



Welcome Dr. Margaret Frey to our Medical & Scientific Advisory Board! Learn more about Dr. Frey in this issue and watch her video from our Annual Conference at mg-mi.org



Get tips on how to *Stay Resilient-With Courage You Can!* from author, lawyer, and Annual Conference presenter Lisa Gigliotti

mgmi MYASTHENIA GRAVIS
FOUNDATION OF MICHIGAN

Communicator

ANNUAL CONFERENCE 2020

Our 2020 Annual Conference went through a lot of changes this year due to the pandemic. We ended up "going virtual" in October, hosting ten expert talks over nine days!

Each day from October 1st through the 9th, we had a new video launch on our online event page. If you missed this or if you want to re-watch one or more of the sessions, you can view the videos by visiting our website, MG-MI.org

We had wonderful presenters who provided great content this year.

1. Dr. Margaret Frey, our newest Medical Advisory Board member and neuromuscular specialist at Memorial Healthcare Neurosciences in Owosso, presented "*Understanding, Living, and Thriving with MG.*"

This provides an overview of myasthenia gravis, its symptoms, and various treatments

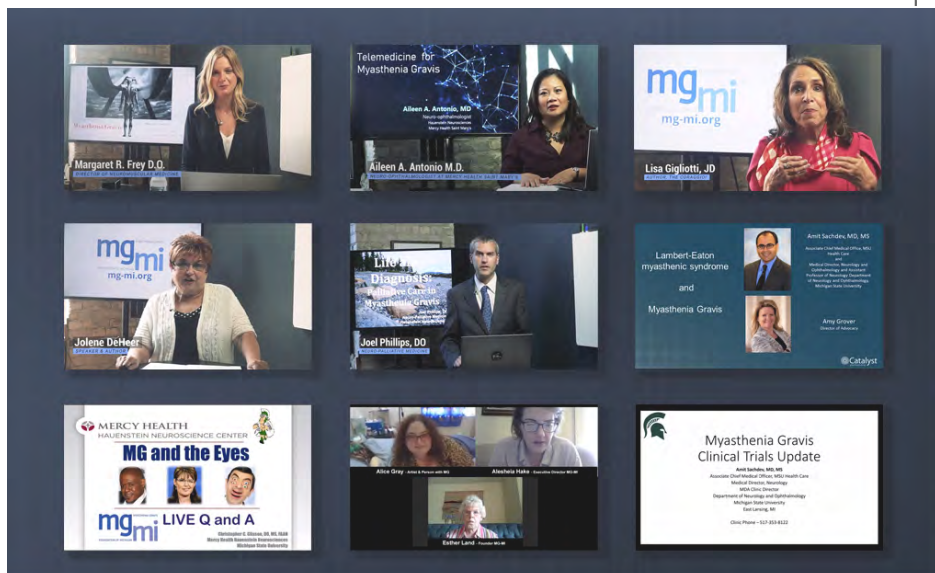
2. Dr. Aileen Antonio, neuro-ophthalmologist at Mercy Health Hauenstein

Neurosciences in Grand Rapids, presented "*Telehealth for MG.*" This shares helpful information for achieving a successful telehealth/telemedicine appointment. She gives insight into how we can best set up our

equipment for a great virtual appointment and what we might expect when we see our neurologist or neuro-ophthalmologist via telehealth.

3. Lisa Gigliotti, JD, author and lawyer in Lansing presented "*Resiliency and Coraggio,*" her message of courage (coraggio in Italian), and overcoming adversity.

Continued on next page...



All newsletter content is for informational purposes and is not intended to be a substitute for professional medical advice, diagnosis, or treatment. Always seek the advice of your physician or other qualified health provider with any questions you may have regarding any medical condition.

ANNUAL CONFERENCE 2020 CONTINUED FROM FRONT PAGE...



Lisa talks about the importance of setting ourselves up for whatever the future might bring, and shares information about a new Michigan law that was recently passed to help protect people who experience communication impediments in the event they are having an encounter with law enforcement.

Lisa provided a wonderful article featured later in this issue, *"Stay Resilient – with Courage You Can!"*

4. Jolene DeHeer, author and speaker from West Michigan, presented *"Finding Hope."* This is an inspiring look at the power of gratitude. Mrs. DeHeer talks about laughter being a great antidote to the struggles we all go through and shares a hilarious personal experience to get us all started.

5. Dr. Joel Phillips, neuro-palliative physician at Mercy

Health Hauenstein Neurosciences in Grand Rapids, presented *"Life After Diagnosis – Palliative Care in MG."*

His presentation looks at how

palliative care can improve quality of life for patients in any state of chronic illness. We learn the differences between palliative care and hospice, and get tips for setting ourselves up to receive the care we want and need regardless of what circumstances we might find ourselves in.

6. Dr. Christopher Glisson, neuro-ophthalmologist at Mercy Health Hauenstein Neurosciences in Grand Rapids, presented *"MG and the Eyes."* His talk covers how myasthenia can impact vision. He shares common and not-as-common ways the eyes can be affected in MG, and when vision problems might not be related to myasthenia.

7. Amy Grover, Director of Patient Advocacy at Catalyst Pharmaceuticals, and Dr. Amit Sachdev, Director of Neuromuscular Medicine at

Michigan State University, presented *"LEMS vs. MG – A Differential Diagnosis."*

Their talk explores the differences between Lambert-Eaton Myasthenic Syndrome (LEMS) and myasthenia gravis, and was very educational.

8. MG-MI founder Esther Land and MG patient Alice Gray were featured in *"MG Real Talk – Crisis from the Patient Perspective."* This frank talk covers navigating myasthenic crisis. We learn about what an MG crisis is, how we might help ourselves avoid having to experience one, how we can have things ready ahead of time in the event we ever do experience a crisis, and are reminded that MG can be a diagnosis with hope.



9. Dr. Amit Sachdev presented an *"MG Research Update,"* which includes an overview of some of the pharmaceutical treatments currently being looked at for myasthenia. He explains the clinical trial process and talks about how some of these potential future treatments are thought to work in the body.

You can watch these videos in full on our website at MG-MI.org or visit our YouTube channel to see these videos

Continued on next page...

ANNUAL CONFERENCE 2020

CONTINUED FROM PREVIOUS PAGE...

and more information from some of our conference sponsors. If you do not have access to the internet, you can call our office (616-956-0622) to order a USB flash drive that you can plug into a device with a USB port to watch the videos.

Head to mg-mi.org to watch the videos from our virtual conference!

Our 10th and final presentation was from Sandra Harding, RN, BSN, IgCN from Optum Infusion Pharmacy. She presented "MG Crisis: A Nurse's Perspective."

This webinar was live and could not be recorded due to copyright.

Sandra shared information about myasthenic crisis and treatments. She also talked about subcutaneous immunoglobulin (Ig) treatments, which can be an alternative to receiving IVIg infusions. You can learn more about subcutaneous Ig in our

February 2020 issue of *MG Communicator*. We also hope to have Sandra back for another webinar in early 2021.

Finally, we would like to thank your 2020 Conference Sponsors for their generous support that made this virtual event a success.

MG United

argenx



OPTUM



Catalyst
pharmaceuticals

SOLEO
HEALTH

ALEXION



Inspired by **patients**.
Driven by **science**.

3 ways to support the programs and events we provide:

1. Donate at mg-mi.org/donate.shtml

Text "MGMI" to 41444 to receive a secure link on your mobile device.

2. If you're making Amazon purchases anyway, consider going to smile.amazon.com and choose MG-MI. A click from you really adds up for us! This is offered at no additional cost to you.



3. Direct Your Dollars

If you shop at a Spartan Nash store (Family Fare, D&W Fresh Market, Martin's Supermarkets, ValuLand, VG's, Forest Hills Foods or the Ada Fresh Market), save your entire receipt and send it to our office - we do the rest! Contact us if you would like a postage paid envelope to send us your receipts.

Mail to: MG-MI
2660 Horizon Dr SE
Suite 235
Grand Rapids, MI 49546



Head to MG-United.com to read helpful articles about navigating myasthenia, find tasty recipes, and to watch a first-of-its-kind docuseries about living with MG, *A Mystery to Me*.

ASK THE DOC CONSULT OUR TEAM OF MG EXPERTS

No question is a bad question - especially when it comes to managing a chronic condition like Myasthenia Gravis. Contact us to get answers to any of your questions, and to get connected to resources for living your best life with MG.

Submit your question for Ask the Doc to info@mg-mi.org, by calling us at 616-956-0622, or by sending us a letter:
2660 Horizon Dr SE, Suite 235, Grand Rapids, MI 49546



Stay Resilient-With Courage You Can!

Contributed by author, lawyer, and Annual Conference presenter Lisa Gigliotti, JD

The Courage to Build Resiliency

The *Coraggio-With Courage I Can!* message reveals that no matter how dire a situation, there is always an aspect over which you have control. That life philosophy was certainly put to the test over the past several months. Suddenly it felt as if I had no control as I watched an evil virus ravish the country of my ancestors and spread to an invasion of my own town.

I wondered if the *Coraggio* tenets of take charge of your health and your joy could stand up to the isolation of quarantine, or the anxiety of unknown infection or continued employment for self and loved ones. Simple tasks over which I believed I had control, such as shopping for my own food and singing with my weekly music group was barred. How could resiliency be possible in this foreboding and solitary setting?

Resiliency does not mean that you are tough enough to avoid feeling fearful or sad over a situation. Instead, resiliency means that you may experience anxiety or depression about a stressful life situation, but you manage to not allow the stressors and emotions determine the outcome of your life. You take a

high-level view, believe you will grow from the challenges, and begin taking charge of aspects over which you have control.

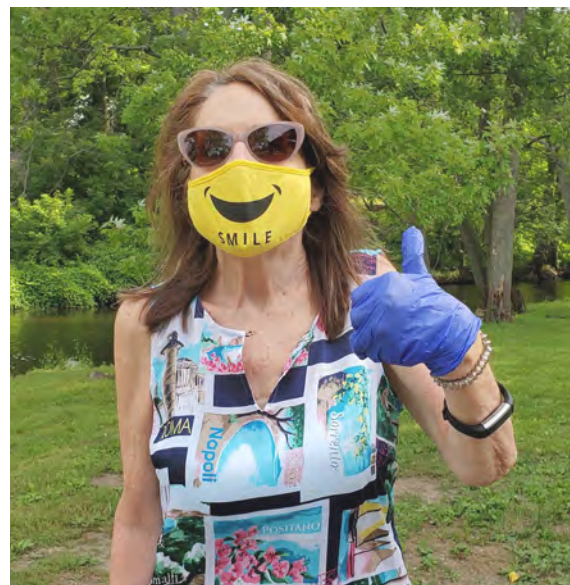
Find a Purpose – Do for Others

The Easter holiday was always a holiday in which my family gathered around our Italian and Hungarian traditional foods and customs. I had chosen to stay home during the March 2020 quarantine. I felt good about my decision, knowing I was protecting my suppressed immune system and finding relief from my perpetually over-scheduled life. But when it was announced that the quarantine would extend through Easter, with no celebratory gatherings, it was hard to fight the feelings of disappointment and sadness.

I confess that for about 60 seconds I dreamed I would indulge my sorrow in a pity party where I would eat by myself all the Italian and Hungarian specialty treats I had gathered to share with my family. Finding a purpose in doing something for others has always helped me through a difficult emotional or physical struggle. I divided up the European goodies by the number of neighbors who I knew were elderly or had

health challenges and who were isolated during the quarantine.

On Easter morning I hung individualized “Easter baskets” on their front door and called from their driveway. They opened the door, found the goodie bag, and I stood in the driveway explaining the significance of the sweets and listening to their stories. They might otherwise not have had human contact, laughter, or an Easter treat that day. I was not with my family



Lisa, reminding us to smile!

but being able to share the European delicacies and uplifting conversations with others more isolated than me made for an inspiring Easter I will never forget. How can you take charge of finding a purpose today and strengthen resiliency?

Stay Positive!

The news reports of the pandemic's devastation on a global scheme and the personal stories of its impact on families

Continued on next page...

STAY RESILIENT

Continued from previous page

and communities can feel overwhelming. Ask yourself who you want to be through the daily turmoil and as an outcome of the adversity. Will you be a person who helps others feel hope and experience goodness?

It is important to stay connected during a period of social distancing and it seems natural to discuss the weighty events of the day during phone and video calls. During a weekly stay-connected call with friends I asked each what favorite act of kindness they had been a recipient of, had bestowed, or had observed. Mine was the unsolicited arrival of a home-sewn face mask at the time masks were unavailable.

The telling of acts of kindness became a favorite part of each call and gathering kindness stories reaped inner joy through the week. Use phone and video to check on acquaintances with whom you have frequent and infrequent contact. Plan stories to evoke laughter, express gratitude and emit hope. Not only will you be stoking positivity in others, you will be reinforcing your ability to bounce back from adverse situations by using positive emotions to cope; you *can* build emotional resilience even in the worst of a pandemic.

Fortify Brain and Body

Okay, let us admit it...there are many jokes about how quarantine food overuse has led to stretchy waistband outfits. For me, my makeshift remote workstation is my kitchen table and all I need do is lean back in my chair to open a cupboard or take four steps to open my refrigerator.

As tempting as it is to fill the void of isolation and boredom with low nutrition munchies or quell anxiety with a big bowl of comforting calorie-dense yumminess, have

courage to reject the temptation by recalling your commitment to using adversity to build coping skills and resiliency.

Take charge to consume nutritious foods to keep your muscles and nerves primed—critical for healthy living with myasthenia gravis.

A balanced diet and plentiful water will keep your brain at peak emotional and physical performance, coordinating all your body systems and fostering mental alertness and balanced mood. Standing on your porch each morning and taking five slow, deep breaths will keep your lungs strong. Dancing to your favorite song or taking a walk will keep your heart and muscles strong. Caring for your body and brain health signals your psyche that you will not only survive, you will thrive through adversity...resilience!

Recognize your resiliency

As you use courage to identify areas of your life over which you have control—finding purpose, staying positive, and fortifying your brain and body—and take charge over those areas, fear, hopelessness, and anxiety diminish, allowing you to steer the outcome for your life. Congrats! You successfully adapted to prolonged hardship! Recognize and affirm your growth in personal strength, confidence, and coping skills, adding to your storehouse of resilience. *With courage you can-Coraggio!*

Learn more about Lisa by visiting her website WithCourageICan.com and watch her Annual Conference Presentation at mg-mi.org

Connect with us on social media!

Facebook.com/MGofMI

Join our private group:
[Facebook.com/groups/MGofMI](https://www.facebook.com/groups/MGofMI)



**YouTube.com/user/
MGGreatLakes**

**Watch Annual Conference
Videos on our YouTube
channel!**

**Be sure to hit "subscribe"
and get notifications for
future videos.**

Instagram.com/mgofmi

@mgofmi

#mgofmi

We will have fun events
happening all winter on our
social media!

"Like" our Facebook page
and subscribe to our YouTube
channel to be the first to
know about what we have
planned.

If you don't already receive
our emails, head to
MG-MI.org and get signed up
today.

— ONE RELENTLESS ILLNESS. THREE UNSTOPPABLE PEOPLE. —

A MYSTERY TO ME

— A MYASTHENIA GRAVIS DOCUSERIES —

DIRECTED BY BEN STRANG

PRESENTED BY
SAROFKY PICTURES

IN ASSOCIATION WITH
KARTEMQUIN FILMS

IN ASSOCIATION WITH
MUSEUM + CRANE



VIRTUAL FILM PREMIERE
NOVEMBER 17th

Visit MG-United.com/a-mystery-to-me to watch the trailer
and register for the premiere now.

Addition to our Medical/Scientific Advisory Board



It is with great pleasure that we welcome Margaret Frey, D.O., to our Medical Advisory Board.

Dr. Frey is a board certified neurologist with Memorial Healthcare's Institute for Neuroscience (Owosso). She provides a wide range of neurology services. She has completed a fellowship in neurophysiology and serves as the Medical Director of the MDA/ALS Care Center in Owosso as well as being an Assistant Professor in the Department of Neurology at Michigan State University and serving as Co-Director of the MDA/ALS Care Center at MSU.

"Ask the Doc" - Submit your questions to our Medical and Scientific Advisory Board!

Ask questions about myasthenia gravis and get answers from knowledgeable clinicians.

Email info@mg-mi.org, call the office at (616) 956-0622, or send us a note in the mail: MG-MI 2660 Horizon Dr SE, Suite 235, Grand Rapids, MI 49546.

The MG-MI Medical and Scientific Advisory Board

Richard H. Benninger, M.D.
Michelle Crooks, M.D.
Margaret Frey, D.O.
Christopher Glisson, D.O.
Evelyn P. Navarro, M.D.
Louise E. O'Donnell, N.P.
Sally O'Meara, R.N.
Amit Sachdev, M.D.
Paul Twydell, D.O.
John R. Visser, M.D.



2660 Horizon Dr. SE | Suite 235
Grand Rapids, MI 49546-7933

mg-mi.org | info@mg-mi.org

President Susan Woolner, CPXP	Trustees James Booth Burr, Jr. Cassie Bos Mallory Cole Paul Copeland, RN Amit Sachdev, MD
Vice President Christopher Glisson, DO	
Secretary Esther Land	
Treasurer Priscilla Walden	Executive Director Alesheia Hake

IN MEMORIUM

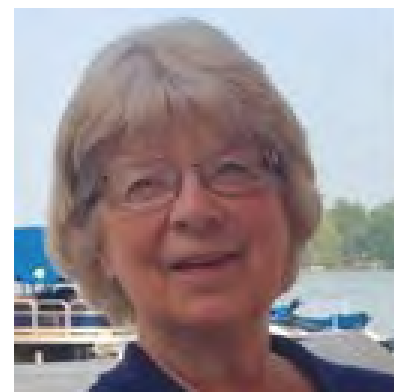
Susan Weinstock; 1937 to 2020

It is with sadness that we report the passing of Susan Weinstock on March 20. Sue was a encourager for promoting awareness of Myasthenia Gravis. Her initial contact with us was an email: "I have MG and am interested in spreading the word — June is MG awareness month. I want to help." She was given brochures on MG and spread the word among friends, neighbors and temple friends. Warm hearted Sue is deeply missed by her family, many friends and all of us.



Stephanie Burr; 1950 to 2020

Our sincere sympathy to long-time Board member, James Booth Burr, Jr., on the passing of his dear wife, Stephanie, on June 1. Stephanie was a vivacious woman and greatly admired for her musical talents throughout Michigan. She was especially admired in the Grand Rapids area where she taught and performed classical piano. Our sincere condolences to Jim and his family on the deep loss of his wonderful wife, mother and friend.





Communicator

Volume XLIII | Issue 1 | Spring 2020

FOUNDATION OF MICHIGAN

2660 Horizon Dr. SE | Suite 235
Grand Rapids, MI 49546-7933

mg-mi.org

Non Profit Org.

U.S. Postage

PAID

Permit No. 127

Grand Rapids, MI

Electronic Service Requested

Moving toward a world without MG

If you don't already receive our emails
be sure to sign up today!

Visit mg-mi.org to sign up for our email list, and see the latest information
about our virtual events throughout the winter.

Did you join us for our 2020
Annual Conference that "went
virtual" in October?

See inside for more
information on how to watch
the videos!

**Stay
Resilient!**
**Get tips in
this issue.**