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.

Conquer MG’s most popular web page is “What Makes MG Worse?” It’s important to know what aggravates MG symptoms – like certain medications, overexertion, pain, and respiratory illness. But what about things you can do to make your MG symptoms better?

Join us April 5 for Conquer MG’s first Wellness Fair at Elmhurst Memorial Hospital. Drs. Julie Rowin, MD, and Maria Zepeda will talk about changes they made to improve their health and how they now work with others to do the same. Check out live demonstrations on nutrition, meditation, yoga, and acupuncture. Enjoy a healthy lunch and sample products at vendor tables. We’ll have raffle prizes and giveaways, too. Your health is worth it!

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

See registration information on page 6

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

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

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,

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

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I always entertain great hopes.
- Robert Frost
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.
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.

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: Julie Rowin, MD, & Maria Zepeda, Certified Health Coach
Followed by demonstrations of Nutrition, Meditation, Yoga, Acupuncture

Vendors include: Personal Chef - CBD & Essential Oils - Skin Care Products

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)

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.”

Clinical Support for Patients with Myasthenia Gravis

We offer comprehensive patient care and personalized customer service for patients with myasthenia gravis

Specialty Infusible and Injectable Therapies

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• Immunomodulatory Therapy

For more information contact:
Phone: 630.478.8240

www.soleohealth.com
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.

“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
Catherine Carroll
Carl Faingold
Cathy Jackson
Rachna Jain
David Kelly
Jonathan Lane
Steve and Dorothy Litwitz
Tom Marino

Drs. William S. and Constance D. Markey
Nancy Rice
Ed Rickert
Sharon Ruddy
Dwain Sims
Ruth Smith
Rita Striegel
Jerry Trojanowski
Nancy Wagner

Fundraisers on Facebook

Christien Appel Esparza
Rod Haskins
Bob Ratzel
Linda Loland
Julie Brown
Venessa Sue Litewski
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!
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Upcoming Events

APRIL 5
Own Your Health Wellness Fair

ONGOING
Support Group Meetings

JUNE 14 - SAVE THE DATE!
Conquer MG 5K Fun Run/Walk

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