

CONQUER

News for our community

Tracy Shackelford MG Service Awardees: SeAndrea Ferguson and Joyce Holste

In June, Conquer MG presented the Tracy Shackelford MG Service Award to SeAndrea Ferguson and Joyce Holste. They both have demonstrated years of dedication and support to the MG community.

SeAndrea Ferguson: MG Community Advocate



(L-R) Conquer MG Executive Director Joan Wincentsen, Tracy Shackelford MG Service Award winner SeAndrea Ferguson and Board Chair Bob Rosecrans.

Diagnosed with myasthenia gravis (MG) at age 18, SeAndrea Ferguson found her way to the MG support group in Merrillville, Indiana, and immediately embraced these newfound friends. Within this comfortable space for sharing experiences and information, she stepped into a leadership role as the group's facilitator. Through the years, she has shared a wealth of information with her support group members, including her own research to learn how to manage symptoms with medications and treatments. When she meets others with MG, she lets them know they are not alone in their fight against the disease.

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11th Annual Viking Challenge for MG



We were lucky to have a beautiful day at Berens Park in Elmhurst. The early morning set-up moved quickly, with more than a dozen volunteers helping to transform the quiet of the park into an exciting day to gather and raise awareness and energy for those with myasthenia gravis. More than 100 people attended the 11th annual Viking Challenge for MG. We talked, walked, laughed, played oversized Connect Four, Kerplunk, and MG Bingo, and took a chance to win various raffle prizes. Friends and family took a momentary step in our shoes—by wearing heavy

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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.

We have a new address!

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

FROM YOUR EXECUTIVE DIRECTOR

You Learn Along the Way



What parting words did you write in your high school yearbook? Mine referenced Velveeta cheese and dill pickle sandwiches. Yes, it was odd. But throughout high school, some years I found a great lunch group and others less so. That sandwich was a touchstone, something that reminded me I would and could face ongoing change.

As with many of you, myasthenia gravis was one of those changes. It diverted my career, scared my family, and eventually brought me to a 10-year stint with Conquer MG. Now, it's time for another change. At the end of June, I stepped aside as the Executive Director of Conquer MG. I've shifted to part-time work and kayaking!

For parting words, I'll skip the cheese and pickles. Instead, I thank Conquer MG and you for how you've enriched my life. I've learned about myasthenia, of course—and I've also learned compassion and determination from our support group leaders, board members, Medical Advisory Board doctors, walk volunteers, and each person I've connected with who experiences MG. I dearly cherish the friendships I have made with many of you.

I want you to know this organization is in the hands of talented, capable staff members who care deeply about their work and you. Gifted communicator Michelle Weber is managing day-to-day operations. Amanda Lovell and Cory Jackson both have a depth of experience to steer our social media and annual walk, respectively. Craig Lagowski and Shea Lichtenstein are committed to tending sponsors, finances, and our database. Melissa Lagowski is the glue that keeps the team together.

If you have myasthenia, I hope you get to know other "MGers" who sit at this "lunch table." If MG changes your life, I hope (when you're able) you can find a way to help others—because it can help you heal.

I'm so glad to have met many of you in person, and I truly wish you well.

Best wishes,

A handwritten signature in black ink that reads "Joan Wincentsen".

Joan Wincentsen
Executive Director, Conquer MG

Conquer MG Patient Assistance Program

This Conquer MG program will help cover the cost of medical bills, prescription drugs and durable medical equipment up to \$1,000 per person per year. We are accepting applications for 2023.

You may be eligible if you are an MG patient, reside in Illinois, Indiana, or Wisconsin, and have some kind of financial hardship. Medical costs don't have to be MG-related. Contact the MG office (call 800.888.6208 or email info@myastheniagravis.org) for the application, or find it on our website.

Support Groups

Our groups:

- Offer information about MG and ways to cope with its symptoms
- Offer good listeners to care about your concerns
- Are open to patients and caregivers alike

Finding Great Comfort in the Support Group Community

Sidney and Meredith Wotman first learned about myasthenia gravis when their daughter suddenly fell ill with symptoms including choking, trouble breathing and seeing, and severe fatigue. “We had never heard of myasthenia gravis,” the Wotmans retell their early learning about the disease. “Our daughter’s physical appearance the day she returned home frightened us. Learning more about MG through doctor visits, Conquer MG support group meetings and reading made us realize how serious the disease can be. Today, we and our daughter have a much better understanding of the disease and how to manage its symptoms—one day at a time.”

Support groups are a great way for people living with MG to connect, share information and talk about their lived experiences so others don’t feel alone.

Both virtual and in-person meetings are offered each month. Email us at info@myastheniagravis.org to receive the link to the virtual group meetings. If you prefer to join an in-person meeting, let us know and we can add your name to the group that works best for you.

| GROUP | 2023 DATES | TIME | LOCATION/NOTES |
|---|---|--|---|
| Monthly Anywhere MG Virtual Group 2nd Tuesday | July 11, Aug. 8, Sept. 12, Oct. 10, Nov. 14, Dec. 12 | 2:00–3:30 PM CT | Group Leader: Kelly Aiken* |
| Monthly Anywhere MG Virtual Group 3rd Thursday | July 13, Aug. 17, Sept. 21, Oct. 19, Nov. 16, Dec. 21 | 2:00–3:30 PM CT | Group Leader: Bob Ratzel* |
| Chicago North In-person MG Support Group | Meets Quarterly Saturday, Sept. 16 Saturday, Dec. 9 | 10:00–11:30 AM CT | Levy Center, 300 Dodge Ave., Evanston Library Room, Evanston, IL Group Leader: Linda Loland |
| Chicago South and West Online MG Support Group | Meets Quarterly Saturday, Aug. 13 Saturday, Nov. 12 | 1:00–2:30 PM CT | Group Leaders: Victor Yipp and Joyce Holste |
| Northwest Indiana In-person MG Support Group | Meets Quarterly Saturday, Aug. 19 Saturday, Oct. 28 | 10:00–11:30 AM CT | Schererville-Dyer Library, 1001 W. Lincoln Hwy., Schererville, IN Group Leader: SeAndrea Ferguson |
| Miastenia Gravis Grupo de Apoyo Cuarto Sábado del mes cada otro mes | 22 de Julio, 23 de Septiembre, 18 de Noviembre | 11:00 AM (pacífico) 1:00 PM (centro) 2:00 PM. (este) | Group Leader: Leah Gaitan-Diaz RSVP: lamgchampions@gmail.com Meets the 4th Saturday of every other month (unless we need to accommodate holidays) |
| Men’s Virtual MG Support Group Open to men with MG, wherever they live | Thursday, Oct. 5 | 6:30–8:30 PM CT | Neurologist David Randall, DO, will be on hand for questions. Advanced registration required: info@myastheniagravis.org Leader: Gary Jackson |

If you are interested in leading a support group in your area, we can help you get started! To lead a group, email us at info@myastheniagravis.org. We are seeking support group leaders in Chicago, Rockford, Peoria, and the Quad Cities.

**Contact us at info@myastheniagravis.org (or call 800.888.6208) to receive the link and phone number to join these groups. At the meeting time, join via computer, tablet, or telephone.*

Kathryn Wotman

Finding a Silver Lining in My MG

Myasthenia gravis snuck into my life and changed everything. I'm sure most people who read this can relate to the sudden change in life's expectations. I am sharing my story to give hope and strength to anyone in this community who feels frustrated and even confused by this disease.

From a very young age I knew that I wanted to be a veterinarian. I worked tirelessly to this end, graduating from the University of Illinois School of Veterinary Medicine in 2002, and completing internships and residencies so I could specialize in the field.

My husband, two dogs and I took a leap and moved to Colorado in 2017 for an exciting career and personal opportunities. But in 2019, I started to experience vision problems — an ironic twist because I specialized in veterinary ophthalmology! With each passing week, I became weaker and unable to fully perform my job or get around on my own. The pandemic hit and trying to work through these health issues proved impossible.

My mom, my angel, was frantic trying to help from a distance in Chicago. I finally had to make the difficult decision to leave my home in Colorado and return to Chicago for medical care. Over the next eight months my parents were my caretakers.

This was both the worst and some of the best moments of my life. As many people who are seronegative for MG may experience, diagnosing the disease can be challenging and we are often made to feel like we must be crazy. My MG made a sharp impact: one day I tried to eat something that I had eaten hundreds of times before—but this time I could not chew. Over the next few weeks, talking and breathing became increasingly challenging, which forced my neurologist to take my symptoms seriously and prescribe aggressive treatment.



My mom continued to drive me to doctors and ocular physical therapy multiple times a week while having to wait in the car for hours. The silver lining while living at home was time. Time spent with my elderly parents, talking about things we have never had time to discuss, cooking together, playing Rummikub, crying because we were all scared of the pandemic and my health crisis, but grateful that we were together and alive.

Eventually, I gained enough physical and mental strength to return to Colorado; however, it was not my life as I had envisioned it. For the first several months, my husband had to drive me everywhere. My reduced work life was physically difficult and far from what I used to do and what people expected.

Over the past three years I have woken up every day and tried to do a little bit more than the day before. There have been too many setbacks to count, but I just start all over again. I have accepted that I can no longer do my whole job, and I have learned to appreciate and fine tune the parts that I can do. I am more conscious of thanking people who help me every day, and I am learning to accept my differences.

Today and most days, I can drive to familiar places, walk my dogs, cook dinner for my husband and myself, and be a contributing member of the veterinary community.

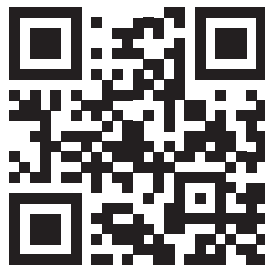
I am grateful to MG for making me stop and take a real look at what is important, appreciate a loving family and a support group that helped me feel like I was not crazy. Joining the support group was a huge turning point in that I did not have to be embarrassed about how I sounded or looked. Seeing others nod their heads in understanding as I spoke gave me strength and alleviated my fears. I am very grateful!

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11th Annual VIKING Challenge for MG



**Thank You
to Our
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Save the Date!

CONNECT • LEARN • SUPPORT



Chicago Regional Conference & Community Health Fair

brought to you by



SATURDAY, SEPTEMBER 9

Regional Conference: 10:00 a.m.–12:00 p.m.

Community Health Fair: 1:00 p.m.–3:30 p.m.

Chicago Marriott Oak Brook
1401 W. 22nd Street, Oak Brook, IL

Join us for a day full of information and support from experts who know.

This year's speakers:

Dr. Rabia Malik, neurologist at Rush University Medical Center, will update us about emerging MG therapies.

Dr. Sonia Caraballo, neurologist in the Advocate Medical Group, will address general wellness strategies for MG patients.

Takeaways from this event include:

- Time with MG patients and medical experts to get your questions answered.
- Information and educational materials.
- Connect with local businesses that cater to MG patients and specialize in their needs.
- Learn more about MG research and treatment developments from MG experts and corporate industry leaders.

This event is **FREE** to attend. You'll find chairs and resting areas throughout the event.

More information and registration will be shared in upcoming emails and on social media.



IN THE FIGHT AGAINST MYASTHENIA GRAVIS, THERE IS STRENGTH IN NUMBERS.

While generalized myasthenia gravis (gMG) may be a rare autoimmune disease, you're not alone. More than 700,000 patients worldwide know how difficult this disease can make daily life. The Prevail Study may be an opportunity to join other patients in important research and add a dedicated team of specialized doctors and researchers to your support system.

To be eligible for this study, you must:

- Be 18 years of age or older
- Have a documented diagnosis of myasthenia gravis
- Have symptoms that involve weakness of more than just the eyes: e.g., affecting speech, swallowing, breathing, arm or leg movements
- Not have had thymectomy or other thymus surgery within the last 12 months
- Not have a tumor of the thymus that has not been treated

To learn more about the Prevail Study, visit PrevailMGStudy.com.

PREVAIL
STUDY

ALEXION[®]
AstraZeneca Rare Disease

Tracy Shackelford MG Service Award *Continued from page 1*

In 2021, Ferguson participated in Rare Disease Week on Capitol Hill led by the RDLA (Rare Disease Legislative Advocates). That year she met virtually with Indiana's Senator Mike Braun and shared her MG journey. She has participated in market research and shared her story in personal interviews. Additionally, she's supported Conquer MG – creating a 50th Anniversary video and securing a \$1,000 grant from the EveryLife Foundation to support Conquer MG's mission. Until there is a cure for MG, Ferguson has vowed to continue her active role to help those affected by this snowflake disease.

Finally, she pushes herself to show up daily for her third-grade students who propel her to excel and conquer any obstacle that may get in the way. SeAnn is a true warrior that stays in control of her MG journey by maintaining a positive mindset.

Showing up is what Ferguson does and this year is no different. Conquer MG was happy to honor SeAndrea Ferguson with the Tracy Shackelford MG Service Award at the 11th Annual Viking Challenge for MG.

Joyce Holste: Recognized for Years of Service and Compassionate Care



For more than a quarter century—half the life of Conquer MG itself—Joyce Holste has eminently served as a Conquer MG board member and South Suburban Support Group leader.

"I still remember the day my family entered her support group in the community room

at the hospital in Blue Island," said Victor Yipp. "It was comforting to learn that others shared my journey, and there were resources available to me."

Holste attended her first support group meeting right after being diagnosed with generalized myasthenia gravis with thymoma in September 1993, and before being scheduled for surgery. She attended that meeting and many more with physical and emotional support from her husband, Randy, who continued to bring Joyce to the South Suburban Support Group meetings until she recovered from surgery.

In 1995, Holste joined the Conquer MG board and served for more than 10 years. Over the years, she has supported the organization's 25th Anniversary at

Maywood Park and 30th Anniversary Chicago boat cruise, helped to create Conquer MG's first website, participated in a one-hour show on Bears radio, hosted garage sale fundraisers at her home, raised funds for Conquer MG's annual walks, and the list goes on and on.

Joyce is a library of resources and a listening ear. In her many years of serving as Support Group leader, she has impacted many individuals with MG and their families—she is a gift to the MG community and well-deserves this recognition.

11th Annual Viking Challenge for MG *Continued from page 1*

weighted bags demonstrating muscle weakness and prism glasses that recreate double vision—to get a sense of what it feels like to have MG. This was all led by Kelly Aiken, an MG support group leader and volunteer who lives with MG.

After talking with several people with and without MG, I got a chance to see how important the sense of community and support is. Connecting to this community, small as it may be, breaks the feeling of isolation that is brought on by any chronic illness, maybe more so with MG since it is so rare. It is also important to see families who live with someone with MG be recognized for their role of supporter, champion and, in some cases, caregiver.

I am happy to report that we raised more than \$40,000. This money supports Conquer MG's educational events and resources, supports MG patients in need, and helps fund important research into new therapies for this rare disease.

Hats off to everyone who helped with this event and to those who showed up to help raise awareness of MG.

Sara Hasemeyer
Conquer MG Volunteer

Share With Us!

We are looking for great recipes to include in the next print edition of Conquer. Send us your best MG-friendly recipes.

Email us at info@myastheniagravis.org so we can share your faves!

In Appreciation

WE ARE GRATEFUL To everyone who supports Conquer MG's mission. These donors recognized a loved one through their generous support between September 2022–May 31, 2023.

| | | | |
|---|--|---|---|
| <i>In Memory of Nicholas Albers</i> Edward and Carolyn Albers | <i>In Memory of Claudia Cox</i> Anne Czolgosz Straube Allan Ulrich | <i>In Memory of Ann Neuman</i> Linda and James Rosenstein Catherine Boyce David and Tamar Chute Eunice Diamond Jaqi Green Rob Koplan James Lanard Maria Pacelli Angela Simonetta | <i>In Honor of Joanna Sherrod</i> Audrey Cooper-Stanton Esther Eisenstein Marci Eisenstein Danielle Sherrod Joanna Sherrod |
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| <i>In Memory of Michael Cerney</i> David Fitzgerald Dorothy Flynn | <i>In Honor of Gary Granat</i> Kevan Granat | <i>In Memory of Alan Rothstein</i> Harriet Rothstein | <i>In Honor of Kathryn Wotman</i> Meredith and Sid Wotman |
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| <i>In Honor of Tamara Chin</i> Thomas Reynolds | <i>In Memory of Sharon Maynor</i> Kim Dixon Gwen Finnegan Barbara Lindquist Mariann Reilly Jennifer Young Ida L. Jamen | <i>In Memory of Duane and Dorothy Seggerman</i> Donald Seggerman | |
| <i>In Memory of Debra Clyden</i> David Clyden | | <i>In Honor of A.H. Shahbain</i> Jack and Judy Trevillian | |

Financial Assistance Programs for MG Patients

In addition to Conquer MG's Patient Assistance Program, these organizations offer financial support for MG patients. Each organization has its own rules about reward renewal applications, and registration periods vary. Check the websites for details.

- National Organization for Rare Disorders (NORD) patient support program for MG patients: rarediseases.org
- The Assistance Fund: tafcares.org
- PAN Foundation: panfoundation.org

Pharmaceutical companies that manufacture specific medications may help with the cost of their medications. Check the individual company websites for details.



Affording MG Prescriptions

Myasthenia gravis can be challenging, and a major challenge is the cost of medications. Let's take a closer look at one drug: Mestinon® (generic: pyridostigmine bromide). This often is the first drug prescribed for people with MG.

What is the retail price difference between Mestinon and its generic alternative before insurance coverage? In a recent price check at a Chicago Walgreens, we found that 90 tablets (60 mg each) of the name brand Mestinon® can cost \$2,292 (\$25.47 per pill). At Jewel-Osco, you're looking at a grand total of \$1,722 (\$19.13 per pill). Meanwhile, the same dosage of the generic pyridostigmine bromide can cost \$64 at Walgreens and \$30 at Jewel-Osco. If you take six tablets a day, the cost adds up quickly.

Insurance coverage for these medications varies from plan to plan. However, keep in mind that some people need to use the name brand version—for instance, because of allergies, or because they need the Mestinon® timespan or syrup formulations.

Here are some alternatives that can lower your drug costs:

- **GoodRx**
 - This free mobile app and website helps you find the lowest prescription prices in your neighborhood. You plug in your prescription, then use the free GoodRx coupon at your local pharmacy.
 - If you don't have insurance for prescriptions, or if your insurance coverage is minimal, this is a good option.
- If you have insurance, you would use the GoodRx discount in place of using your insurance. You may be able to save more with the GoodRx discount than you do using your insurance.
- For example, by using the GoodRx discount coupon we found nearby chain pharmacies charged \$1,722 to \$1,870 for a 90 count of Mestinon® 60 mg tablets and \$31 to \$42 for 90 count total of generic pyridostigmine bromide 60 mg tablets.
- Visit www.goodrx.com or download the mobile app in your App Store for information on medications near your location.
- **Rx Outreach**
 - This online mail-order pharmacy provides low-cost medication to qualifying individuals and families whose income is below 400% of the Federal Poverty Level. For example, a single person whose income is below \$58,320 in 2023 can purchase 90 tablets of the generic pyridostigmine bromide for \$36, with no shipping cost.
 - Visit <https://rxoutreach.org/> to learn about eligibility and enrollment.
- **Northwest Pharmacy (Canada)**
 - Carries brand name Mestinon in several forms and generic pyridostigmine bromide at lower cost.
 - Visit online www.northwestpharmacy.com; or call (866) 539-5330 (USA Toll-Free); or email customerservice@northwest-pharmacy.com

We invite you to research different pharmacies to find the most affordable option for your needs. You can use these pharmacy options for your other prescriptions, too. And please let us know on our Conquer MG social media channels to inform others of the best pricing options you've discovered.

Recap: Emerging Therapies for MG

A number of new therapies to treat myasthenia gravis are in the works. During Conquer MG's October 2022 patient webinar, neurologist Priti-kanta Paul, MD, Assistant Professor, University of Illinois Chicago, reviewed these therapies.




Dr. Paul explained the disease mechanism - how cells interact to create the immune response that results in MG muscle weakness. As this interaction becomes better understood, scientists are identifying specific targets to interrupt the mechanism, which eases MG weakness. Dr. Paul reviewed terms like "complement inhibitor" and "Fc receptor inhibitor" and addressed FDA-approved Ultomiris, Soliris, and Vyvgart, as well as emerging therapies that target B cells, T cells, and other disease pathways.

While not all MG patients respond to the new treatments, Dr. Paul noted that many see significant improvement, often in a shorter time and with fewer side effects than experienced with medications that suppress the whole immune system.

For Dr. Paul's presentation, visit <https://www.youtube.com/watch?v=ip0MxGi4x3U>

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Upcoming Events

JULY THROUGH DECEMBER ONLINE
AND IN-PERSON SUPPORT GROUPS
FULL SCHEDULE ON PAGE 3

Anywhere MG Virtual Support

Chicago North

Chicago South and West

Northwest Indiana

Myasthenia Gravis

Grupo de Apoyo

Men’s Virtual MG Support Group

SATURDAY, SEPTEMBER 9

Regional Conference and
Community Health Fair