



# COMMUNICATOR

## 2023 MG-MI AWARD WINNERS

During our MG Patient Education Conference in October we were honored to recognize four people who have exemplified exceptional service to MG-MI during this past year. Honorees were presented with the following awards:



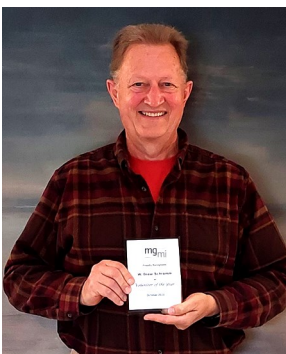
**Esther M. Land Founder’s Award**—was proudly awarded to Lisa K. Gigliotti for her 20 plus years of unswerving initiative, compassion, courage, and inspiration. As a beacon of hope to patients throughout Michigan and across the U.S., she graciously shares her God-given talent of encouragement by inspiring others with warmth and compassion to live their best life with MG. She is the author of the “With Courage I Can” series books, and annually presents the *Coraggio Spirit Award* at our MG-MI conference.

Congratulations, Lisa!

**Coraggio Spirit Award**—was honorably presented to Aimee Jazdyk Smithem for her courageous pursuit of a career that would help others struggling with health challenges, despite experiencing 20 years of fluctuating MG symptoms.



Aimee was diagnosed with myasthenia gravis (MG) at 12 years old and, with her parents’ support, tried several MG treatments to improve her quality of life. Meeting these challenges, she used her faith and a mindset of adaptability to pursue and achieve an occupational therapy license. Through her career, and a desire to help others with MG, Aimee encourages patients to see that coping and wellness are improved by recognizing what is meaningful, including work-arounds of energy conservation, that can help achieve a meaningful life. Aimee truly exemplifies the *Coraggio Spirit*!



**Volunteer of the Year Award**—was gratefully presented to W. Drew Schramm. Upon retirement from the corporate world, he wanted to give back to MG-MI for the support given to him during his early years with MG. He stepped forward by joining our Board of Directors and giving invaluable corporate management skills to our strategic planning process. He also applied his business expertise and resources by bringing in over \$5,000 for our *MG-MI MovesMG summer fundraiser*. Thanks Drew!

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A big  
**THANK YOU**  
to our  
newsletter  
sponsors

(See ad on Pg 2 & 3)



**BOARD OF DIRECTORS**

James Booth Burr, Jr.  
Mallary Cole  
Janet Gentle  
Lisa Gigliotti  
Esther Land, Secretary  
Bradford Mathis  
Amit Sachdev, M.D.  
W. Drew Schramm  
Priscilla Walden, Treasurer  
Susan Woolner, President

**DIRECTOR**

Rhonda Wentworth

**MEDICAL ADVISORY BOARD**

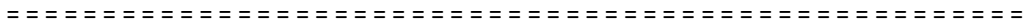
Richard H. Benninger, M.D.  
Michelle Crooks, M.D.  
Christopher Glisson, D.O.  
Louise O'Donnell, N.P.  
Sally O'Meara, R.N.  
Amit Sachdev, M.D.  
Paul T. Twydell, D.O.  
John R. Visser, M.D.

**2023 MG-MI AWARD WINNERS—cont.**



**In Appreciation** award—Doug Amidon has been instrumental in providing computer assistance to MG-MI over the past year and we wanted him to be recognized and know how much he is appreciated! This additional award was given to Doug in appreciation for his generous contribution of computer technology and many hours to enhance and upgraded our computer system, making our office more efficient. Thanks!

**Remembering Dr. James Teener**—a year ago our MG community lost a champion, top notch advocate, neurologist and friend with his sudden passing. We took a few minutes during the conference to give tribute to this giant in the neurology field. He will be remembered for his winsome smile, compassionate care and expertise to help patients achieve the best treatment for living with MG. U of M is working to ensure the seamless transfer of patient care to his colleagues.



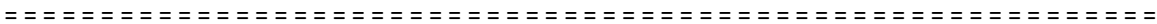
**MG-MI LAUNCHES NEW WEBSITE**



We invite you to visit our new website [Home - MG-MI](#) that launched in October. The format and design include a search bar and menu listing resources, ways to stay involved, YouTube link, newsletters and tips on “Living your Best life with MG.” An ADA accessibility tool (lower left “eye”) allows text enlargement and more. Check it out! As the site continues development, we anticipate adding additional features. Keep watching!



*The world is hugged by the faithful arms of volunteers—they are love in motion.*



**FDA AUTHORIZES ZILBRYSQ®**

17 Oct. 2023—UCB announced the U.S. FDA approval of ZILBRYSQ® (zilucoplan) for adults with generalized MG (gMG). The new treatment is the first once-daily self-administered subcutaneous C5 complement inhibitor for gMG. For more information, go to [ZILBRYSQ® \(zilucoplan\) Injection Is Now Approved For gMG!](#)

This is an exciting era for MG with the release of several new FDA approved treatments for MG:

- SOLIRIS & ULTOMIRIS by Alexion
- VYVGART & VYVGART HYTRULO by argenx
- RYSTIGGO & ZIBRYSQ by UCB

Talk to your healthcare provider to learn if any of these treatments may be an option for you.

**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](http://KLARASBOOK.COM)**

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## LISA K. GIGLIOTTI JOINS MG-MI BOARD

Our MG-MI Board of Directors is honored to welcome Lisa to this leadership role in our organization. Utilizing her organizational skills and charismatic personality, we look forward to her continued support and encouragement to our Michigan MG community.

Lisa received her JD degree from the University of Detroit School of Law, serving the State of Michigan for over 25 years. She is currently an adjunct law professor in Michigan and Florida. She has encouraged many persons within the MG community through her "With Courage I Can" book series ([Coraggio – Lessons for Living from an Italian Grandmother \(withcourageican.com\)](#)) and as originator of the

*Coraggio Spirit Award*. She attributes the information and support MG-MI has provided her to being able to live a full and positive life with MG and rheumatoid arthritis for over 30 years. Recognizing MG-MI's invaluable role, she has volunteered through the years with planning the MG-MI Annual Conference and support groups around the state. Lisa lives in the Detroit area.

## HIGHLIGHTS FROM THE 2023 MG-MI PATIENT CONFERENCE

The second full weekend in October was an exciting time as we learned virtually from MG patients and medical professionals the many variables of living with MG and the potential of advanced treatments on the horizon. Patients with various types of MG shared how they navigated living with MG. Medical professionals shared their expertise on MG topics that included: Generalized, Seronegative, Wellness, Sleep Apnea, Emerging Treatments, and Living Your Best Life. The conference was well attended with great Q&A. Most sessions are available on our website ([Home - MG-MI](#) —go to menu then YouTube) A sincere thank you to our conference speakers and partners:



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### BOARD OF DIRECTORS & OFFICERS

At our November 18 Board meeting, elections of Directors and Officers took place. Directors voted in for a 3-year term were: Mallery Cole, Dr. Amit Sachdev, Priscilla Walden.

Officers for 2024 will be: Pres., Susan Woolner, Vice Pres.; Drew Schramm, Secy., Esther Land, Treas. Priscilla Walden. Thanks for serving!

To better serve our MG Community, the Board also approved hiring two part-time staff: an Office Assistant and a Communications Manager.

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### ASK THE DOCTOR

Do you have general questions about MG that you would like discussed in this newsletter? We have medical professionals who are willing to answer your questions. For example: My brother and I both have MG. Is MG hereditary? Or, Is it safe for MG patients to get the flu shot?

Please email your questions to [info@mg-mi.org](mailto:info@mg-mi.org) and we will get some answers published for you.

**NOW APPROVED**

Ask about  
**VYVGART<sup>®</sup> Hytrulo**  
(efgartigimod alfa and hyaluronidase-qvfc)  
Subcutaneous Injection  
180 mg/mL and 2000 U/mL vial

Scan to learn more

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# BULLETIN BOARD

Check out our new website  
[Home - MG-MI](#)

*True friends are like diamonds,  
precious and rare.  
False friends are like Autumn leaves,  
found everywhere.*

**2024 Virtual Support Sessions**  
Jan. 13, Sat., 11 am—New Patients Info  
Informal Discussion  
Jan. 24, Wed., 6:30 pm—MG Antibodies  
Presented by Dr Gary Gallagher  
Feb. 13, Tues., 6:30 pm—Care Partners  
presented by Alexion  
The sessions will be available via Zoom:  
[Launch Meeting - Zoom](#)  
or by phone:  
**13092053325—Meeting ID: 6169560622**  
More sessions coming soon.

**Wondering what to give this Christmas?**  
To your enemy, forgiveness  
To your opponent, tolerance  
To a friend, your heart  
To a customer, service  
To all men, charity  
To every child, a good example  
To yourself, respect  
—Oren Arnold

**2024 Support Group Planning**  
During early months in 2024 we begin  
planning in-person support groups.  
Please let us know if you have  
suggestions for speakers or locations.  
Interested in assisting? Please call  
our office at 616-956-0622.

**Thought to Ponder**  
The trouble with doing nothing is that  
you never know when you're done.

**Stay Informed—Go Green**  
Headed south this winter or prefer  
emails? Send your email address to  
[info@mg-mi.org](mailto:info@mg-mi.org) and we'll keep you up  
-to-date with virtual programs and  
newsletters.



**MuSK Myasthenia**  
MGNet, a NIH-supported MG Rare  
Disease Clinical Research site, has  
initiated an effort to collect 1000  
samples of saliva DNA analysis from  
patients with laboratory confirmed  
MuSK myasthenia. For more  
information, see their website at  
[Welcome | Musk 1000 \(gwu.edu\)](#)

**BREAKING NEWS**  
**2023 MG Patient  
Education Conference**  
**Speaker sessions now available  
on our website [Home - MG-MI](#)  
or our YouTube site  
[MG-MI – Myasthenia Gravis Foundation  
of Michigan - YouTube](#)**

**Our Mission**  
The Myasthenia Gravis Foundation  
of Michigan is committed to our MG  
Community by providing patient  
support, community connections,  
education and advocacy.  
**Our Vision**  
Living your best life with MG

**Myasthenia Gravis Foundation of Michigan**  
2660 Horizon Dr. SE, Ste. 235  
Grand Rapids, MI 49546-7933  
616-956-0622 • [info@mg-mi.org](mailto:info@mg-mi.org) • [www.mg-mi.org](http://www.mg-mi.org)

Find us on Facebook. Search:  
Myasthenia Gravis Michigan • You will see our logo!