

CONQUER

News for our community

At the Hospital

Story by Alicia J. Peconio, Board Chair of Conquer MG

I was diagnosed with myasthenia gravis in the fall of 2016. For the most part, my journey had been fairly stable, with some flare-ups and seasons of ups and downs, but nothing that completely upended my daily life, until this past summer.



I had been dealing with an upper respiratory infection and an infected tooth that needed attention. Over several weeks, I began to notice extreme fatigue, particularly in my legs, and everyday tasks started to feel more challenging. I realized it was time to seek care, so I went to the emergency room. I brought my medical information but had forgotten my medications.

Even though the situation was difficult, it became an opportunity to learn how important it is to be prepared and to advocate for myself. I started keeping an emergency bag ready with my medications, a full list of prescriptions, my medical history, a fact sheet about myasthenia gravis, and care directives. I also added chargers, comfortable clothing, a neck pillow, and books or headphones to keep myself occupied. Each of these steps became a small but meaningful way to feel in control and empowered.

Having a trusted friend or family member to support me made a world of difference. Even when my energy was low, their presence helped ensure that my medical history and needs were clearly communicated. Learning to speak up, ask questions, and clarify my care turned every small action into a victory, helping me feel confident and supported.

I also learned to pay close attention to medications and instructions, and to ask for guidance whenever something seemed unclear. Reviewing care directions and involving a patient advocate when needed became part of reclaiming my voice and protecting my health. Every time I could communicate my needs, it reminded me that I am the expert on my own body, and that even small actions can make a real difference.

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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



13th Annual Viking Challenge for MG

The 13th Annual Viking Challenge for MG on June 8 was a bright, feel-good day full of connections and community. Friends, families, and supporters visited Berens Park in Elmhurst to raise awareness for myasthenia gravis and support those affected by it.

The vibe was relaxed and positive, with lively discussions, cheering, and simply being surrounded by one another all for a good cause. Our raffle was a big hit, and tickets went quickly. We had amazing prizes from our generous donors and all of the winners were thrilled to win!

Joan Wincentzen kept things moving with her amazing energy as emcee. From start to finish, it was easy, fun, and meaningful.

One of the most memorable parts of the day was honoring two incredible advocates with the Tracy Shackelford MG Service Award. Tammy Carter and Janet Bauer have each made a huge impact in the MG community through their leadership and care. Everyone was proud to celebrate their work and the difference they've made.

The Viking Challenge also created space for people who were newly diagnosed or just learning about myasthenia gravis to meet others and feel supported. The MG Experience stations provided a hands-on way to understand how living with MG can feel like. With vision-blurring glasses, ankle and wrist weights, and a few challenges, participants got a real sense of the physical struggles that come with the condition. It was eye-opening in the best way.

The whole day concluded with new friendships, lots of laughs, and a strong sense of community. Whether people were walking the course, trying out the MG stations, or just soaking in the sunshine, it felt like everyone left with more understanding and a deeper connection. Myasthenia gravis can be a hard journey, but this event reminded everyone that *no one has to go through it alone!*

Stay Tuned for 2026 Event Updates!



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	2026 MEETING DATES	TIME	GROUP LEADER(S)
Thursday Monthly Anywhere MG Support Group (via Zoom)	Meets Monthly, 2nd Thursday Jan. 8, Feb. 12, Mar. 12, Apr. 9, May 14, June 11, July 9, Aug. 13, Sept. 10, Oct. 8, Nov. 12, Dec. 10	2:00 PM CT	Kelly Aiken
Men's MG Support Group	Meets Quarterly, 3rd Thursday <i>(Beginning in March)</i> Mar. 19, June 18, Sept. 17, Nov. 19	6:00 PM CT	Gary Jackson and Dr. David Randall
Chicago South and West MG Support Group (via Zoom)	Meets Quarterly, 2nd Sunday <i>(Beginning in February)</i> Feb. 22, May 17, Aug. 9, Nov. 8	1:00 PM CT	Joyce Holste and Victor Yipp
Women's MG Support Group	Meets Quarterly, 4th Thursday <i>(Beginning in February)</i> Feb. 19, May 28, Aug. 27, Nov. 19	6:00 PM CT	Tammy Carter

IN-PERSON GROUPS	2026 MEETING DATES	TIME	LOCATION GROUP LEADER(S)
Springfield, IL MG Support Group	Meets Monthly, 3rd Sunday Feb. 15 (virtual on ZOOM), Mar. 15, Apr. 19, May 17, July 19, Aug. 16, Sept. 20, Oct. 18, Nov. 15 No meeting in January, June and December	2:00 PM	Kelly Aiken Parkway Christian Church 2700 Lindbergh Blvd. Springfield, IL
Chicago North MG Support Group	Meets Bi-Monthly, 2nd Saturday <i>(Beginning in February)</i> Feb. 7, April 11, June 20, Aug. 8, Oct. 10, Dec. 12	10:00 AM	Linda Loland Levy Center 300 Dodge Ave. Evanston Library Room Evanston, IL
Northwest Indiana MG Support Group	Meets Quarterly, 2nd Saturdays <i>(Beginning in March)</i> March 14, May 9, August 8, October 10	10:00 AM	SeAndrea Ferguson Scherrerville-Dyer Library 1001 W. Lincoln Hwy. Scherrerville, IN

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



Become a Support Group Leader!

Are you interested in leading a support group in your area? We can help you get started!

Email us at info@myastheniagravis.org to lead a group. We are seeking support group leaders in **Chicago, Rockford, Peoria,** and the **Quad Cities.**

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					





Monica Seles Partners with argenx to Raise MG Awareness

Nine-time Grand Slam tennis champion Monica Seles is speaking out for the first time about her diagnosis with myasthenia gravis (MG), a chronic autoimmune disease that causes muscle weakness and can make even everyday activities extremely challenging. Seles, who has been living with MG since 2022, first noticed symptoms such as double vision and weakness in her arms and legs—changes that gradually affected her ability to perform routine tasks and enjoy the activities she loved.

Despite these challenges, Seles is now using her voice and platform to raise awareness of MG and to support others living with the condition. She has partnered with argenx on their Go for Greater initiative, a program designed to empower patients through access to resources, community connections, and advocacy opportunities. The initiative will be highlighted at the 2025 U.S. Open Tennis Championships, where Seles will help bring global attention to the disease.

“My MG journey over the past five years has not been easy,” Seles shares. “I felt isolated and defeated as many of the activities I enjoyed were no longer physically possible. I’ve since realized that by sharing my story, I can raise awareness of this disease, empower patients to advocate for themselves, and help them connect with the MG

community for support. I am excited to partner with the argenx team to inspire others living with MG to rally against this disease, pursue their goals, and live a fulfilling life. We’re all in this together.”

Karen Massey, Chief Operating Officer at argenx, adds, “We applaud Monica for sharing her personal story and are excited to collaborate with her to amplify the voices of MG patients and caregivers. Her journey and dedication to this cause will help people living with MG engage in meaningful conversations and build a supportive network around this challenging disease.”

In the U.S., over 120,000 people live with MG, which can cause fatigue, difficulty walking, blurred or double vision, and muscle weakness in the arms and legs. By sharing her journey and partnering with argenx, Seles hopes to not only raise awareness but also empower patients to seek the support and resources they need. Her story is a reminder that even in the face of a challenging chronic condition, it is possible to find community, advocate for oneself, and continue pursuing personal goals.

Visit www.mg-united.com for more information about the Go for Greater campaign and MG resources.

Photo courtesy of argenx.



EXPLORE THE POSSIBILITIES

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(efgartigimod alfa and 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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Tammy Carter and Janet Bauer Honored with 2025 Tracy Shackelford MG Service Award

Conquer myasthenia gravis has named Tammy Carter and Janet Bauer as recipients of the 2025 Tracy Shackelford MG Service Award, recognizing their longstanding dedication, leadership, and advocacy within the MG community.



Tammy Carter (left) is presented with the Tracy Shackelford MG Service Award by Victor Yipp.

Tammy Carter has served as a Conquer MG board member since 2011, holding the role of Secretary and contributing to numerous organizational events and initiatives. She was instrumental in the creation and coordination of CMG's annual events, including the Resource Fairs held in Lombard

and Springfield (with Indianapolis soon to follow), and the Conquer MG annual challenge walk.

Carter also founded a dedicated Women's MG Support Group, addressing the specific needs of women who are often diagnosed earlier and face unique challenges related to MG. Known for her compassion, energy, and unwavering commitment, Carter brings both heart and humor to every gathering she leads. "She does it all masterfully," wrote her nominator, Janet Bauer.



In turn, Janet Bauer was also recognized for her tireless contributions to MG awareness and peer support. Diagnosed with MG over 30 years ago, Bauer has used her personal experience to uplift others while advancing the mission of Conquer MG. Since 2014, she has captained a team

consistently for Conquer MG's annual challenge walk, mobilizing 20 to 40 participants and raising thousands of dollars annually for the organization. To maintain momentum during the pandemic, Janet quickly pivoted, organizing a successful virtual walk. Bauer is also known for curating creative raffle prize baskets, cultivating community partnerships, and most recently, launching the MG Strong Together Support Group at Ascension Alexian Brothers Hospital in Elk Grove Village. Her warmth, humor, and generosity have left a lasting impression on both MG patients and supporters alike.

The Tracy Shackelford MG Service Award honors individuals who demonstrate exceptional commitment to improving the lives of those affected by myasthenia gravis. Carter and Bauer exemplify that mission in both action and spirit.

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 can find the 2026 application on our website at, 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.

No-Cost Technology Available

Sponsored by Amgen, PCs for People and the Myasthenia Gravis Foundation of Michigan are partnering to provide access to technology for patients living with rare, auto-immune and severe inflammatory diseases.



Equipment Available

- ✓ Full-set desktops
- ✓ Laptops
- ✓ Mobile hotspot and internet service for one year

Offer Eligibility:

To receive a sponsored computer and/or hotspot through PCs for People, customers must provide:

- A photo ID AND
- Verification of household income (less than 60% of area median income) OR
- Proof of enrollment in a government assistance program (Medicaid, SNAP, federal public housing, etc.)

CONQUER



**More information about PCs for People eligibility requirements can be found at www.pcsforpeople.org/eligibility.*

Place your order at
<https://ConquerMG.pcsrefurbished.com> and use coupon
code **conquermg100** to bring the cost down to \$0.

In Appreciation

WE ARE GRATEFUL To everyone who supports Conquer MG's mission. These donors recognized a loved one through their generous support this year.

*In Memory of Kim and
Joan Bychowski*

Janet Bauer

In Memory of Charles (Chuck)

Edward Carlson

Galarnyk & Associates LTD

In Memory of Debra Clyden

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In Memory of Michael J. Jamen

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In Memory of Nancy Van Laten

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Janet Bauer

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Sandra Stewart

Anthony and Linda Tovella

Deborah Volpe

John Volpe

Rosemary & Filomena Volpe

Heidi Wolter

In Honor of Joan Wincensten

William (Bill) Hargreaves

Pat McGonigle

In Honor of Victor Yipp

Mary Bertulfo

Kurt Etchingham

Jane Horan

Sonia Preiser

Curtis Raisig

Katherine and Bradley Stephens

Walter Szymkiewicz

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.

Conquer MG Welcomes a New Board Member

We are thrilled to welcome our newest member to the Conquer MG Board, Kelly Aiken. In this interview, Kelly shares her personal connection to myasthenia gravis, what inspires her, and what she hopes to contribute to our mission of empowering patients and raising awareness.

Kelly Aiken on Living with Myasthenia Gravis and Joining Conquer MG



Q: What's your connection to myasthenia gravis? Can you share your MG story?

Kelly Aiken: My MG journey began suddenly, one morning I woke up with severe, unexplained symptoms. It took time and persistence, but I eventually saw a neurologist who diagnosed

me with myasthenia gravis. Since then, I have experienced a wide array of symptoms, including weakness in my eyes, neck, shoulders, arms, hands, back, legs, and hips, along with challenges with breathing and speech. It has been a complex and often exhausting journey, and I have tried many treatments along the way. I have taken medications such as Mestinon, Prednisone, and two immunosuppressants, and I underwent a thymectomy followed by five years of plasma pheresis. Later, I tried IVIG and Rituxan, which offered a real sense of hope and improved my quality of life. Living with MG has taught me a plethora of lessons over the past 13 years about being grateful for abilities, for the people around me, and for the small things in life.

Q: Why did you decide to join the Conquer MG Board?

Kelly Aiken: I decided to join the Conquer MG Board because I want to contribute to a cause that has personally affected my life. Being part of an organization that advocates for the MG community gives me the opportunity to help others navigate their own journeys, offer support, and make a meaningful difference. Even small actions can create real change, and I hope to be part of

initiatives that improve access to resources, raise awareness, and foster connection among people living with MG.

Q: What do you hope to bring to the organization or the MG community?

Kelly Aiken: I hope to bring compassion, empathy, and a willingness to help wherever I can. Living with MG has shown me how valuable support and understanding can be, and I want to extend that to others in the community. I also hope to offer a listening ear and encouragement to those who are just beginning their MG journey, reminding them that they are not alone and that there are people and resources ready to help.

Q: What are your favorite hobbies or ways to relax?

Kelly Aiken: I enjoy reading, working on jigsaw puzzles, listening to music, and spending time with my two cats. These activities give me moments of calm and allow me to focus on things I love, which can be grounding when living with a chronic condition like MG. Even small moments of joy, like getting lost in a good book or putting a tricky puzzle together, can make a big difference in maintaining balance and perspective.

Q: What inspires you, or what message would you share with the MG community?

Kelly Aiken: I am inspired by positive people, those who face challenges with determination and continue moving forward even when things are difficult. Their strength reminds me that perseverance matters and that even small victories are worth celebrating. To the MG community, I would say, lean on each other, embrace the support that exists, and remember that resilience is built one day at a time. Even in difficult moments, there is hope, progress, and the potential for a meaningful life.

Fall Resource Fair in Springfield

Conquer MG held another successful Resource Fair on September 13th in Springfield, Illinois.

Thank you to our experts who provided important information to our MG patients:

Karen Horath, Licensed Massage Therapist

Jennifer Long-Leckrone, Licensed Clinical Social Worker

Dr. Bruce Marshall

Anna Miller, OTR/L, ATP

Lora Roberts

Angie Schneider, COTA/L, ATP, CAPS
Illinois Assistive Technology Program

Springfield Center for Independent Living (SCIL)

And to our generous partners for supporting the event:



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Even in moments of uncertainty, there is hope. Being prepared, informed, and willing to advocate for yourself creates a sense of confidence and strength. By sharing our experiences and supporting one another, we can empower the MG community, improve care, and find reassurance that we are not alone.

No matter the challenge, there are ways to take control, stay informed, and feel supported. Every step forward is a small victory, and together, we can face MG with hope and determination.

For resources on hospital visits, emergencies, or ways to get involved in patient advocacy, learn more here:

<https://myastheniagravis.org/life-with-mg/emergencies/>

If you are interested in learning more about patient advocacy or becoming an advocate yourself, consider joining the Conquer MG Board. We are always looking for community members to help expand our reach:

<https://myastheniagravis.org/about-us/board-of-trustees-and-staff/>

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 challenges
into strength!**



Give by mail:
4055 W. Peterson Ave., Suite 105
Chicago IL 60646

Give online:
www.myastheniagravis.org/

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