

CONQUER

News for our community

Treating MG: How Early Insights Led to Exciting Advances



Dr. Rabia Malik

A leading neurologist shares insights at September's Regional Conference and Community Health Fair

Dr. Rabia Malik, a prominent neurologist and member of Conquer MG's Medical Advisory Board, gave an inspiring presentation at the Conquer MG and MGFA Regional Conference

in September. For our community who missed the live event, here are the highlights of Dr. Malik's address.

How MG affects patients and families

Myasthenia gravis, a rare disease, can cause profound suffering, Dr. Malik told the patient audience. Muscle weakness can move from one side of the body to the neck and limbs, making basic movements more difficult and, in the worst cases, attacking the muscles that control swallowing and breathing.

Dr. Malik reviewed the science that led to the treatments that help MG patients live and manage symptoms today. From Thomas Willis, the first clinician to name the disease in 1672, to the observations of

Dr. John Simpson in the 1960s, we have learned a great deal about MG and how to treat it.

As a fellow at the National Hospital, London, Dr. Simpson was the first to compare MG with other autoimmune conditions such as hyperthyroidism, rheumatoid arthritis, systemic lupus erythematosus (SLE) and sarcoidosis. This supported the theory that myasthenia gravis was also an autoimmune disorder, opening the path to future treatments.

A look at the first generation of MG treatments

Some 60 years after Dr. Simpson's groundbreaking insights, we now have an array of research-based approaches to MG. The first wave of therapies sought to address muscle-specific tyrosine kinase (MuSK) MG, an especially severe form of MG. Researchers looked for an antibody that would disrupt an antigen on the surface of specific B-cells. This search led to the development of Rituximab, which a 2017 study showed to be effective in controlling MuSK MG symptoms in nearly 60% of patients as compared with 16% of those receiving a placebo.

Treatments that combine surgery with steroids emerged around the same time, Dr. Malik noted. Prednisone, a cortisone-like steroid long used to ease inflammation, was one of the earliest treatments for MG. A 2016 study showed that removal of the thymus gland, followed by moderate doses of Prednisone, provided significant relief—and fewer side effects than treatment with Prednisone alone.

Continued on page 7

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



Myasthenia gravis diagnosis and treatment have come a long way in 50 years. Technological advances have led to more timely and accurate diagnosis, and new and enhanced therapies have improved management of the disorder. Much knowledge has been gained about the structure and function of the neuromuscular junction, the fundamental aspects of the thymus gland and of autoimmunity, and the disorder itself. Despite these advances, however, there is still much to learn.

Through MGNet, Conquer MG works with academia, pharma and other patient advocacy groups to target its medical research funding. Three MGNet representatives responded with their thoughts about thymectomy.

Health Consequences of Thymus Removal in Adults

As myasthenia gravis (MG) investigators studying the role of thymectomy in management, we read with interest the article by Kooshesh et al.¹ that observed higher risks of mortality and cancer after thymectomy vs. controls. Thymectomy in a prospective randomized trial was proven to significantly improve clinical outcomes and reduce glucocorticoid requirements vs. medical regimens alone in non-thymomatous generalized myasthenia gravis.^{2,3}

Our concern with the retrospective, matched study¹ does not center on thymomatous MG patients; indeed, cancerous or suspected thymic mass was the indication for thymectomy in 871 of 1146 surveyed cases. Instead, we are concerned that study conclusions will dissuade physicians and the majority of generalized MG patients who are non-thymomatous from considering a procedure that yields clear benefits. We invite the authors to analyze risk in MG subjects alone and appreciate that increased risks persisted after excluding confounding disorders. Still, we question whether the increased relative risks relate more to thymus irregularity or to its removal. Finally, we note that MG studies including one cited did not observe increased risks of cancer from thymectomy.^{4,5}

MGNet/MGTX Investigators. (The authors have no financial relationships that relate to this letter.)



Gil I. Wolfe, M.D., Dept. of Neurology, Univ. at Buffalo Jacobs School of Medicine and Biomedical Sciences/ SUNY, Buffalo, NY



Henry J. Kaminski, M.D., Dept. of Neurology and Rehabilitation Medicine, George Washington University Medical Center, Washington, DC



Gary R. Cutter, Ph.D., Dept. of Biostatistics, University of Alabama at Birmingham, Birmingham, AL

References

1. Kooshesh KA, Foy BH, Sykes DB, Gustafsson K, Scadden DT. Health consequences of thymus removal in adults. *N Engl J Med* 2023;389:406-17.
2. Wolfe GI, Kaminski HJ, Aban IB, et al. Randomized trial of thymectomy in myasthenia gravis. *New Engl J Med* 2016;375:511-22.
3. Lee I, Kuo H-C, Aban I, et al. Minimal manifestation status and prednisone withdrawal in the MGTX trial. *Neurology* 2020;95:e755-66.
4. Vessey MP, Doll R. Thymectomy and cancer—a follow-up study. *British J Cancer* 1972;26:53-8.
5. Evoli A, Punzi C, Marsili F, et al. Extrathymic malignancies in patients with thymoma. *Ann Oncol* 2004;15:692-3.



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.

MONTHLY VIRTUAL GROUPS	2024 MEETING DATES	TIME	GROUP LEADER(S)
Tuesday Monthly Anywhere MG Support Group (via Zoom)	Meets 2nd Tuesday Jan. 9, Feb. 13, 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
Thursday Monthly Anywhere MG Support Group (via Zoom)	Meets 3rd Thursday Jan. 18, Feb. 15, Mar. 21, Apr. 18, May 16, June 20, July 18, Aug. 15, Sept. 19, Oct. 17, Nov. 21, Dec. 19	2:00 PM CT	Bob Ratzel

OTHER VIRTUAL GROUPS	2024 MEETING DATES	TIME	GROUP LEADER(S)
Men's MG Support Group	Meets Quarterly, Thursdays Mar. 14, June 13, Sept. 12, Nov. 14	6:30 PM CT	Gary Jackson and David Randall
Chicago South and West MG Support Group (via Zoom)	Meets Quarterly, Sundays Feb. 18, May 19, Aug. 11, Nov. 10	1:00 PM CT	Joyce Holste and Victor Yipp
Spanish MG Support Group	Meets Every Other Month on the 2nd Saturday Jan. 13, March 9, May 11, July 13, Sept. 14, Nov. 9	1:00 PM CT	To register, contact Leah Gaitan-Diaz at lamgchampions@gmail.com

IN-PERSON GROUPS	2024 MEETING DATES	TIME	LOCATION GROUP LEADER(S)
Springfield, IL MG Support Group	Monthly, Sundays Jan. 21, Feb. 18, Mar. 17, Apr. 21, May 19, June No Meeting, July 21, Aug. 18, Sept. 15, Oct. 20, Nov. 17, Dec. 15	3:00 PM	Parkway Christian Church, 2700 Lindbergh Blvd., Springfield, IL Kelley Aiken
Chicago North MG Support Group	Meets Quarterly, Saturdays March 9, June 8, Sept. 14, Dec. 14	10:00 AM	Levy Center, 300 Dodge Ave., Evanston Library Room, Evanston, IL Linda Loland
Northwest Indiana Support Group	Meets on Saturdays March 16, May 25, August 10, October 19	10:00 AM	Schererville-Dyer Library, 1001 W. Lincoln Hwy., Schererville, IN SeAndrea Ferguson

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



Become a Support Group Leader!

If you are 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					



Sara Hasemeyer

From Active to Grateful: Sara Hasemeyer's Journey with Myasthenia Gravis

Sara Hasemeyer's life was a whirlwind of movement and passion for Spanish dance including Flamenco, Classical, and Folkloric – teaching and performing. For 21 years, dance was her world, her rhythm, and her soul's expression.

Sara's dance career took her to stages nationally and in Poland and China, where she delved deeper into her passion. Her encounters with extraordinary individuals in the dance community shaped her perspective, even during the hiatus caused by an injury. Little did she know that this pause might have heralded the onset of her MG.

Eight years ago, Sara's life took an unexpected turn when she was diagnosed with myasthenia gravis (MG), altering her tempo and leading her onto a new path. Her MG story began subtly, with challenges in her vision. Driving became a struggle, her eyelids refusing to stay open, accompanied by relentless fatigue and double vision. These symptoms were brushed off by Sara – because she in no way could have considered a disease that would change her life until testing positive with antibodies signaling the onset of generalized MG.

After many months and a few doctors, she found the right one for her, and yes, some overnight stays at the hospital, Sara's life transitioned to a place of calm, albeit at a much different pace. Her days, once filled with the grace of dance, now revolve around stabilizing her MG. Medications introduced their own set of challenges, reshaping her body and redefining her limits.



Navigating life with MG introduced Sara to a new normal, where fatigue and limitations are companions she's learning to accept. With all of these adjustments, she found solace in attending Conquer MG support groups, drawing strength from shared stories of resilience and hope. Her perspective shifted from dwelling on limitations to celebrating victories big and small. With her husband, Matt, and family by her side, Sara found pillars of strength that enable her to cherish life's simple joys—a leisurely walk with her dogs, the vibrant hues of autumn leaves, and cherished moments with loved ones.

Hope shines on the horizon for Sara and others battling MG. Advances in research and treatment offer promise for a brighter future. She advocates not just for a cure but for awareness and connection. Sara's journey is a poignant reminder that life's tempo may change unexpectedly, but the melody continues. Each day, she chooses gratitude, embracing the glass-half-full mentality. Moments of despair coexist with moments of immense gratitude for the life she leads.

NOW APPROVED

Ask about

VYVGART[®] Hytrulo

(efgartigimod alfa and
hyaluronidase-qvfc)

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



Scan to learn more

VYVGART is a registered trademark of argenx.
VYVGART Hytrulo is a trademark of argenx.
For U.S. audiences only.
©2023 argenx US-ESC-22-00141 V1 06/2023



The second wave: complement inhibitors prove effective

Newer treatments quickly followed these findings. Dr. Malik pointed to the FDA's 2017 approval of Soliris for MG patients who test positive for AChR-antibodies. Soliris binds to C5 receptors in muscle cells, preventing C5b-9 antibodies from forming, thus interrupting MG's path.

A study of 125 patients with high life impairment scores who had not found relief on Prednisone revealed the value of Solaris. Over a 26-week period, patients who took the drug saw disease severity scores drop nearly four times as much as those taking a placebo. A quality-of-life measure geared specifically to MG showed an improvement of nearly 50% as compared with patients on placebo.

Dr. Malik also described the development of ULTOMIRIS, a treatment approved by the FDA in 2022. This medication is specially formulated for long-lasting inhibition of C5 antibodies.

Complement inhibitors have been shown to increase risks for meningitis, a condition that can be life-threatening, Dr. Malik noted. Vaccinating patients at least two weeks before starting a course of Soliris (or other complement inhibitor) may reduce (but not eliminate) infection risks.

Progress in treating pediatric gMG

Dr. Malik also outlined the advances in caring for generalized MG (gMG), which can affect children from birth. A new drug therapy known as RYSTIGGO focuses on the FcRn receptors in muscle cells, where harmful antibodies bind with the receptors, blocking nerve signals.

These antibodies are not absorbed by muscle cells in the same way as other antibodies that are not involved in gMG. The harmful antibodies stay in the cells, disrupting nerve signaling and interfering with muscle function. RYSTIGGO binds to FcRn receptors, helping to block harmful antibodies from binding at the site. RYSTIGGO has earned FDA approval for the treatment of both gMG and MuSK MG in adults.

Another new treatment known as VYVGART has shown potential in recent drug trials, Dr. Malik noted. Researchers found this treatment was more than twice as effective in reducing gMG symptoms as measured by Myasthenia Gravis Activities of Daily Living Scale (MG-ADL), and more than 4 times as effective in easing symptoms as measured by physicians using Quantitative Myasthenia Gravis (QMG) scores.

Concerns with FcRn antagonist treatments include higher risks for upper respiratory tract infections and urinary tract infections. When active infections are noted, treatment can be suspended until the infection clears. Patients using RYSTIGGO have also experienced severe headaches and, in some cases, aseptic meningitis. Hypersensitivity reactions such as rashes or swelling have also been noted.

Promising treatments on the horizon

Dr. Malik introduced us to several new pharmaceuticals that are not yet approved for use, but may soon benefit MG patients.

- **Zilucoplan**, a complement inhibitor that acts on the SC terminal, has been shown safe and effective against treatment-resistant AChR gMG in Phase II trials. Phase

III trials showed significant drops in MG-ADL scores at 12 weeks.

- **A new generation of B-cell inhibitors** may improve on the results seen with Rituximab. These treatments include two drugs that target CD20 antibodies and two more that target CD19.

- **Belimumab** is a B-cell activating factor (BAFF) that helps B-cells live longer so they can produce more helpful autoantibodies that block MG's path.

- **Bortezomib** is a proteasome inhibitor that causes certain proteins to accumulate in muscle cells, promoting earlier death in the highly active cells that drive MG symptoms.

- **CAR T-cell therapies** are an emerging group of treatments that equip T-cells with specially engineered receptors known as chimeric antigen receptors (CAR). This boosts the T-cells' ability to attack and destroy cells that drive MG symptoms. CAR T-cell therapies, which may someday help patients living with many different kinds of autoimmune disorders, have shown promise in preclinical studies and are now in Phase I and II drug trials.

Rabia Malik, MD is an Associate Professor in the Department of Neurology at Rush University Medical Center (RUMC). She completed her neurology residency at the University of Iowa Hospitals and Clinics. Following which she was a clinical neurophysiology/neuromuscular fellow at University of California, San Francisco.

Dr. Malik currently serves as the director of the MDA Care Center and EMG Laboratory at Rush University Medical Center and is the associate program director for the Clinical Neurophysiology Fellowship.

SUPPORT FOR MYASTHENIA GRAVIS (MG)



Find what makes you MORE THAN MG

Join the community of patients, caregivers, and other advocates

Whether you're looking to hear more about MG, find a friend with the same diagnosis, or receive some motivation, there's a place for you in the More Than MG community.

Visit More Than MG to explore:

- Patient stories shared through social media
- Tips for living life beyond an MG diagnosis
- Encouraging reminders and motivation
- Resources for you and your loved ones



MORETHANMG.COM

Follow
@MoreThanMG



Use our More Than MG Instagram filter
to help spark awareness about vision impairment.



GO TO @MoreThanMG ON INSTAGRAM



TAP THE SPARKLES ICON



SELECT THE "SEE MG" FILTER





Tips for Eating

This time of year, we tend to gravitate to comfort food that may not be ideal for your MG. Here are some ingredient swaps that bring dishes brimming with seasonal flavor for you and your family to enjoy.

A Non-Coarse Main Course

Ham, turkey, duck, Cornish hens, fish, stew, brisket—the list of meat-based main courses goes on and on. Small cooking tweaks can make these seasonal classics more tender and possibly even tastier.

- Look for cuts of meat with less cartilage or chewy fat.
- Debone poultry, fish or ham after cooking.
- Marinate meat in a closed container in the refrigerator.
- Cook meat longer but at a slightly lower temperature.
- Consider dark poultry meat, which tends to be softer than white meat.



Curb the Carbs

Sugar, carbs and fats can add up quickly in traditional holiday side dishes, but a few tweaks can help make a more balanced meal.

- Buy lower-calorie versions of a recipe's most common ingredients (be careful that you don't accidentally include too much salt or artificial sweeteners when making these swaps).
- Slightly decrease the total amount of sugar, butter, gravy or dressing called for in the recipe.
- Bake your traditionally fried food, like latkes (potato pancakes), instead.
- When frying food, use oils that are considered heart-healthy and have a higher smoke point. Think avocado, peanut, soybean or canola oil.
- Let fried food drain thoroughly before serving.
- Mix finely ground cauliflower into mashed potatoes.
- Swap grated cauliflower in for grated potatoes when making latkes.
- Use spaghetti squash in place of pasta noodles.
- Use seasonings instead of gravy or sauces.



Dessert

Hold on ... You don't have to reject all sweets. Here are some great ways to make "light" versions of classic cookies, pies or other baked goods that will be just as yummy!

- Replace some sugar with artificial sweeteners approved for baking like Stevia (many artificial sweeteners are much sweeter than sugar, so be careful with how much you add).
- Cut out half of the butter and use plain Greek yogurt, egg whites, applesauce or puréed bananas or prunes instead.
- Use reduced-fat cottage cheese or part-skim ricotta cheese in place of half the cream cheese.
- Swap cream with equal parts of evaporated skim milk.



We wish everyone a happy new year.

In Appreciation

WE ARE GRATEFUL To everyone who supports Conquer MG's mission. These donors recognized a loved one through their generous support between June 2023—November 30, 2023.

In Honor of Janet Bauer
Patricia Schranz

In Memory of Carl Bundy
Karen Bundy

In Memory of James Bychowski
Janet Bauer
Jean Boquist
Steven Bychowski
Peter Bychowski
William Bychowski
Joyce Hummel
Stephen and Rhonda Little
Robert and Kimberlee Little
Linda Pusateri
Regina Rowe
Josephine Stressler
Victor Yipp

In Memory of Debra Clyden
David Clyden

In Memory of Claudia Cox
Gregg and Christine Botkin
William and Judith Chapman
Jennifer Corcoran
Joyce Cox
Michael Cox
Anthony and Jennifer Crowley
Jessica Degrassi
Janet Eilers

Joaquin and Rose Marie Espejo
Vicki Felger
Wayne and Donna Granneman
Kathleen Hawley
Judith and William Hawthorne
Alvin and Rita Diane Holst
James Kelly
Christine Rice
Walter and Judith Roll
Bev Rosenbohm
Kenneth and Betty Lou Ruefer
Emily Shenk-DeMay
Thomas and Lucy Tucker
Gail Votroubek

In Memory of Denise Gordon
James P. Gordon

In Memory of Gary Granat
Dianne Miller

In Memory of Thomas Gries
Catherine Beattie
Richard and Eve DeMayo

In Honor of Joyce Holste
Loretta Nelson

In Memory of Andrew Jansen
Patricia Routon

In Memory of John Johnson
Louis Ferrari

In Memory of Nancy Van Laten
Arlene Sangmeister

In Memory of en MacLeod
Barbara Kramer

In Memory of Connie Ratzel
Bob Ratzel

In Honor of Bob Rosecrans
Linda Tieman
Anna Wildermuth Bridgman

In Honor of A.H. Shahbain
John (Jack) and Judith Trevillian

In Memory of Natalie Rose Striegl
Constance Kauffman

In Honor of South Suburban Walking Team
Joyce Holste
Emmy Bates

In Memory of Sharon Vance
Sandra J. Rowell

In Honor of Joan Wincentzen
Julie McCracken
Edward and Cherie Rickert

In Honor of Victor Yipp
Steve Shyman

CONQUER MG
Conquer Myasthenia Gravis

Interview With MG Patient
J'Sean Nunnery
Part 1 of 3
Sponsored by: argenx

Main Ideas

- Foods to avoid
- Foods to eat
- Importance of label reading
- Tips to stay on track

LET'S GET SOCIAL!

Gain access to more myasthenia gravis information and hear from the experts by subscribing to our YouTube channel!

@MyastheniaGravisOrgIllinois

Financial Assistance Programs for MG Patients

Conquer MG offers the Patient Assistance Program to help 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 2024 application by emailing info@myastheniagravis.org or find it on our website, www.myastheniagravis.org.



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.




Save the Date!



Mark your calendar and join us for the **12th Annual Viking Challenge 5K** in June 2024. Registration for the event will open in early spring.

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

CONNECT WITH US!

-  @ConquerMyastheniaGravis
-  @ConquerMG
-  @ConquerMG



In this issue

Conquer – Winter 2023

Treating MG: How Early Insights Led to Exciting Advances 1

Health Consequences of Thymus Removal in Adults 2

Support Group Meeting Schedule 3

Myasthenia Gravis Activities of Daily Living Chart 4

Sara Hasemeyer In Person 5

Tips for Eating 9

In Appreciation 10

Affording MG Prescriptions 11

Upcoming Events

2024 DATES FOR ONLINE AND IN-PERSON SUPPORT GROUPS
FULL SCHEDULE ON PAGE 3

Anywhere MG Virtual Support

Men’s Virtual MG Support Group

Chicago South and West

In-Person Groups:

Springfield Support Group

Chicago North Support Group

Spanish Support Group

SPRING 2024

12th Annual Viking Challenge!