OCTOBER 2022

CONQUER

News for our community

FDA Approves Ultomiris

In April 2022, the U.S. Food and Drug Administration approved ULTOMIRIS® (ravulizumab-cwvz) for the treatment of generalized myasthenia gravis in adults who test positive for the acetylcholine receptor (AChR) antibody. There now are three disease-modifying drugs approved to treat generalized MG.

ULTOMIRIS was originally developed by Alexion Pharmaceuticals, which was acquired by AstraZeneca in 2021. The FDA's approval was based on positive results from a Phase III trial that included 175 adults with generalized MG at multiple centers worldwide. Participants were randomly assigned to take ULTOMIRIS or a placebo for 26 weeks and were allowed to continue with their established MG medications throughout the study. The results showed ULTOMIRIS significantly outperformed a placebo at easing MG symptoms.

Study results also showed that ULTOMIRIS, with treatments every eight weeks, has long lasting benefits through 60 weeks of treatment. This compares favorably with eculizumab (Soliris®) which is dosed every two weeks.

Emerging Therapies for MG

After years of research and clinical trials, a number of new therapies for myasthenia gravis have arrived or will do so soon. Instead of suppressing a person's entire immune system (as with drugs like prednisone, azathioprine, and others), these therapies target and interrupt the immune system missteps caused by MG. For many, this means quicker response times, a more favorable side effect profile, and the potential for sustained and long-term remission.

Join us at 6:30pm CT on Tuesday, October 25, when neurologist Pritikanta Paul, MD, University of Illinois at Chicago, (pictured) will discuss "Emerging Therapies for Myasthenia Gravis." He'll explain terms like "complement inhibitor" and "Fc receptor inhibitor," and what these mean for MG treatment options such as Ultomiris, VYVGART, and Soliris. He'll also address new therapies in the works that target B cells, T cells, and other disease pathways.

To register, visit https://bit.ly/EmergingtherapiesMG

About MG

Myasthenia gravis (MG) can strike anyone at any age. 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
275 N. York Street, Suite 201
Elmhurst, IL 60126-2752
800.888.6208
www.myastheniagravis.org

FROM YOUR EXECUTIVE DIRECTOR

The Changing MG Landscape

A young co-worker recently asked me if I still had a CD collection. Her eyes grew wide and we laughed when I described my box of "45s" from 7th grade. In some ways, recent changes in the MG community rival in the music industry. New medications are less "clunky" (my neurologist's word). Delivery methods are improving, and clinical trials are trying to include our niche groups – like those with seronegative MG, or pregnant women.

At the same time, you can't turn an e-magazine page without reading about exercise, sleep, and nutrition. For those of us with autoimmune disease, wellness topics give us a way to take charge of our own health – and make a big difference in our MG disease.

In any case, as new medicines come to market, cost of care is a growing issue. Assistance programs can help (see page 15), and low-cost things like diet and movement actually can benefit our finances. By participating in the Autoimmune Association's National Coalition of Autoimmune Patient Groups, Conquer MG is working to make an impact on the legislative front, too. It's a complex problem that will take work from many different directions.

Wishing you well,

Joan Wincentsen

Joan Wincentsen, Executive Director

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 2022.

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 (800-888-6208 or info@myastheniagravis.org) for the application, or find it on our website.

Contact Update Form (PLEASE PRINT)

Mail to: Conquer MG, 275 N. York Street, Suite 201, Elmhurst, IL 60126

Name _____

Address _____

City _____ **State** _____ **Zip** _____

Email _____

○ Please note the above change in my contact information.

○ Please remove my name from your mailing list.

○ Please send ***Conquer*** via e-mail instead.

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

GROUP	2022 DATES	TIME	NOTES
Anywhere MG Group	2nd Tuesday of the Month: Oct 11, Nov 8, Dec 13	2:00 PM - 3:30 PM CT	Led by Kelly Aiken; Some meetings offer speakers, others focus on sharing concerns. Contact us for the Zoom link.
Chicago - North	Wednesday December 5	10:00 AM - 11:30 AM CT	Led by Linda Loland. Contact us for the Zoom link.
Chicago - South & West	Sunday November 13	1:00 PM – 2:30 PM CT	Led by Victor Yipp and Joyce Holste. Contact us for the Zoom link.
Nortwest Indiana	Saturday October 15	10:00 AM - 11:30 AM CT	Schererville - Dyer Library, 101 W Lincoln Hwy, Schererville, IN. Led by SeAndrea Ferguson.
Northeast Wisconsin (an independent MG group)	Thursdays Oct 13, Nov 10, Dec 8	6:00 PM - 7:30 PM CT	Alleluia Lutheran Church; 6725 Elmro Rd, Green Bay, WI Contact leader Niki Grossheim at new4mg@gmail.com for details.
Junta en Espanol - Spanish Language Meeting - Miastenia Gravis Grupo de Apoyo	Saturday November 26	1:00PM CT 11am (pacificó), 1pm (centro), 2pm (este)	RSVP to leader Leah Gaitan-Diaz at lamgchampions@gmail.com

*Contact us at info@myastheniagravis.org (or call 800-888-6208) to receive the link and phone number to join these groups. Be sure to say which group(s) you want. At the meeting time, join via computer, tablet, or telephone.

STATE OF ILLINOIS

EXECUTIVE DEPARTMENT

Proclamation

WHEREAS, myasthenia gravis (MG) is a disorder causing extreme muscle weakness which can impact a person's ability to see, smile, walk, talk, and breathe, and it is often misdiagnosed; and,

WHEREAS, myasthenia gravis is controllable by medication and other treatments for most MG patients, and although rare, it can prove fatal; and,

WHEREAS, because of its rarity (approximately 100,000 people are living with MG in the United States today), many Americans are often undiagnosed; and,

WHEREAS, Conquer Myasthenia Gravis is a not-for-profit organization founded in 1972; and,

WHEREAS, Conquer MG's mission is 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;

THEREFORE, I, JB Pritzker, Governor of the State of Illinois, do hereby proclaim June 2022 as Myasthenia Gravis Awareness Month and urge all residents to join with me in efforts to focus attention on the need for education, treatment, research, and ultimately, a cure, for this currently incurable disease.

In Witness Whereof, I have hereunto set my hand and caused the Great Seal of the State of Illinois to be affixed.

Done at the Capitol in the City of Springfield, this TWENTY-THIRD day of JUNE in the Year of Our Lord, two thousand and TWENTY-TWO and of the State of Illinois two hundred and FORTY-FOURTH

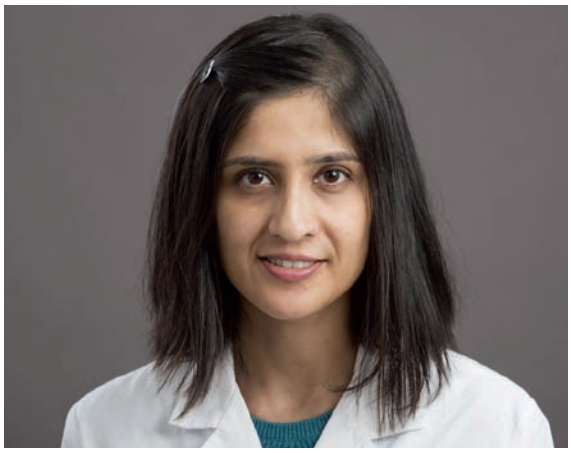
SECRETARY OF STATE

June: MG Awareness

Conquer MG obtained an official proclamation from Illinois to promote MG awareness! Governor JB Pritzker declared June 2022 to be Myasthenia Gravis Awareness Month and urges all residents to focus attention on the need for education, treatment, research, and ultimately a cure, for this currently incurable disease.

Calendar Club Winners - 2022

January – Steve Kuhnhofer, Gail Olley, Charles VanWinkle, Nancy Verity
February – Bob and Cindy Carna, Linda Loland, Rosemarie Manzell, Francisco Menchaca
March – Terry Haas, Arlene Sangmeister, Anonymous (2)
April – Sue Holloman, Cecil Johnston, Darren Madigan, Nancy Verity
May – Eadie Gardner, Darlene Perrone, Natalie Striegl, D. Weber
June – Peggy DeLaurentis, Sharon Gutkowski, Laura Littner, Anonymous
July – Jenny Berman, Bruno Czernoch, Bill Hargreaves, Julie McCracken
August –Sue Kennedy, Trudi O'Neill, Maureen Sandstrom-McGrath, Anonymous
September – Loretta Fleming, Niki Grossheim, James Gaba, Robert Smania



Seronegative MG: Why is it so hard?

By Rabia Malik, MD, Associate Professor
Department of Neurological Sciences
Rush University Medical Center

Myasthenia gravis is an autoimmune disease that is caused by autoantibodies. Autoantibodies are blood proteins formed by a person's own body. In MG these target the nerve muscle junction and can lead to its dysfunction. MG can be classified by different subtypes. One factor that determines a person's MG subtype is which MG-causing antibody is present in the person's blood.

Antibody testing is an important part of diagnosing MG. About 80-85% of MG patients will have antibodies against acetylcholine receptors (AChR) and about 1-10% carry the muscle-specific kinase (MuSK) antibodies. Being seronegative for myasthenia gravis means that **your blood ("serum") test does not reveal (or is "negative" for) the antibodies commonly seen in patients with MG.** In 15% of generalized MG and up to 50 % of ocular MG no antibodies against AChR or MuSK are detected. Experts believe that these patients likely carry low levels of antibodies that are below the detection level of current blood tests or carry different antibodies that have yet to be recognized.

Seronegative MG **behaves** a lot like MG that's related to AChR antibodies. Similar muscle groups are affected, with symptoms characterized as fatigable muscle weakness of the eyes, speech and swallowing function, neck, diaphragm, and limbs. Disease severity varies from one person to the next. For instance, seronegative ocular MG (where there is only eye weakness) that does not develop into generalized MG in the first two years usually remains a milder disease.

How can MG be **diagnosed** if the patient's blood test doesn't reveal known MG antibodies? Diagnosis in seronegative MG is based on symptoms, exam findings, and a specialized test called single fiber EMG test. The single fiber EMG test is a procedure that is offered at only a few medical centers. When a patient has a clear, objective response to treatment – for instance, sees improvement of droopy eyelids following treatment with Mestinon® - it can help clinicians make the diagnosis of seronegative MG. Without specific weakness that can be measured, the response to treatment may not always be apparent. It is important to remember that other diagnoses can mimic MG and should be excluded especially if symptoms are not clearly responsive to medications. Misdiagnosis can potentially expose patients, who do not have MG, to treatments that would not lead to any benefit and can cause serious side effects.

Seronegative patients respond to **medications** that are used for treatment of AChR-antibody MG including Mestinon®, steroids, mycophenolate, and plasma exchange. Since patients with seronegative MG are a diverse group that are not easily diagnosed and do not have a clear target antibody, these patients are **frequently excluded from clinical trials.** Newer medications that are receiving FDA approval for MG may be denied by insurance for seronegative MG patients as these group of patients were not included in the research studies and therefore the benefit of these medications in this group is not known. Additionally, the role of **thymus gland removal surgery** is not clear in this group of patients.

There is increased interest in helping patients with seronegative MG. Clinical trials are starting to include seronegative MG and there is ongoing research to better understand this type of MG with the hope that we can get better at diagnosing and managing this challenging disease.

Need Help?

In 2021, the Conquer MG Patient Assistance Program paid over $25,000 in medical expenses for MG patients who are residents of Illinois, Indiana, and Wisconsin.

"I want to sincerely thank Conquer MG for accepting my application for patient assistance. I have used the money toward my home ventilator and respiratory care." ---- A grateful recipient

VYVGART (Efgartigimod alfa-fcab)

By Kourosh Rezania, MD

Associate Professor, Department of Neurology, University of Chicago

Myasthenia gravis (MG) is caused by autoantibodies that impair transmission of the signal from the nerve ending to muscle, which leads to muscle fatigue and weakness. The acetylcholine receptor (AchR) antibody, which belongs to the IgG class of immunoglobulins, is the most common type of autoantibody associated with MG, representing about 85% of generalized MG cases.

For some, pyridostigmine (Mestinon®) alone can control MG symptoms. Still, most patients with generalized MG require medications that suppress or control the immune responses. Steroids (usually oral prednisone) and non-steroid immunosuppressants (such as tacrolimus, mycophenolate mofetil, or azathioprine) are widely used for this purpose. Often a patient needs high doses of these drugs over a long period of time, which results in significant side effects. That's why targeted treatments are being developed – to provide more effective treatment with fewer side effects.

One of these "more targeted" MG treatments works by reducing the level of disease-causing autoantibodies that circulate in the blood. This approach blocks the neonatal Fc receptors (FcRN). FcRN plays a major role in recycling IgG antibodies which include antibodies that cause MG, and increasing their lifespan in the circulation. Therefore, treatment that blocks FcRN clears IgG (which causes myasthenia) from the blood.

In December 2021, the U.S. Food and Drug Administration approved the first FcRN blocker for treatment of generalized myasthenia in adults who test positive for the AChR antibody. The drug was developed by the biotechnology company argenx, and is called VYVGART® (efgartigimod alfa-fcab). FDA approval was based on findings of the ADAPT study, which showed superiority of VYVGART compared to placebo in patients with AChR-antibody MG.

One of the measures of effectiveness in the ADAPT study was the myasthenia gravis activities of daily living (MG-ADL) score (See page 7.) In the study, sixty-eight percent of AChR- antibody positive MG patients who received VYVGART vs 30% of those on placebo had an improvement in their MG-ADL score by two or more points. A favorable response was seen within two weeks of treatment in 84% of treatment-responsive patients.

The ADAPT study also included MG patients who are "seronegative," meaning they don't have AChR-antibody myasthenia. However, there were too few seronegative patients in the study to draw conclusions about VYVGART effectiveness for this group. VYVGART has since been approved in Japan for generalized MG patients who do not have sufficient response to steroids and nonsteroidal immunosuppressants, regardless of the antibody status.

VYVGART is administered intravenously over one hour, once a week for four weeks. Patients

receiving VYVGART experience a decrease in both disease-causing and normal IgG. The effect of

VYVGART is of limited duration; most patients need follow-up cycles (each cycle defined as four weekly infusions) for the improvement in MG symptoms to continue.

The timing between cycles differs from one person to another and depends on when the effectiveness of VYVGART starts to wear off. In

(continued)

the ADAPT study, those who didn't respond to the initial VYVGART cycle received a repeat cycle in seven weeks, while 27% of participants received their repeat cycle at 12 or more weeks. The safety of a repeat VYVGART cycle before 50 days has not been established.

In practice, the timing of the cycles may be determined by a patient's individual circumstances such as occupation, functionality, (for instance, some occupations like airline pilot, can't accommodate dips in strength) and other existing medical factors. The author advises his patients on VYVGART to reach out through the electronic medical system when their MG symptoms start to increase after a VYVGART cycle.

Patients should be watched for allergic reactions for one hour after every VYVGART infusion. As VYVGART decreases the level of normal antibodies as well the disease-causing ones, infection is a potential side effect. Respiratory and urinary infections occurred in 33% and 10% of patients who received VYVGART (compared to 29% and 5% in patients who received placebo) in the ADAPT study. The infections were generally mild to moderate in nature. Headaches, tingling, and muscle ache are other potential adverse effects of VYVGART. Although there are no mandatory vaccinations before starting VYVGART, it is recommended that patients receive all age-appropriate vaccinations before starting VYVGART and avoid taking live and attenuated live vaccines while on that drug. VYVGART should not be administered in combination with gamma globulin products and may decrease the effectiveness of certain monoclonal antibody treatments.

Myasthenia Gravis Activities of Daily Living (MG-ADL)

Physicians use this tool to score a patient's MG symptoms based on the patient's recall of the symptoms during the prior week. A person's score can range from 0 (normal) to 24 (most severe)

	Score = 0	Score = 1	Score = 2	Score = 3	Your Score
Talking	Normal	Intermittent slurring or nasal speech	Constant slurring or nasal speech, 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	
Brushing teeth or hair	Normal	Extra effort, but no rest periods needed	Rest periods needed	Cannot do one of these functions	
Arising from chair	Normal	Mild, sometimes uses arms	Moderate, always uses arms	Severe, requires assistance	
Double vision	Normal	Occurs, but not daily	Daily, but not constant	Constant	
Eyelid droop	Normal	Occurs, but not daily	Daily, but not constant	Constant	
				Your Total Score =	

Sponsored content

You're invited to connect with the gMG community at a

free in-person event

Join others living with generalized myasthenia gravis (gMG) and their caregivers. Ask questions, gather information, and learn more about the condition at a free in-person event.

WHEN

Saturday, October 15, 2022 at 12:30 PM CT

Wildfire Oakbrook
232 Oakbrook Center
Oakbrook, IL 60523

Andrew Gordon, *MD*

Find more dates at the website below.

WHO

US gMG patients and caregivers at least 18 years of age

HOW

visit AlexiongMGEvents.com

Alexion encourages all participants to follow CDC guidance for COVID safeguards, available at https://www.cdc.gov/coronavirus/2019-ncov/, and to abide by any additional local health requirements. (Note any individualized venue requirements.) Your attendance at this event is voluntary. Please understand that there is a risk that you may be exposed to COVID-19 or other communicable diseases during this event. We have taken measures to provide a safe and sanitary meeting space, but we cannot fully eliminate your risks of exposure and you are responsible for taking all necessary precautions. By choosing to attend in person, you are voluntarily assuming any risk of exposure that may occur in connection with this event.

Making Connections
Education and support for generalized myasthenia gravis

Making Connections is a program sponsored by Alexion that provides education and support for patients and caregivers in the gMG community.

ALEXION®
AstraZeneca Rare Disease

Gary Jackson

A Mental and Physical Adjustment: "I did not know how to stop exercising or the meaning of moderation."

My name is Gary and I am from Chicago. I grew up in the inner city with six sisters and brothers, and parents who were married for over 50 years. At age 10, I had a stroke that launched my health and fitness lifestyle. After graduating college in 1993, I was recruited as an electronic engineering technician in Sacramento, California. I designed and patented a piece of fitness equipment in 2010. I have four children and one is deceased.

I was a life fitness coach for over thirty plus years before being diagnosed with myasthenia gravis in October 2013. I was in the best shape of my life at that time and getting ready to celebrate my 50th birthday.

I was training four people a day, five days a week. I completed a century bike ride every Monday and ran nine miles in the evenings, five days a week. I lived an intense fitness lifestyle in California.

My MG started in 2012 with double and blurred vision at dusk. Unaware that this was the start of something life changing, I ignored it. This would happen to me once or twice a month late in the evening. My first true scare happened while roller skating around 2 am. I was frightened because there appeared to be twice as many people skating fast on the crowded floor. Faith would have it that my daughter skated up next to me and she escorted me off the floor. After sitting for thirty minutes with my eyes closed the double vision cleared up and I drove a half mile home.

The episode that sent me to the emergency room happened in October 2013. I awoke on a Wednesday morning with double and blurred vision that continued for three days straight. A weeks' worth of in-hospital tests and an EMG were negative, but the droopy eye lid, headache, blurred and double vision remained. I took Mestinon with no positive result for the next three months. A second EMG test around my right eye in January of 2014 confirmed the diagnosis. I took prednisone and Mestinon for the next six months.

In June of 2014, I awoke one morning with shortness of breath and was rushed to the hospital. The doctors discovered both my lungs were filled with blood clots. I was treated with blood thinners for the next two years. A CT scan confirmed the blood clots had cleared and the neurologist cancelled the Mestinon and prednisone and prescribed CellCept. After two months on Cellcept, my white blood cell count dropped very low and I received a bone marrow biopsy for cancer. It was determined I did not have AIDs or cancer. In 2016, I suggested that we start over with no treatments because I was physically and mentally exhausted. My white blood cell count returned to normal.

With MG, I went from being superman to just being alive. I suffered ten falls; one fall resulted a torn rotator cuff. I had to face a new reality that high intensity sports are no longer a part of my life. I saw a therapist for two years to deal with mental stress and depression. I gained over thirty pounds from taking high-dose prednisone. I was mentally and physically exhausted from the side effects from the drugs and the muscle fatigue. I decided I wanted to die.

There was no confirmation that the complications I was suffering were side effects from the drugs used for treatment, but the most serious complications went away when we stopped the drug treatments.

(continued on page 11)

Finding Strength One Day at a Time

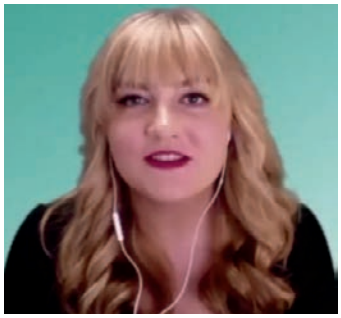
We asked Sarah Bolton, Resilience Coach and Rare Disease Advocate (@boltysbazaar), to talk to individuals who have MG, and learn about their resilience. You can find the "Finding Strength One Day at a Time" series of conversations on Conquer MG's YouTube Channel. (Visit YouTube.com and enter "Conquer Myasthenia Gravis".)

Garry Morehouse, a retiree in Midland, Ontario, describes a slow and steady return to exercise and pickleball.

Aimee Zehner, CEO/founder of EveryBody Empowered in New York City, followed her instincts through a 7-year journey to get diagnosed (yes, someone actually has those rare LRP4 autoantibodies!).

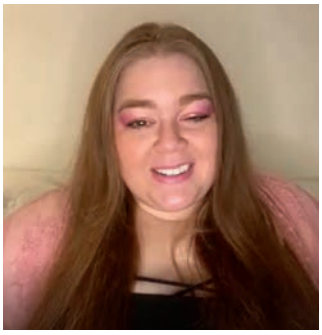
Aleece Maree, aesthetician in California, has developed a healthier relationship with food, found ways to calm her mind and body, and has learned to see others' support as an expression of love.

Alicia Angel, a singer/songwriter/artist in New York City, discovered life hacks that saved her energy. MG changed her traveling lifestyle and now she works to keep a positive viewpoint.



from left Sarah Bolton, Aleece Maree

Garry Morehouse



from left Aimee Zehner, Alicia Angel

(Gary Jackson continued from pg 9)

That is when I realized that anger, stress, depression, and sadness worsen my MG symptoms. So every day I find ways to see the good beyond the bad and love myself a little more.

I started to pray, and my prayer changed from asking God why me, to thanking him for what remained. I can no longer do the high intensity sports, but today I am back down to two hundred pounds. I feel great and I know my physical and mental limitations. I stay within my window of safety to keep myself and others safe. I've worked with Rush University students and neurologists to educate and support others who are diagnosed with MG. I wrote my first book, Stroke: My Road to Total Recovery, and it can be purchased on Amazon. My second book, The Message Art of Poetry, can be purchased at Themessageartofpoetry.com

I started painting in 2019, and it keeps me busy and happy. My world is centered around keeping my stress level to a minimum, preventing depression and anger, and keeping a positive state of mind to minimize my MG symptoms.

IMMUNOVANT

Re-thinking Possibilities

for people with autoimmune diseases

At Immunovant, we are dedicated to enabling normal lives for people with autoimmune diseases. As a leader in FcRn inhibitor technology, we are boldly developing innovative therapies for a range of debilitating autoimmune diseases with significant unmet patient needs.

Explore our commitment to addressing patient needs at **Immunovant.com**

Hoffman and Wincentsen Recognized for Service

from left, Conquer MG Chair Bob Rosecrans, Mary Kay Hoffmann and husband Bill

At this year's Viking Challenge for MG walk, Mary Kay Hoffmann of Glenview received Conquer MG's first Tracy Shackelford MG Service Award. Up until the pandemic Mary Kay led the Chicago North Suburban MG Support Group. In nominating Mary Kay, a group member explained, "She made meetings informative, accessible, comfortable, and fun. She encouraged each of us on a path to be successful in our health goals, and always was available to answer questions. Mary Kay continues to go the extra mile to reach out and keep MG patients connected.

Like its inspiration, the Tracy Shackelford MG Service Award recognizes an individual who advocates for others in the MG community with persistence, compassion, and care.

In a surprise move, the Conquer MG Board elected to announce a second service award. Board Secretary Tammy Carter presented long-time Executive Director Joan Wincentsen with the Above and Beyond Award, "for always exceeding expectations, always reaching above and beyond in the service of individuals who have myasthenia." Carter and Rosecrans lauded Wincentsen's commitment to those who have this rare disease, citing her work with individuals,

from left, Bob Rosecrans, Joan Wincentsen, Tammy Carter

wellness initiatives, and MGNet – through which the organization funds cutting edge research.

Wincentsen thanked the Board, adding "I never thought my own illness would lead to meaningful and interesting work!"

50 Years of Milestones

In celebration of Conquer MG's 50 year anniversary, support group leader and patient advocate Victor Yipp has assembled 50 years of milestones. Here are some of our favorites.

- **1972**: First patient meeting draws 200 people; the organization creates its first Board and Medical Advisory Board
- **1977**: Mayor Michael Bilandic proclaims "Myasthenia Week" for the city of Chicago
- **1988**: Survey sent to 650 members reports countless positive comments
- **1995**: organization changes from Greater Chicago Area Chapter to the Myasthenia Gravis Foundation of Illinois
- **1997**: Joyce Holste, Helen DeWitt, and Dr. Scott Heller are interviewed about MG on Chicago radio
- **1998**: Dr. Wayne Rubinstein produces the organization's first webpage
- **2007**: Eight support groups in Illinois and Northwest Indiana are meeting regularly
- **2010**: Our Pilot Grant program awards its first MG research grant to Premkumar Christadoss, University of Texas at Galveston. Twelve more grants follow
- **2013**: 1st Annual "Strides Against MG" Walk raises MG awareness and funds
- **2014**: Patient Assistance Program for MG patients in Illinois, Indiana, and Wisconsin begins. Since its start, 150 requests for support have been fulfilled with over $100,000
- **2016**: The organization becomes Conquer Myasthenia Gravis (Conquer MG for short)
- **2019**: Conquer MG joins MGNet; the consortium of academia, patient groups, and pharma; to fund MG research
- **2020-21**: Conquer MG's Medical Advisory Board provides COVID guidance for those with MG
- **2022**: We celebrate 50 years of serving those who have myasthenia!

We invite you to see more at *www.myastheniagravis.org/conquer-mg-celebrates-50-years/*

10TH ANNUAL Viking Challenge for MG

CONQUER MG celebrates 50 YEARS

Thanks, Sponsors!

argenx

ALEXION AstraZeneca Rare Disease

janssen

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In Appreciation

WE ARE GRATEFUL for everyone who supports Conquer MG's mission. These donors recognized a loved one through their support between February 1 and August 31, 2022

In Memory of Fred Arnold
Loretta Fleming

In Memory of Robert R. Brodeur
Susan Lizine

In Memory of David Brown
Sandra Brown

In Memory of Ronald Gacek
MaryAnn Fahey
Carol Nelson
Members of Primary Care Psychology Associates
Alice Smith
Lizabeth Smith

In Memory of Peggy Greene
Daniel D Greene

In Memory of Michael J Jamen
Ida L. Jamen

In Memory of Robert Lenhardt
Joy Gifford

In Memory of Jack Mendelson
Stephen Kleinman

In Memory of My Mother who had MG
Renee Swanger

In Memory of Alexander Niemczura
Darlene Niemczura

In Memory of Agnes Pezl
Daniel France
Kenneth France
Alila Hollander

(Agnes Pezl continued)
Marlene Karnosh
Georgann Kramer
Janet Migaki

In Memory of Connie Ratzel
Pamela Samuels

In Memory of John Gilbert Relvas
Sylvia Salomon

In Memory of Philip M Ringle
Kathryn Henson

In Memory of Lorrie Schohn
Joel Schohn

In Memory of Tracy Cartwright Shackelford
Ann Butterman
Norman Cohen

In Memory of Tracy Shackelford
Gail Maru

In Memory of Larry Swanson
Bonnie Zeigler

In Memory of Walter Wasel
Jean Hill

In Memory of Wally Wasel
Cozen Karen

In Memory of Paul Watland
Thomas Brown
Linda Watland

In Honor of Kelly Aiken
Pennie J. Robinson

In Honor of Kate Carlson
Meredith and Sid Wotman

In Honor of Peggy Cashman
Michael and Sally Pope

In Honor of Sara Hasemeyer
Daniel Chiss

In Honor of Katie Jasmon
Pat Landgrebe

In Honor of David Kennedy
Susan Kennedy

In Honor of Cheryl Meltzer
Ann and Bob Neuman

In Honor of Bob Rosecrans
Al Chan
Linda Osborne
Linda Strain

In Honor of Joanna Sherrod
Esther Eisenstein
Danielle Sherrod

In Honor of Larry Slager
Joe and Dee Schram

In Honor of Victor Yipp
Katherine and Bradley Stephens

Financial Assistance Programs for MG Patients

In addition to Conquer MG's Patient Assistance Program, these organizations offer financial support for MG patients. Perhaps because it's near year end, some are temporarily closed or waitlisting. Each one has 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: *https://rarediseases.org/wp-content/uploads/2021/01/MG-PAP-FAQ-1-2021.pdf*
- **The Assistance Fund**: *https://tafcares.org/*
- **PAN Foundation**: *https://www.panfoundation.org*
- Various programs help with the cost of medications. To find links to NeedyMeds, RXHope, and other sites, visit *www.myastheniagravis.org/we-can-help/other-organizations-can-help/*
- Pharmaceutical companies that manufacture specific medications may help with the cost of their medications. Check the individual company websites for details.

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CONQUER MG celebrates 50 YEARS

In this issue

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Upcoming Events

MONTHLY - 2ND TUESDAY
Anywhere MG Virtual Support Group Meeting

TUESDAY, OCTOBER 25
Webinar: Emerging Therapies for MG

OCTOBER 15
Northwest Indiana MG Support Group

NOVEMBER 13
Chicago South/West MG Support Group

DECEMBER 5
Chicago North MG Support Group