



COMMUNICATOR

2022 ESTHER M. LAND FOUNDERS AWARD

This award honors a person dedicated to the success of MG-MI and who supports MG patients throughout Michigan



Esther Land & Jim Burr

James Booth Burr, Jr, Esq. (also known as Jim) is a legacy to the Myasthenia Gravis Foundation of Michigan. It all began in May of 1987, 35 years ago, when he was introduced to MG and our organization by a friend who had recently been diagnosed with the condition. Jim is an attorney by profession. As a tribute to his friend, he joined our Board of Directors in July of that year serving as our legal counsel. Not wanting to over-commit, he was given the privilege of a 1-year term. Finally, after six years

he committed to the normal 3-year term and remains with us today!

A few examples of Jim’s generous donation of expertise include facilitating MG-MI to obtain our 501(c)(3) status from the IRS and our Michigan Nonprofit Corporation licensure, and rewriting our Bylaws. He has presented on the legality power of attorney, guardianship, wills and trusts at support meetings. A low-key, fun-loving personality, he brings humor to our Board where he serves as an engaged Director while providing thoughtful legal advice.

Jim exemplifies the criteria for the award, giving us the distinct privilege of presenting this award to Jim!

Memorial • James Teener, M.D.

On November 28, 2022, the Myasthenia Gravis (MG) community lost a champion and friend in the untimely passing of James W. Teener, MD. Dr. Teener was known as a caring and competent neurologist with a memorable smile. He was Co-Chief of the Neuromuscular Division at University of Michigan Health—Taubman Center in Ann Arbor, and served in the University Hospital EEG/EMG Lab. His depth and breadth of expertise in neuromuscular diseases made him invaluable to patients and medical colleagues.



Dr. Teener was also a professor for the University of Michigan Medical School where he passed on his vast neuromuscular medicine knowledge and enthusiasm to nearly two decades of health professional students.

Dr. Teener was the primary neurologist for many MG patients throughout Michigan and will be deeply missed by them, his family and colleagues. The UofM Department of Neurology is currently working to ensure the seamless transfer of patient care to other providers.

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A big
THANK YOU
to our
newsletter
sponsors

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2022 CORAGGIO SPIRIT AWARD

The *Coraggio* Spirit Award is presented annually to a recipient who embodies the *Coraggio* theme: that With Courage You **Can** persevere and resiliently lead a life of purpose and joy.

The 2022 *Coraggio* award recipient is a young woman who, after being diagnosed with a challenging case of myasthenia gravis, has courageously pursued her personal, professional, and volunteer goals with purpose, passion, and joy!



Lisa Gigliotti & Ashley Boucher

Ashley Boucher was starting her college years when she experienced facial muscle weakness and slurred speech so severe she had to write out what she was trying to say, and subsisted on smoothies. Through the three years it took her to get diagnosed with MG, she continued to search for medical answers while continuing to pursue her career goals. She achieved her goal of earning a Business Administration Bachelor's Degree from Ferris University in December 2022. At her local MG-MI support group meetings she positively encourages other MG patients and caregivers by sharing the treatments she has used, the work-arounds she uses to accomplish MG safe and restorative exercise and muscle strengthening, as well as other activities which bring purpose and meaning to her life. She and her mother Dawn have offered to organize the Saginaw-Bay City area support groups to spread MG awareness and positive encouragement. Her latest exciting *With Courage I Can* news is her recent marriage engagement!

If you ask what motivates her *Coraggio* Spirit and desire to volunteer for MG-MI, her enthusiastic response is to bring hope, information, and encouragement to others, especially young people with MG. For Ashley's indomitable and passionate determination to live a life of purpose and joy despite having MG, and for encouraging others to a life with similar zeal, she is proudly awarded MG-MI's 2022 *Coraggio* Spirit award!

2022 VOLUNTEER OF THE YEAR AWARD



Jennifer Frohm & Esther Land

Jennifer Frohm's interest in MG began when her husband, Jim, was diagnosed with the condition in 2014. To learn more about MG and understand what Jim was experiencing, Jennifer educated herself by searching out as much information as she could about this puzzling disorder. She also attended MG-MI support groups in the Lansing area with Jim, where the knowledge and tidbits they gleaned from others helped them better understand life with MG.

When Jim's symptoms became worse, Jennifer studied up on the newer treatment option like Soliris® and was a great supporter when the decision was made to begin this therapy. As Jim struggled with increased weakness, her courage became stronger as she advocated for his well-being.

Sadly, other physical complications claimed Jim's life in May of 2021. During the days following his passing, she reached out to us with a determination to volunteer and share the insights she learned with others who live with MG. During that summer she began volunteering at the MDA/MG clinic at MSU. She willingly drives the 100 mile round-trip drive every month to assist during clinic appointments. She supports and encourages patients from newly diagnosed to those who have lived with MG for many years. In addition to inspiring others, her desire to volunteer for MG-MI comes from gratitude for the support it gave her husband and her, and to honor her beloved husband.

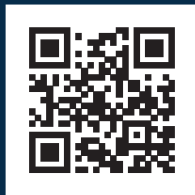
It is with sincere appreciation we present the 2022 Volunteer of the Year award to Jennifer Frohm.

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MICHIGAN HEROES AWARD

On November 17, 2022 Lisa Gigliotti, Esther Land and Susan Woolner were privileged to attend the 2022 Governor's Service Awards ceremony at the beautiful Fox Theatre in Detroit. The ceremony is hosted by the Michigan Community Service Commission to recognize and celebrate individuals and organizations that have made a difference for Michigan.



During the ceremonies, Esther proudly accepted the *Michigan Heroes* award from Michigan's Lt. Governor Garlin Gilchrist, II.



It was a delightful evening and an honor for Esther and whole MG-MI community!

Susan Woolner & Esther Land



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THANK YOU

A special thanks to John Twist of University Motors Limited for again supporting MG-MI with a 50/50 drawing at your 48th Birthday Party on January 21.

Thanks also Kay Cobb for donating back your half of the drawing. We and our MG community appreciate your support!

Safety First!



HOW DO YOU EXPLAIN YOUR RARE DISEASE TO A LOVED ONE?

Take a page out of *Klara's Talent*, a free children's book all about generalized myasthenia gravis (gMG), sponsored by Alexion Pharmaceuticals!



REQUEST A FREE COPY OF KLARA'S TALENT AT
KLARASBOOK.COM

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UPCOMING SUPPORT GROUPS

April 20, Thursday • Grandville, 12:00 noon • Russ' Restaurant

4440 Chicago Dr SW, Grandville 49418. • Lunch on your own

April 27, Thursday • Livonia, 2:00 pm • Livonia Civic Center Library—Michigan Room

2777 Five Mile Rd, Livonia 48154

New locations are being added so check our website for a venue near you at www.mg-mi.org

COVID-19 and MYASTHENIA GRAVIS

"Can my dad take Paxlovid?" I sensed a tone of great urgency in her voice. I was returning the call from the daughter of my 101-year-old, myasthenia gravis (MG) patient. He had tested positive for COVID after developing mild symptoms. His primary care physician suggested they contact me to ascertain if Paxlovid was OK for him.

I know my patients well and, in this case, I knew he was taking Mestinon (pyridostigmine). I reviewed his medication list to check if there were other medications he was on that could be contraindicated with Paxlovid. Fortunately, there were none. I informed his daughter that it was OK for him to take Paxlovid.

He did take the medication and had a good recovery despite feeling a slight rebound in symptoms—likely a COVID rebound—which seems to be a frequent occurrence following the prescribed 5-day course of Paxlovid. Later on, at his follow-up visit with me, we discussed COVID rebound following Paxlovid. It has happened to him, me, and many others.

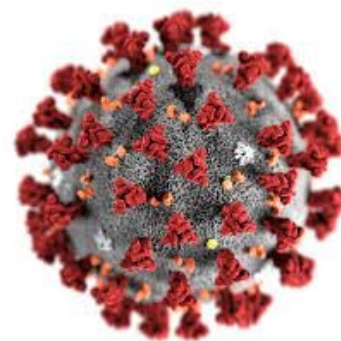
Paxlovid contains two different drugs (nirmatrelvir tablets; ritonavir tablets) and was authorized for emergency use by FDA under an EUA (emergency use authorization), for the treatment of mild-to-moderate COVID-19 in adults and pediatric patients (12 years of age and older weighing at least 40 kg) with positive results of direct SARS CoV-2 viral testing, and who are at high-risk for progression to severe COVID-19, including hospitalization or death. We know infection has been the leading cause of exacerbations in myasthenia gravis. Those who use immunosuppressive therapies (ISTs) are likely to be at increased risk of contracting COVID-19 or having a more severe course of the virus.

Paxlovid can be safely used with any of the immunosuppressant medications used in the treatment of myasthenia gravis, with the exceptions being cyclosporine and tacrolimus. The blood concentrations of these two immunosuppressants increase and have to be monitored carefully. Physicians and other prescribers can use the [PAXLOVID Patient Eligibility Screening Checklist Tool for Prescribers 07182022 \(fda.gov\)](https://www.fda.gov/paxlovid-patient-eligibility-screening-checklist-tool-for-prescribers-07182022) to help their patients decide if they can take Paxlovid.

The table below lists the options of drugs that are used as COVID-19 treatment pertaining to MG patients.

Drug treatment option	Recommendation for use in MG patients
Chloroquine, hydroxychloroquine	Avoid; could worsen MG
Azithromycin	Avoid, could worsen MG
Colchicine	Probably safe to use; no effect on MG, myopathy develops rarely.
Remdesivir, lopinavir, ritonavir, favipravir	Safe to use, no known effects on MG
Monoclonal antibodies (MABs)	Safe to use, no known effects on MG

Continued on Page 5



The following table lists MG treatment options with comments on COVID-19.

Drug treatment option	Recommendation for use in COVID-19
Pyridostigmine (Mestinon)	Continue treatment.
Corticosteroids	Continue existing treatment with dose escalation to stress dose in severe or critically ill patients with COVID-19.
Mycophenolate mofetil (CellCept)	Probably safe to use.
Azathioprine (Imuran)	Probably safe to use.
Cyclosporine, tacrolimus, methotrexate	Probably safe to use.
Rituximab	Results in more severe COVID disease. If possible, delay initiation until the peak of the outbreak is over; consider extending dosing intervals.
Complement inhibitors: eculizumab (Soliris) and ravulizumab (Ultomiris)	Safe to use; probably beneficial
FcRn inhibitors: efgartigimod (Vyvgart)	Probably safe to use.
IVIg and plasmapheresis	Probably safe to use. Plasmapheresis is avoided in critically ill patients with septic shock. IVIg is avoided in critically ill patients with renal failure, blood clots, and heart failure.

I would encourage readers to check out the COVID-19 Resource Center at the Myasthenia Gravis Foundation of America (<https://myasthenia.org>) and share it with their primary care providers.

— Abbas Jowkar, M.D.
Trinity Health-Mercy Health
West Michigan



FUN & FUNDRAISING EVENT

Saturday
June 24, 2023



Cascade Township Park
3810 Thornapple River Dr SE, 49546 • 9:00 am to Noon

Join us for our 4th annual summer family fun event in beautiful Cascade Park. Activities are being planned for all ages with prizes, entertainment, food, and connections with MG patients.

Form a team, collect donations or sponsorships to support programs for MG patients. More information will be in your mailbox or email soon— watch our website for updates!

SAVE THE DATE

The views expressed in this newsletter are those of the individual author and do not reflect any official position of the Myasthenia Gravis Foundation of Michigan. Each person's situation is unique. If you have any medical questions, please discuss them with your neurologist as he/she knows your situation best.

OFFICE UPDATES

Hot off the Press
Drew Schramm joins
MG-MI Board. Meet
him in the next issue.

**Notes from Dec. 3, 2022
Board of Directors Meeting:**
Re-elected to Board
James Burr, Brad Mathis,
Amit Sachdev, MD
2023 Officers:
President: Susan Woolner
Secretary: Esther Land
Treasurer: Priscilla Walden

Seeking Board Members
If you are interested in joining our Board of
Directors, please contact the office for an
application or with questions.
Meetings may be attended via Zoom so
distance is not a factor.

Found
Water Resistant watch, at our
Summer 2022 **MG-MI MovesMG**
event. Please call our office to
identify it and to give mailing
instructions.

SAVE THE DATE:
7th Annual Conference
Oct. 12, 14 & 15, 2023
Via Zoom

Support Groups - 2022
15 meetings
12 cities throughout MI
9-10 average attendance
Volunteers are needed to help
organize our 2023 groups.
Training provided. Please
contact our office.

PLEASE NOTE:
Spartan-Nash has discontinued their
Direct your Dollars program so we
are no longer collecting cash register
receipts from D&W, Forest Hills
Foods, Family Fare, Valueland, VG's.

THANK YOU FOR YOUR PAST
SUPPORT OF THIS PROGRAM!

MG-MI MovesMG
Sat, June 24
9:00am—Noon
Cascade Park



Get a shirt today!

T-Shirts
Want to help promote MG and
MG-MI? Stop by our office for a
t-shirt, or call/email us to have a
shirt or two sent to you (donations
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Charitable organizations no longer receive
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through this program is appreciated.



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