

CONQUER

News for our community

Own Your Health Wellness Fair

For Myasthenia Gravis Patients*, Families & Friends

*And anyone with an autoimmune disease



Conquer MG's most popular web page is "MG Worse?" It's important to know what aggravates your MG. Learn about medications, overexertion, pain, and other things you can do to make your life easier.

Join us April 5 at the Wellness Fair at Elmhurst Memorial Hospital. Meet Dr. Julie Rowin, MD, and Maria Zerkow, MD. They will talk about changes they made to improve their lives. They now work with others to do the same. Check out demonstrations on nutrition, meditation, yoga, and acupuncture. Enjoy a free lunch and sample products at vendor tables. We'll have raffle prizes and giveaways, too. Your health is worth it!

POSTPONED
Until October 2020

See registration information on page 6

Save the Date!
Viking 5k Fun Run & Walk
Grove 1, Busse Woods
Elk Grove Village
June 14, 2020!



Thymectomy Q&A

By Rabia Malik, MD
Rush University Medical Center

Q1: Who is a good candidate for thymectomy? Who is not?

A1: Generally, patients with "early onset" myasthenia gravis (MG), i.e., individuals whose MG symptoms started before age 50 and those who have blood tests that show high acetylcholine receptor (AChR) antibodies, are good candidates for thymectomy. Thymectomy is also recommended for patients who have a "thymoma," a tumor of the thymus gland which is typically picked up on a CAT scan. There is no clear benefit for thymectomy in patients with MuSK antibody type MG.

Continued on page 3

— 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

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www.myastheniagravis.org

FROM YOUR EXECUTIVE DIRECTOR

Changing Things Up



If we're going to support our readers in making life changes, then Conquer MG needs to make a few, too! For starters, the Chicagoland spring patient meeting will have a new format. You're invited to the Own Your Health Wellness Fair, April 5, where you can learn firsthand through samplings and demonstrations. Traveling to attend? We've provided area hotel information on the website. See page 6 to learn more.

Second, Conquer MG's Chicagoland 5K Walk/Run will have a new west suburban location. Watch your mail for details, and save Sunday, June 14, to support those who struggle with this rare autoimmune disease.

Wishing you well,

A handwritten signature in cursive script that reads "Joan Wincentzen".

Joan Wincentzen, Executive Director

— “ —

I always entertain
great hopes.

- Robert Frost

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) for the application, or find it on our website.



We are delighted to welcome New Board Members Jim Dee, Tracy Shackelford, and Maria Zepeda. Each person brings unique gifts to the team!



Thymectomy FAQ

By: Rabia Malik, MD, Christopher W. Seder, MD,
Michael J. Liptay MD; Rush University Medical Center

Continued from p.1

Q2: What are the different surgical approaches to thymectomy?

A2: There are two primary approaches to thymectomy. The traditional approach to thymectomy involves opening the sternum (breastbone) down the middle (sternotomy). This allows the surgeon access to the entire thymus and surrounding structures. More recently, minimally-invasive approaches to thymectomy, including video-assisted thoracoscopic surgery (VATS) and robotic approaches, are also being used. These approaches use a camera and key-hole incisions in the side to remove the thymus.

Q3: What are the pros and cons to each? (Or actually, why would anyone choose a full sternum break? Is robotic surgery not available everywhere?)

A3: Minimally-invasive approaches to thymectomy are ideal for patients with small tumors in the thymus or patients having their thymus removed for myasthenia gravis. It is not clear if a VATS or robotic technique is better than the other. However, if a patient has a large tumor that cannot be removed with a minimally-invasive approach, or if a surgeon feels they can provide a safer surgery and more effectively remove a cancer with a sternotomy, a full sternal break may be required.

Q4: What's the recovery like for each type of surgery?

A4: Most patient who have a minimally-invasive approach thymectomy leave the hospital in 1-2 days. Patients who have a sternotomy usually stay in the hospital for 2-3 days. In both cases there is usually a drain that is left in the chest after surgery that is removed prior to discharge home. Patients are generally sore for 4-8 weeks following surgery, but do not require pain medications much beyond 1 week. Patients can go back to most activities when they feel up to it after a minimally-invasive approach, however if a sternotomy is required, activity restrictions are necessary for 6-8 weeks.

Q5: What steps do surgeons and anesthesiologists take to make the procedure safe?

A5: Anesthesiologists ensure that appropriate monitoring equipment is used throughout the operation and they administer special anesthetic agents for patients with myasthenia gravis. Surgeons have an expert understanding of the anatomy and are familiar with the best techniques to use in individual patients. Together, the anesthesiologist and surgeon help to ensure that thymectomy is a safe operation associated with very few complications.

Q6: What outcome can you hope to get from a thymectomy? Does this vary by type of MG?

A6: Thymectomy is not a cure for MG. Following thymectomy, we hope to see improvement in MG symptoms which in turn may allow a patient to be maintained on a lower dosage of steroids. Thymus gland removal surgery does not have a clear benefit for MuSK MG patients.

Jeri Aiello

A New Cane for Ocular MG

Jeri Aiello is a retired nurse and psychotherapist, and lifelong artist. Through her blog at jeriaielloart.wordpress.com, she shares thoughts about hope, MG, jewelry making, and much more.



I shopped online for a cane to help me deal with the double vision and altered depth perception that I experience as a symptom of myasthenia gravis. I was thrilled to find a metallic purple one. **PURPLE CANE, PURPLE CANE!** When telling my husband about my find, he said "Didn't Prince use that for the title of a song?" Now I cannot get the tune out of my head.



The photo shows what I experience as I approach a single step or curb. I have been coping by tapping the back of my heel to the structure to determine where it is. One day I had the thought of how handy it would be to tap with a stick. Then I burst out laughing. They call that

a cane! My neuro ophthalmologist absolutely agreed with the cane decision. He said, "The last thing you need is a fall."

The medical term for double vision is diplopia. Diplopia and ptosis (drooping eyelids) are often the early signs of myasthenia gravis. This was my situation for two years before my other muscles were affected. I experience multiple vision. I see several images rather than simply double. Usually my multiple images are vertical (side by side). Sometimes they are horizontal (on top of each other). When this happens together my brain gets so jumbled. Our eyes are simply the camera lens. Vision happens in our brains. The jumbling causes anxiety. I have learned that daily meditation, mindfulness, and other relaxation habits can help ward off the anxiety caused by the visual disturbance. I need to do this on a regular basis, rather than wait for the anxiety to arrive.

My eye doc is wise. He schedules his MG patients for late afternoons and early evenings, when double vision is worse. I suggest patients find a neuro-ophthalmologist if they have MG.

During a recent visit with friends, three people on a sofa suddenly became six people on a sofa. It becomes difficult to know where to look. I find myself feeling embarrassed and inferior. I am learning that when I do share my experience, most people understand.

I believe my new amazing purple cane will boost my confidence. When I lose my depth perception, I will tap my beautiful purple stick, rather than turning back in terror and feeling embarrassed.

I am so fortunate that my double vision begins at four feet and further. I am able to write, use digital devices, read, and make art. I have recently started to have some close up diplopia. Closing my eyes for a while helps. Closing one eye or wearing a patch always helps. My Doc feels confident that he will be able to treat this with added prisms in my glasses if it progresses.

In the meantime, I am joyfully and gratefully bopping around with my purple cane.



**argenx is a global immunology company
developing antibody-based medicines
for patients suffering from severe
autoimmune diseases, including
Myasthenia Gravis, and cancer.**

By translating immunology breakthroughs into innovative drug candidates, argenx is building a world-class portfolio of first-in-class antibodies in both early and late clinical-stages of development.

Own Your Health Wellness Fair

For Myasthenia Gravis Patients*, Families & Friends

*And anyone with an autoimmune disease

Healthy Lunch
Vendors
Raffle Prizes



Opening speakers:
Followed by demonstrations
Vendors include: Products

POSTPONED
Until October 2020

and Health Coach
Acupuncture
in Care

Register Today! Visit the website: <https://www.myastheniagravis.org> or call 800-888-6208 to register by phone.

Staying in the area? A list of hotels nearby is provided on the website.

April 5, 2020 - 12:00 to 3:00pm - Elmhurst Hospital -
Register by March 31st - Cost is FREE (donations appreciated)

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*2018 SoleMetrics® data



For more information contact:
Phone: 630.478.8240

www.soleohealth.com



What Are Autoimmune Disorders?

The overall function of the immune system is to prevent or limit infection. According to WebMD, "immune system *disorders* cause abnormally *low activity* or *over activity* of the immune system." With MG, the body becomes *overactive in producing antibodies* that attack the body's own tissues, instead of fighting infections. This "overactivity" is why it is classified as an autoimmune disease.

The National Institutes of Health (NIH) recognizes over 80 autoimmune diseases in which the immune system attacks the body's own organs, tissues, or cells. Examples include rheumatoid arthritis, systemic lupus erythematosus (lupus), inflammatory bowel disease (IBD), type 1 diabetes, psoriasis, Graves' disease, Hashimoto's thyroiditis, and Sjogren's syndrome.

The NIH website notes, "Although the causes of many autoimmune diseases remain unknown, a person's genes in combination with infections and other environmental exposures are likely to play a significant role in disease development."

In Appreciation

SPECIAL THANKS to everyone listed who supported our mission in January, 2020. Your continuing financial support keeps our organization going!

Jim and Kathy Bingley

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Jan Prodehl Bees

Christine Durtka

In honor of Shirley Jordan
Donald and Joyce Franklin

In honor of Jenny Printen
Janice and Ken Printen

In honor of Jan Slomiany
Elizabeth Aasen

In memory of Arnold and
Frances Dahl
Lisa Dahl

“There were things I wish I knew
when I first developed MG. I insisted
on working. I would work myself to
illness...
to where I had to be hospitalized.”

--Julie M., MG patient



Conquer MG would like to thank friends and
colleagues at the National Center for Advancing
Translational Sciences and the NIH Clinical Center
who co-sponsored the 10th #RareDiseaseDay!

MG Support Group News



The Chicago South Suburban MG support group has set its next date: Saturday, May 16, 2020, at the Alsip-Merrionette Park Library, 11960 S Pulaski Rd, Alsip, Illinois.




A new MG support group is being hosted by Northwest Neurology, Ltd. the third Tuesday of the month, 10:30am, at the Vernon Hills Park District Community Center, 635 N. Aspen, Vernon Hills, Illinois. Email Dfrycek@northwestneuro.com to register.

Looking for a support group beyond the primary Conquer MG service area? Check the home page of the Myasthenia Gravis Foundation of America website, www.myasthenia.org.

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Volunteers hard at work,
planning the 2020 Viking 5K!



Upcoming Events

- APRIL 5
Own Your Health Wellness Fair
- ONGOING
Support Group Meetings
- JUNE 14 - SAVE THE DATE!
Conquer MG 5K Fun Run/Walk