

# CONQUER

News for our community

## Clinical Trials and MG



### Conquer MG Joins MGNet Consortium

Conquer MG is excited to share news that the National Institutes of Health (NIH) has awarded a team at the George Washington University (GW) \$7.8 million to establish a rare disease network for myasthenia gravis. Conquer MG will join scientists and physicians from academic institutions, other patient advocacy groups, and biotech/pharma companies, to better understand and treat MG.

Conquer MG has made a commitment (\$50,000 per year for at least two years) to fund pilot projects through the network that explore MG's underlying pathogenesis and treatment. Commitments from Conquer MG and the Myasthenia Gravis Foundation of America were key in showing the support of the MG Community for the project – which the NIH stated was an essential part of its criteria for funding.

With many potential treatments in the clinical trial stage, it's an exciting time for myasthenia gravis research. At Conquer MG's Fall Patient Seminar last October, panelists Rabia Malik, MD, Rush University, and Angela Pontius, Ra Pharma, explained the various roles of patient, physician, and biotech company. We also received study updates from representatives from argenx and Momenta Pharmaceuticals. Key points of the discussion:

#### What is "informed consent"?

Dr. Malik: It's the process of providing information about the study, to help you decide whether or not to enroll. When you sign an informed consent form, it means you understand the risks and benefits of the study. But it is not a contract. At any point during the study you have the right to change your mind.

(continued on page 6)



## 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](http://www.myastheniagravis.org)

## FROM YOUR EXECUTIVE DIRECTOR

### "Own Your Health" Fair for MG Patients

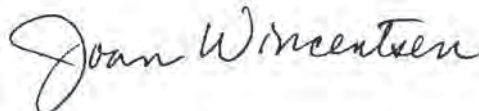


The most-watched videos on Conquer MG's YouTube channel are the two that address *exercise* and *nutrition*. We are truly thrilled science is developing new therapies for MG. But we ache to improve health on our own, too.

*And we can.* That's the message from Julie Rowin, MD, who has expanded her practice to include integrative medicine. And from Maria Zepeda, who, in the process of taking charge of her own health has become a certified health coach.

With their guidance, Conquer MG is planning a new emphasis on *wellness*. We aim to bring you content about nutrition and exercise – plus topics like stress management, the gut biome, and meditation. We hope you'll join us Sunday, April 5, in Elmhurst, Illinois – for Conquer MG's "Own Your Health" Wellness Fair for MG Patients. Watch for details in our next newsletter.

Should MG define or defeat us? NO!

  
Joan Wincentzen, 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 2020.

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](mailto: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.

# Events & Activities

## ► MG and Clinical Trials

Thank you to our speakers and sponsors who attended the “MG and Clinical Trials” seminar in October:

- Rabia Malik, MD, Rush University Medical Center
- Angela Pontius, Senior Director of Clinical Operations & Patient Advocacy at Ra Pharmaceuticals
- Jenna Casey, Medical Research Liaison, argenx
- Marie-Helene Jouvin, MD, Sr. Medical Director, and Amy DeWerth, Clinical Site Liaison, Momenta Pharmaceuticals

You can find a video recap of the session on [www.YouTube.com](http://www.YouTube.com) (search “Conquer Myasthenia Gravis”) or our website, [www.tinyurl.com/mgtrials](http://www.tinyurl.com/mgtrials).

## Fall Meeting Sponsors - Thank You!



## ► Patient Assistance Program

Conquer MG provides financial assistance to MG patients in need who live in Illinois, Indiana, and Wisconsin (our primary service area). In 2020, Conquer MG paid out over \$22,000 to help 25 people with the cost of medical bills, prescriptions, and durable medical equipment. If you'd like to help with this effort, add a note “For Patient Assistance Program” with your donation.



## ► Donate When You Sell on eBay

It's now possible to donate up to 100% of your sales on eBay to the charity of your choice. You can customize the donation percentage and the charity you want to support for each item you list. To learn more, visit <https://www.ebay.com/rpp/charity-sellers>

## ► Conquer MG at the Zoo!

For the 4<sup>th</sup> year, Apex Management & Special Events has sponsored a tree to raise awareness of myasthenia gravis at Brookfield Zoo's Holiday Magic. Thank you, Apex!



## ► All Hands on Deck!

The Viking 5K Committee needs you! Call 1-800-888-6208 if you can find sponsors or raffle prizes, or can pitch in the day of the walk – JUNE 14.

Can you or a Chicago-area family member serve for two years on the Conquer MG board? Appreciated (and needed!); skills in planning, budgeting, fundraising support, social media, plus attendance at 5-6 meetings a year in Elmhurst, Illinois.

## Calendar Club Winners

2019 \$500 Grand Prize – Joyce Holste

2019 \$100 Runner Up – Warren Hanssen

December – Cathy Jackson, Sue Kennedy, Deanne Scanlan, Anonymous (1)

November – Jackie Green, Anne Smith, Barbara Weaver, Anonymous (1)

October – Steve Malinovich, Barbara Scherg, Geri Volpe, Anonymous (1)

September – Ken Koss, Julie McCracken, Anonymous (2)



## Maria Zepeda

Certified Health Coach

### The Hardest Thing: Asking for Help



Take a second and think about what you need help with. Laundry, cleaning up the garage, maybe yardwork around the house? A few weeks ago, I could have used a hand putting my carry-on in the overhead compartment. I would like to plant some mums in my front yard, I really could use help rearranging my office...

Here is a second question, what are you actually going to ask for help with? Anything on your list? Hmmm, unlikely.

#### Why is that?

Do you think you should be able to figure it out, or that you will be perceived as weak? Does the fear of appearing "needy" paralyze you? Or the fear of imposing? Or the fear of revealing your struggles and having people realize that you don't have it all together after all? Or does it mean that if you ask for help you are relinquishing some notion of power you have? The power to feel like

you can do things on your own? For yourself? For your loved ones?

It took a long time for me to accept help, decades actually. Call it stubbornness, pride, shame, or all of the above.

It finally hit me that I was focusing on my own made-up notions of help rather than the many benefits of asking and RECEIVING it. I thought that asking for help was a sign of weakness, when in fact it's a sign of strength. Having the courage to say "I need help" means that you are wise and humble enough to know that you can't always do it alone.

Now that you have mustered the courage, you ask will they want to help me. Yes, they will. When a person does something for others it makes the helper feel good. Seriously. There is science behind it. People love sharing their gifts and in fact feel better when they are sharing. When you don't ask for help, not only do you assume all

of a burden that might easily (and gladly) be shared; you also deprive those who'd love to assist you of the opportunity to do so. All those times I didn't ask for help I was depriving others of feeling good.

Another benefit? Someone else can see your problem from a different angle. Together your solution will more likely be better.

Lastly, guess what? You are not perfect. I will let that sink in. I am not perfect either. No one is. No one really thinks you should know everything and can do everything, chronic condition or not. Accepting that is quite liberating. It lifts the pressure of thinking that I have to know everything and allows me to give myself permission to ask for help when I need it.

So gather your courage, show your strength, and ask for help. You and those around you will be the better for it.



## How can I avoid prednisone side effects?

*"'Cut the sugar.' It's a tough message."*

By Julie Rowin, M.D.

<http://www.julierowinmd.com>

People want to know how to avoid the weight gain, hypertension, high triglycerides, insulin resistance, diabetes, and bone loss that can be associated with chronic prednisone use. In my experience, there are nutritional and lifestyle interventions that can definitely help to avoid these side effects.

**Food makes a difference.** Most of the immune system resides in the digestive tract. That means that what we eat has a direct impact on how our bodies are able to cope with autoimmune disease like MG. Certain foods fight inflammation and balance immunity and certain foods increase the inflammatory response. For example, excess sugar drives up inflammation and may interfere with a healthy immune response. You don't need to worry about the small natural sweetness in fruit. This is about cookies, cakes, white flour, white rice and the hidden sugar in processed and prepared foods. Refined sugar is also likely to displace essential nutrients that help to balance our immune system.

*"I could soft-pedal it. But In my heart of hearts, I believe the message of 'reducing' sugar intake – say, drinking 3 sodas instead of 4 just doesn't work."*

**It's the #1 tactic.** There are many facets to the best nutritional plan to follow while on prednisone, but probably the number one tactic is to completely avoid refined/processed sugar, simple carbohydrates and other sweeteners. Because sugar is habit forming, the transition off sugar can be tough. So, hang in there! The fact that added sugar and simple carbohydrates are generally detrimental to health is backed by plentiful scientific evidence. Evidence links sugar intake to obesity, hypertension, high triglycerides, insulin resistance, diabetes and possibly bone loss. Notice that this is the same as the list of prednisone side effects!

Avoid all sweeteners including artificial sweeteners. Both sugar and artificial sweeteners send "hunger" signals to the brain. They decrease the chemical dopamine in the brain, reducing the reward from eating, and signaling the brain to eat more. If you don't want to gain weight, the best tactic is to avoid sugar.

**Stick with whole foods.** My advice is to limit your food to whole foods: Vegetables, legumes, nuts, seeds, eggs, fish, meat and a limited amount of whole fresh fruits, healthy fats (such as avocado, olive oil), plain yogurt, kefir and cheeses and whole grains like oats (unsweetened oatmeal) and quinoa. Make sure you are pairing carbohydrates such as oats, quinoa and starchy vegetables with a healthy fat such as avocado, olive oil, nuts and seeds to lower their glycemic impact.

What do you snack on? Try hummus with veggies, nuts and seeds, nut butters, green smoothies, a piece of whole fruit such as an apple or orange or plain full-fat yogurt with berries.

This nutritional approach will reduce your risk of diabetes, weight gain, and other prednisone-related side-effects.

— “ —

**Do not be fooled by the marketing of healthy sounding names like natural cane sugar or brown rice syrup, etc. It is still "processed sugar."**

## Clinical Trials and MG continued from p.1



### What should I ask before participating in a trial?

*Malik:* As a patient, you should ask:

- What is being studied? Is it new, or has it been studied before?
- Why do researchers believe that this intervention would be effective?
- Has it been tested before?
- What possible interventions might I receive? A drug, placebo, blood tests, other tests?
- How will it be determined which interventions I receive – for instance whether I get assigned to receive the drug or a placebo?
- How often do I have to visit the hospital and clinic?
- Will I be reimbursed for the extra clinic visits, travel, or other costs?

### Does anyone get a placebo or “no treatment”?

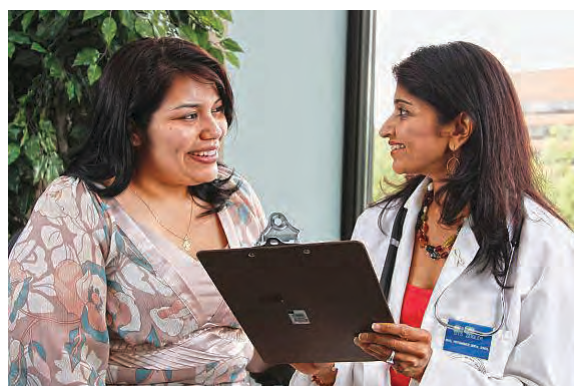
*Malik:* Some studies are set up so some participants are randomly placed in a placebo group.

*Jouvin/Momenta:* It's not possible for a drug company to ask you to stop all your current treatments and go on a placebo. The FDA would not allow that. If you are on a treatment, you could continue current treatment even if you are randomized to the placebo.

### Are there misconceptions that keep people from participating?

*Malik:* Some people feel participants are “guinea pigs.” But these treatments have been studied extensively in the lab before being brought to the clinical stage. There is a lot of brain power behind the design.

*Pontius/Ra Pharma:* There is a very rigorous process to get a clinical study approved. The FDA confirms there is enough potential benefit to patients for the study to go forward. Then the study goes through an approval process at each site with an Internal Review Board that includes scientists, doctors, and lay members. Also, you're never stuck in a study. The consent process doesn't stop with the initial consent.







## New Year's Resolution: Be Prepared for an MG Emergency

Excerpted with permission from materials by Sally O'Meara, RN and Nurse Educator



Here are things you can do in advance to be prepared to be prepared in the event of MG health emergency.

Ensure first responders can see your house address from the street, especially at night.

Wear medical alert jewelry at all times.

List emergency contacts in your cell phone under "ICE." If your phone is password-protected, there is a way to make that information accessible.

Have a packet of up-to-date medical information ready on your refrigerator and car glove box. Include physician contact information, medical history, emergency contacts, medication list (with dose and frequency), allergies.

MG is a rare disease so it's not unusual for patients and families to educate providers. Keep these links on your phone for providers.

Emergency Care: <http://www.myasthenia.org/HealthProfessionals/EmergencyManagement.aspx>

MG medication precautions list: <http://www.myasthenia.org/LinkClick.aspx?fileticket=zmlaFltarOQ%3d&tabid=318>

If the patient has a BiPAP machine at home, bring it to the hospital so that respiratory support can be provided without interruption.

It is important for patients to get medical care right away when symptoms of myasthenic crisis develop. A "crisis" is when breathing muscles become so weak that breathing is impaired. Sometimes it is hard to tell if shortness of breath is due to anxiety or MG muscle weakness. You can do simple assessments at home to check respiratory function. Signs that breathing function is worsening include:

- Cannot lay flat in bed without feeling short of breath or gasping for air
- Rapid shallow breathing (especially more than 25 breaths/minute)
- Having to pause in the middle of a sentence to take a breath
- Weak cough, especially when mucus/saliva cannot be cleared from the throat
- Cannot count out loud past 20 after a full breath of air (single breath count)
- Sweating even when the room is not too warm
- Waking up frequently during the night gasping for air
- Feeling restless, agitated, drowsy or confused
- Breathing worsens even after taking MG medications
- Feeling too tired to keep breathing

### **From Bob Rosecrans, Conquer MG Chairperson**

Conquer MG's existence requires people to step up and volunteer to assist with numerous programs. The organization is supporting an NIH-funded grant MGNet, working with a local Medical Advisory Board, providing patient financial assistance, hosting educational patient-related seminars, organizing fundraising activities, managing an office, and so much more. These services and activities cannot be sustained without volunteers. Please consider stepping up, volunteer, and get involved in direction Conquer MG.

# Support Groups



## Our groups offer:

- Information about myasthenia gravis and ways to cope with its symptoms
- Good listeners who care about your concerns
- Assurance, comfort, and friendship

AREA	2020 DATES	TIME	LOCATION
<b>Chicago - North Suburban</b>	Friday, March 20 Tues, September 22	9:30 AM - 11:00 AM	Glenbrook Hospital, 2100 Pfingsten Road, Glenview, IL. 2nd floor conference rooms A1-A2 Use main entrance and South (Blue) parking.
	Saturday, June 20 Tues, December 8	11:30 AM - 1:00 PM	Potluck indoor picnic and potluck holiday party
<b>Chicago - South Suburban</b>	Saturday, Feb 8 Other dates TBD	1:30 PM - 3:30 PM	NEW LOCATION - Alsip - Marionette Park Library, 11960 S. Pulaski Road, Elevator to lower level conference room. Use main entrance and adjacent parking.
<b>Chicago - West Suburban</b>	Sundays February 9, May 17, August 9, November 8	1:00 PM - 2:30 PM	West Suburban Medical Center, 3 Erie Court, Oak Park IL, lower level conference room A-B. Use main entrance or enter via parking garage lower level. Near CTA Green Line, Austin Station
<b>Rockford</b>	Saturdays April 11, July 11, October 10	1:00 PM - 3:00 PM	St. Anthony Medical Center, St. Francis Room, 5666 E. State St., Rockford, IL. Use main entrance and adjacent parking.
<b>Springfield</b>	Sundays Jan 19, Mar 15, Apr 19, May 17, July 19, Aug 16, Sept 20, Oct 18, Nov 15	3:00 PM - 5:00 PM	Parkway Christian Church, 2700 Lindbergh Blvd. in Springfield, just east of the Parkway Point Shopping Mall. Use office entrance and adjacent parking.
<b>Northwest Indiana</b>	Saturdays Mar 21, May 23, July 18, Sept 19	10:00 AM - 12:00 PM	Schererville Public Library, 1001 W. Lincoln Highway, Schererville, IN. Use main entrance and adjacent parking. Ask the front desk for meeting room,
<b>Quad Cities Iowa / Illinois</b>	Saturdays March 14, June 13, Sept 12, Nov 14	10:00 AM - 12:00 PM	Davenport Public Library - Eastern Avenue Branch, Room A, 6000 Eastern Avenue, Davenport, IA. Use main entrance and adjacent parking.

## Research Updates

Ra Pharma has begun a phase 3, multicenter, randomized, double-blind, placebo-controlled study of zilucoplan as an MG treatment. The study, "RAISE," is recruiting at 31 U.S. sites. This and other currently recruiting sites are listed at <https://www.myastheniagravis.org/looking-for-a-myasthenia-gravis-clinical-trial/>.

In a retrospective review of 71 patients who were diagnosed with ocular MG (ocular symptoms only) 36 experienced conversion to generalized MG. The Thailand study found female gender, smoking history, and abnormalities of the thymus to be risk factors. Receiving immunosuppressant medication and pyridostigmine "were protective factors." Source: American Journal of Ophthalmology, November 15, 2019. DOI: <https://doi.org/10.1016/j.ajo.2019.09.019>



# In Appreciation

**SPECIAL THANKS** to everyone listed who supported our mission from August to December, 2019. Due to space constraints, we are listing those who donated \$50 or more. Your continuing financial support keeps our organization going.

Jeri Aiello  
Peggy and Willard Anderson  
Thomas Cawley  
Claudia Cox  
John Davenport  
James Dee  
Winnie Fanelli  
SeAndrea Ferguson  
Richard Galitz  
Fred and Sharon Grabenhofer  
Gary Granat  
Joyce Holste  
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Sharon Ruddy  
Rosemary Sprague  
Alberta Steinhoff

Geraldine Volpe  
Robert Walsh  
Victor Yipp  
Bonnie Zivich  
  
**In Honor of Moroj Alhajeri**  
Muradi Alhajeri  
  
**In Honor of Anne Breuker**  
Janice Arrott  
  
**In Honor of Gary Granat**  
Dianne Miller  
  
**In Honor of Linda Loland's birthday**  
Catherine Quintero  
  
**In Honor of Jackie Macbeth**  
Janie Dougall  
  
**In Honor of Dr. Michael P. Merchut, F.A.C.P.**  
Jack and Judy Trevillian  
  
**In Honor of Charles Rice**  
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**In Honor of Bob Rosecrans**  
Clyde Partner and Julie Victor  
  
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Marcella Holt  
Elaine Johnson

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**In Memory of Arnold and Frances Dahl**  
Lisa Dahl  
  
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Marty and Judy Small  
Martin and Thelma Greenstein  
  
**In Memory of Patricia "Jo" Elmore**  
Henry County Republicans Central Committee  
  
**In Memory of Joseph Fallico**  
Lorraine Diven

**In Memory of Ronald O. Hill**  
John and Wanza Hill  
  
**In Memory of Harold Kimmel**  
Hanna Sue Matthews  
  
**In Memory of Alexander Niemczura**  
Darlene Niemczura  
  
**In Memory of Bonnie Ostarello**  
John Ostarello  
  
**In Memory of Warren Perlman**  
Jim and Sandy Apple  
  
**In Memory of Ethyl Rogers**  
Maureen McGrath  
  
**In Memory of Lorraine Schohn**  
Joel Schohn  
  
**In Memory of Donald R. Weir**  
Phyllis Weir  
  
NOTE: In our September issue, Patricia Gilmartin should have been listed as making a donation in support of Peggy Cashman and the Park Place Pacers walk team.




**"I love chair Tai Chi. It relaxes the muscles from head to toe. I no longer have muscle spasms at night. It just makes you feel better all over. It doesn't exert you like regular Tai chi. My balance is much better."**

**--Judy Richter, MG patient**

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Raising Awareness at Brookfield Zoo



Upcoming Events

- APRIL 5**  
Spring Patient Seminar, Own Your Health Wellness Fair
- JANUARY - DECEMBER**  
Support Group Meetings
- JUNE 14 - SAVE THE DATE!**  
Conquer MG 5K Fun Run/Walk