



MYASTHENIA GRAVIS ASSOCIATION OF NEW ENGLAND

FALL 2018 – Newsletter Volume 4

Welcome to the Fall edition of the MGANE Newsletter. We hope that you will find this information interesting and helpful. If you have any suggestions for our newsletter or would like to contribute “your story”, please contact Denise Trombly @ Trombly1@myfairpoint.net

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What is the Myasthenia Gravis Association of New England – MGANE

MGANE is a volunteer organization whose mission is to improve the quality of life for all people affected by the neuromuscular disease, Myasthenia Gravis. Our intent is to raise public awareness and promote education of patients and their families, and health care professionals. We welcome participants from throughout New England. Meetings of MGANE are held at the Newton-Wellesley Hospital in the Allen Riddle Room. For more information, please go to our website at www.mgane.org. or 508-435-3808.

The MGANE Board of Directors

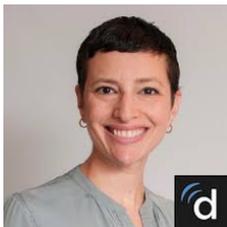
Executive Committee: Pam Cerullo, President; Glenda Thomas, Vice-President; Jim Buckner, Treasurer; Denise Trombly, Secretary

At Large Members: Tom Atherton, Jim Cerullo, Jeff Palmer

ANNOUNCING MGANE 2018 FALL CONFERENCE



Nancy Law
CEO - MGFA



Dr. Amanda Guidon
- MGH
Neuromuscular

On November 4, 2018, MGANE will hold its annual Fall Conference at the Verve Hotel in Natick, Massachusetts. Brunch will be served from 11AM. Guest Speakers will include Nancy Law, CEO of the Myasthenia Gravis Foundation of America and Dr. Amanda Guidon, Massachusetts General Hospital, Department of Neurology. This conference gives participants the opportunity to interact with our local Medical Advisory Board members as well as other MG patients and caregivers. A great way to gather up to date information about MG! Also, our gift basket raffle provides fun and excitement for all. Please join us. Call 508-435-3808 for more information.

NEWS YOU CAN USE

Phone App --- The MyMG phone app contains information about MG and drugs that are inadvisable and possibly dangerous for MG patients. This is especially important in emergency situations.

Medical Emergency bracelets and cards --- Available at Laurens Hope; MedicAlert.com and N-Styleid.com. Cards are available from MGFA.

Myasthenia Gravis Foundation of America, Inc. (MGFA) --- Information nationwide regarding MG research, helpful podcasts by physicians in the field of MG research, and additional support information for those affected with MG, including the Patient Registry for MG patients. See past national conference presentations at mgfa.org

MGANE --- Our local organization is here to help support those in the New England area. Please visit our website at www.MGANE.org; our Facebook page at Myasthenia Gravis Association of New England MGANE; or our email contact at Support@MGANE.org. There is also an MGFA support group that meets in Rochester, New Hampshire every 3rd Thursday at 6PM. Please contact Deb Correia (deblcorreia@yahoo.com) for more information.

MG Registry --- The Myasthenia Gravis Patient Registry is an active database of persons with Myasthenia Gravis (MG), developed for the purposes of research, treatment, and patient information. The MG Patient Registry is a confidential and patient-driven research project, funded by the Myasthenia Gravis Foundation of America (MGFA), managed by the MGFA and the Coordinating Center of the University of Alabama at Birmingham (UAB) with oversight by the MGFA Patient Registry Committee*. Sign up at MGREGISTRY.ORG

Maintaining
Your
Attitude
Sense of humor and
Timing
Hope
Enthusiasm and
Normal life
Is
Absolutely essential

YOUR QUESTIONS ANSWERED by Dr. David Weinberg Department of Neurology, St. Elizabeth's Medical Center



Q. I have heard much about the new Shingles vaccine. Is it safe for MG patients? When should they get it? What if they had the old one?

A. There are 2 forms of shingles vaccines available on the market today. The first is Zostavax, released in 2006. This vaccine is an inactivated live virus that requires a single dose to become effective. This vaccine reduces the risk of developing shingles by 51% and postherpetic neuralgia by 67%. Because it is a live virus, patients who are immunosuppressed should **not** receive this vaccine and that is relevant for many patients with myasthenia gravis (for medications such as prednisone, azathioprine, mycophenolate, cyclosporine, etc.).

A new shingles vaccine was released this year under the brand name Shingrix. This is not a live virus so there are no restrictions with regard to immunosuppressive medications. Therefore, all patients with myasthenia gravis can receive this vaccine and should if they are in the appropriate age range. This vaccination requires 2 separate doses separated by 2-6 months. If two doses have been received, the risk of developing shingles and postherpetic neuralgia are both reduced by 90%.

I would recommend that all people over the age of 50 receive the Shingrix vaccine. If you have previously received the Zostavax vaccine, you need to wait at least 8 weeks but you can and should get Shingrix. You can get the vaccine even if you have had shingles in the past but if you have an active shingles infection, you should wait until it heals before receiving the vaccine. The side effects of the vaccines are relatively mild.

Q. Tell me about clinical trials. How do I know if it is right for me? How do I get involved?

A. Clinical trials are very important for the development of new treatments in myasthenia. Most studies evaluating different myasthenia gravis treatments have very specific requirements for the details of an individual patient's medical history so many patients would not qualify. Most studies are performed at academic medical centers so most of the potential study sites in Massachusetts are in Boston, Burlington, or Worcester.

Active clinical trials can be identified by going to the website "clinicaltrials.gov" and searching for myasthenia gravis studies. This is a National Institute of Health database that includes most active and recently completed trials. Current active trials in Massachusetts that are still recruiting patients include:

- 1) "Disease Modifying Treatments for Myasthenia Gravis (PROMISE-MG)" with participating sites at Beth Israel Deaconess Medical Center, Massachusetts General Hospital, and Saint Elizabeth's Medical Center.
- 2) "Innovative Measures of Speech and Swallowing Dysfunction and Neurologic Disorders" at Beth Israel Deaconess Medical Center.

Anyone interested in participating in any of these sites should contact:

1. MGH: Amanda Guidon, MD
2. BIDMC: Pushpa Narayanaswami, MD
3. LAHEY CLINIC: James Russell, DO
4. ST. ELIZABETHS MEDICAL CENTER: David Weinberg, MD

Opportunity for MG patients to participate in MGH study:

"An evaluation of automated techniques for decoding movement and speech abnormalities"

The purpose of the study is to develop a safe non-invasive tool to accurately diagnose early neurological disease and to monitor disease severity. This study consists of several typical neurological tests of eye and limb movement as well as speech.

The second half of the study consists of tracking dots on a computer, repeating sounds and a small amount of arm and leg movement. It will take about 1 hour. If you are interested, or have further questions, please call Mary Donovan @ 617-726-4879

CURRENT RESEARCH

There is a considerable amount of good news these days for MG patients as you will see in the following newsworthy pharmaceutical report courtesy of MGFA E-newsletter:

+++As always, it is recommended that you speak with your physician about all of this information+++

Clinical Trials and Research:

Phase 2 Trial for Generalized Myasthenia Initiated and Examines Experimental Drug RA101495 is now fully subscribed. Stay tuned for next steps.

Protalex Announces Lead Drug Candidate PRTX-100 Reduces Disease Activity in a Mouse Model of MG

Protalex, Inc. (OTCQB: PRTX), a clinical-stage biopharmaceutical company, announced preliminary findings that its lead drug candidate PRTX-100 reduced disease activity in a second, confirmatory mouse study of myasthenia gravis (MG), an autoimmune

disorder mediated by anti-self antibodies that react with the neuromuscular junction. The study was conducted by the Laboratory for Myasthenia Gravis Research at George Washington University. The study demonstrated potential clinical benefits of PRTX-100 in mice with established MG symptoms. Treatment with PRTX-100 preserved grip strength and decreased disease activity scores relative to control animals.

Rituxan a Promising First-line Immunotherapy in Late-onset MG, Study Suggests

Treating late-onset myasthenia gravis (MG) with Rituxan (rituximab) eases disease symptoms, shows a positive safety profile, and allows patients to reduce other medications, researchers say. Their study, “B-cell depletion in late-onset myasthenia gravis is safe and effective; a case series (P6.439),” was presented as a poster at the 2018 American Academy of Neurology (AAN) Annual Meeting last month in Los Angeles. The study’s abstract was also published in the journal Neurology.

New Therapeutic Targets Needed for Patients with Refractory MG

An opinion piece, “[Refractory Myasthenia Gravis – Patient Burden and the Need for New Therapeutic Targets](#),” written by Saiju Jacob, Consultant Neurologist and Clinical Lead, Queen Elizabeth Neuroscience Centre, University Hospitals of Birmingham NHS Foundation Trust, Birmingham, UK was published in the European Neurological Review. Dr. Jacob stated that, despite an increasing number of immune therapies available for myasthenia gravis, about 10 percent of patients remain refractory, or resistant, to treatments. Dr. Jacob further stated that there is no consensus on the definition of refractory MG since different countries have different guidelines or recommendations or have no definition at all. Dr. Jacob stated that, although refractory MG is rare, it has a severely detrimental effect on the health and quality of life of patients and their careers.

HIGHLIGHTS FROM THE 2018 NEW ENGLAND MG WALK



More than 150 participated in the 2018 Walk for MG held in Boston. Significant funds were raised for MG. Congrats to all.



UPCOMING EVENTS

2018-2019 MGAN Support Group Meetings --- All meetings are scheduled from 2:00 pm – 4:00 pm at Newton-Wellesley Hospital, Allen Riddle Bldg.

September 8, 2018	Dr. Doreen Ho	Lahey Hospital and Medical Center
November 4, 2018	Annual Conference Brunch	The Verve, Crowne Plaza Hotel in Natick, MA
February 10, 2019	Sean Lauziere, MPA	Emergency Preparedness
April 7, 2019	Liisa Jackson	Nutrition
June 2, 2019	Petra Duda	RaPharma Representative
September 8, 2019	TBD	
March 30 - April 2, 2019	MGFA National Conference will be held in Atlanta, GA	
May 2019	Annual New England MG Walk	