy Toolkit on our website:

<https://myastheniagravis.org/what-you-can-do>

This toolkit provides a template for the letter so you know exactly what to say, but also allows you to add your personal experience with MG and other chronic illnesses to help paint the picture of your lived experience. The details of your story can educate the person reading your letter so they can better understand the struggle so many of us with chronic illnesses face every day.

If you are unsure who your elected officials are, look on these websites:

U.S. House Representative: www.house.gov

U.S. Senate: www.senate.gov

Myasthenia gravis and other diseases and disorders take much from us. Do not let your health condition take your voice.



About the Award

The Tracy Shackelford MG Service Award honors Tracy Shackelford, an important and compassionate member of the MG community who passed away in 2021 after a long battle with myasthenia gravis. This award was created in her name to recognize others who demonstrate a high level of service to the MG community.

Tracy Shackelford MG Service Award

Do you know someone who has given back to the MG community? Nominate them for the Tracy Shackelford MG Service Award.

Submit a 500-word explanation of their contribution, including why you think their contribution is meaningful and what is the lasting impact.

Also include:

- The nominee's full name
- Your name if you are nominating someone other than yourself
- A phone number for the nominator and nominee
- Both the nominator and nominee's email addresses
- Nominee's mailing address (only individuals who live in our service area are eligible – Illinois, Wisconsin and Indiana)

Submit nominations by email to info@myastheniagravis.org **by Tuesday, May 20 at 5:00 p.m.** The winner will be announced at the 13th Annual Viking Challenge for MG on Sunday, June 8.



AMGEN

Committed to the Myasthenia Gravis Community

At Amgen, we are committed to advancing science and developing treatments for patients with serious illnesses, including many rare diseases. There are more than 10,000 different rare diseases impacting 400 million people globally. Rare diseases are complex and often underserved. They demand urgent attention and are a core and growing part of Amgen's mission to serve patients. For more info, visit www.amgen.com

Support Comes in Many Forms— Yours Can Help Conquer MG!

Myasthenia gravis (MG) weakens muscles—but your support is powerful. A donation to Conquer MG helps lift the weight from those battling this condition by providing patient support, raising awareness and funding research.

Give strength. Give hope. Give today.

Every dollar moves us closer to a future where MG is no longer a challenge.

Are you in?

**Together, we turn weakness
into strength!**



Give by mail:

4055 W. Peterson Ave., Suite 105
Chicago IL 60646

Give online:

www.myastheniagravis.org/

In Appreciation

WE ARE GRATEFUL to everyone who supports Conquer MG's mission. These donors recognized a loved one through their generous support between December 2024—March 30, 2025.

In Honor of Joan Wincentsen
Jim and Katherine Bingley

In Memory of Don Carsten
Don and June Carsten

In Memory of Debra Clyden
David Clyden

In Memory of Jeanne Schultheis
Diane Corbett

In Memory of Claudia Cox
Michael Cox

In Honor of Alicia Peconio
Mark and Linda Cribben

In Memory of Christine Crisanti
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In Memory of Beatrice Feinstein
Fred Feinstein

In Memory of Gustav John Frey
Delores Frey

In Memory of Gary Granat
Kevan Granat

In Memory of Peggy Greene
Daniel Greene

In Honor of Joan Wincentsen
William (Bill) Hargreaves

In Memory of Nancy Van Laten
Joyce and Randy Holste

In Memory of Michael J. Jamen
Ida Jamen

In Memory of Ethyl Rogers
Maureen McGrath

In Memory of Gary Granat
Dianne Miller

In Honor of Andrea "Drea" Carbone
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In Memory of Alexander Niemczura
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In Memory of Lorrie Schohn
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In Honor of Larry Slager
Joe and Dee Schram

In Memory of Rosemary Sprague
Ralph Sprague

In Honor of Bob Rosecrans
Linda Strain
Linda Tieman

In Memory of Paul Watland
Linda Watland

In Honor of Heather Green
Geri Weber

If your tribute gift is not listed here, please accept our regrets and notify us in the office. We will recognize you in the next print newsletter.

Passionate about helping others? Join us in making a difference!

We are seeking dedicated individuals to lead support groups in their communities. As a support group leader, you will help foster a sense of community for those affected by myasthenia gravis (MG). Conquer MG provides its leaders with the necessary resources, information and on occasion scheduled speakers to talk with your group.



Why Lead a Support Group?

Make an Impact: Help others navigate their MG journey and provide much-needed support.

Build Community: Connect with others who understand the challenges of living with MG.

Grow Together: Share experiences, resources and hope with your group members.

Email us at info@myastheniagravis.org to learn more and sign up to lead a group.

Together, we can grow our community and conquer MG!

Are You Ready to Make a Difference?

Sign up today and start your journey to conquer MG!



Step up to the challenge and join us for the **13th Annual Conquer MG Viking Challenge!** Whether you are a seasoned warrior or a first-time participant, your involvement will help us fight against myasthenia gravis.

How You Can Help?

For more information and to sign up for the Viking Challenge:

runsignup.com/VikingChallengeforMG

Every participant helps us deliver valuable resources to MG patients and allows us to fund research in the hope that we can one day find a cure.

Sunday, June 8 • 9 - 11:30 AM
Berens Park
493 N. Oaklawn Ave., Elmhurst, IL

Participate in person or virtually.

- **Support a Worthy Cause:** Every step you take and every dollar you raise goes directly towards supporting those affected by MG.
- **Challenge Yourself:** Push your limits and achieve new personal goals while making a positive impact.
- **Community Spirit:** Join a passionate community of individuals dedicated to making a difference.



Thank you to our Viking Challenge for MG sponsors!



Vaccination And Myasthenia: What You Should Know?



By Raghav Govindarajan,
Neurologist and Conquer MG
Medical Advisory Board Member

What is a vaccine?

Vaccination is a safe and effective way of protecting you or your loved one against harmful diseases. It uses your body's natural defenses to build resistance

to specific infections and makes your immune system stronger.

How do vaccines work?

Vaccines train your immune system to create antibodies, just as it does when it's exposed to a disease. However, because vaccines contain only killed or weakened forms of germs like viruses or bacteria, they do not cause the disease or put you at risk of its complications.

Do MG patients need to get vaccinated?

Getting vaccinated is an important aspect of MG care. With a weakened immune system, illnesses that other people can fight, like the flu, or pneumonia, can become life-threatening. Preventing sickness from happening in the first

place through vaccination helps keep people with MG healthier overall. Further, preventing respiratory infections in people with generalized MG can reduce the risk of an exacerbation.

Which vaccines are safe and recommended for MG patients?

Most vaccines are safe for people with myasthenia gravis. Age-appropriate vaccination is recommended for MG patients. These include Tdap (tetanus, diphtheria and pertussis), HPV (human papillomavirus), Hepatitis B, inactivated varicella (chickenpox and shingles). In patients on complement inhibitors, meningococcal vaccine is also recommended. This author also recommends, pneumonia vaccine along with inactivated flu and COVID vaccine for MG patients.

What vaccines to avoid with MG?

Patients with MG who are taking immunosuppressants should not receive live vaccines. This includes the nasal flu spray, certain types of shingles vaccines, the yellow fever vaccine and the measles, mumps, and rubella (MMR) vaccine. However, the non-live versions of the flu shot and shingles vaccine are safe and recommended for individuals with MG.

Join Our Board of Directors at Conquer MG!

Do you want to make a difference in the lives of people who live with a rare disease? Take on a leadership role with Conquer MG and help us in our mission to support those affected by myasthenia gravis.

Why Join Our Board?

Lead with Purpose: Play a key role in shaping the future of our organization.

Make an Impact: Use your skills and expertise to drive meaningful change.

Collaborate: Work with a dedicated team committed to conquering MG.

Interested?

Contact us at info@myastheniagravis.org to learn more and express your interest.



Conquer Myasthenia Gravis
4055 W. Peterson Ave., Suite 105
Chicago, IL 60646

CONNECT WITH US!

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