



The Myasthenia Gravis Foundation
of Illinois, Inc.

Conquer

"Strength in Hope"

December 2014

275 N. York Street, Suite 401 * Elmhurst, IL. 60126
Phone: 1-800-888-6208 * www.myastheniagravis.org

Highlights...

- * **From Your Executive Director, p. 2**
- * **Rituximab in MG Study, p.2**
- * **News, Activity Updates, p. 3**
- * **Exercises for Posture and Breathing, p.4**
- * **Preparing for Flu Season, p. 4**
- * **Research Updates p. 5**
- * **Support Group Meetings, p.6**
- * **Contributions, p.7**

MGF of IL Patient Assistance Program

The MGF of Illinois board of trustees understands very well the high cost of medical care, and how difficult it is for many MG patients to afford treatment. The board has decided to put aside funds to support MG patients in need. If you are a myasthenia gravis patient, live in Illinois or Indiana, and suffer financial hardship from the high cost of medical treatment and prescription drugs, we may be able to provide some relief.

To the extent funds are available, MGF of Illinois will cover the cost of medical treatment and medication after all insurance payments are applied, up to \$1,000 per person per year. Payment will be made to your healthcare provider to reduce the amount you owe. Requests will be reviewed as they are received.

To obtain a copy of the Patient Application, call the office at 1-800-888-6208 or visit www.myastheniagravis.org.

Azathioprine Update

Some MG patients have found it difficult to get a full prescription of azathioprine (the generic form of Imuran®) filled recently. It's our understanding this is a temporary situation. A Zydus Pharmaceuticals representative explained to MGF of Illinois, "We are on backorder of the product until the beginning of December. Another manufacturer of the product, Roxane Laboratories, left the market which has caused a severe shortage in the market and caused our customers to order above forecast, which in turn has caused our backorder of the product. We apologize for our situation and hope to have it rectified within the next few months." The temporary shortage has not applied to the brand name drug Imuran.

Happy Holidays!

MG is coined
the "Snowflake Disease"
because it affects
no two people the same.



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.

The Myasthenia Gravis Foundation of Illinois, Inc. 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.

**The Myasthenia Gravis
Foundation of Illinois, Inc.**
275 N. York Street, Suite 401
Elmhurst, IL 60126-1530
1.800.888.6208
www.myastheniagravis.org

From Your Executive Director

Happy Holidays! What's on your wish list this year? We at the Myasthenia Gravis Foundation of Illinois wish you *a season of good health*.

After hearing physical therapist Brittany White speak at our October seminar, we also wish you *good posture*. Ms. White explained how proper posture helps with breathing, speaking and swallowing – all crucial for MG patients. Think of how much more air you can inhale when you sit up, compared to when you slouch. Cleveland Clinic notes good posture is essential for avoiding back and neck pain, and muscle fatigue. I'm planning to follow Ms. White's simple exercises this month. I hope you can, too.

Speaking of posture, we hope you'll take a stand and be part of our mission to help those who battle myasthenia gravis. You can make a difference when you contribute to our annual Calendar Club fundraiser, purchase Bakers Square Sweet Returns™ cards, or use iGive.com when you shop online. Be a part of the cause!

All the best to you!

Joan Wincentsen
Executive Director

*"A good stance and posture reflect a proper
state of mind." – Morihei Ueshiba*

Rituximab in MG Study

A Phase II Trial of Rituximab in Myasthenia Gravis soon will begin recruiting study participants in the Chicago area. The study's primary purpose is to learn if rituximab will help people take less prednisone to manage their MG or possibly be able to discontinue prednisone.

This national trial is being led by Dr. Richard J. Nowak at Yale University School of Medicine. It is a multi-center randomized, double-blind, placebo-controlled clinical trial. The study is coordinated by NeuroNEXT, the Network for Excellence in Neuroscience Clinical Trials, with support and funding from the National Institute of Neurological Disorders and Stroke (NINDS), a division of the National Institutes of Health (NIH).

Participants must be between the ages of 21 and 90, have moderate to severe generalized MG, and meet additional requirements.

To learn more about the study, visit www.clinicaltrials.gov and search on "NCT02110706." If you are interested in participating, contact the Yale clinical research coordinator, Hong Vu, at hong.vu@yale.edu or 203-737-6385.



Activity Updates

Calendar Club Winners

August 2014: James Begale, Chuck Carlson, Anita Skurski, Cecil Stuart

September: Barbara Lehotan, Daniel Platt, William Prather, Anonymous

October: Marilyn Beckman, Rita Holz, John Sturtevant, Anonymous

Practical Strategies for Living with MG

On October 19th, 53 people gathered to learn about MG nutrition and exercise issues at Palos Community Hospital. We're grateful for presenters Angela Seitz, RD; Jennifer Koman, RD; Brittany White, PT; and Kathy Adam, SLP, as well as the hospital's terrific support staff. Call 1-800-888-6208 if you'd like a copy of meeting handouts.

Thank you, meeting sponsor, AxelaCare!



Volunteers Needed

Would you like to make a difference in the lives of MG patients? If you have skills in finance, fundraising, marketing, strategic planning, social services, legal or communication, consider joining the MGF of IL board. This commitment involves 5-6 board meetings a year in Elmhurst, IL. Call us at 1-800-888-6208.

The Strides Against MG Walk planning committee meets monthly in Elmhurst starting in January. Call the office to join the team!

Calendar Club 2015

Join the fun and support our mission! Donations for our annual Calendar Club Fundraiser are \$12 per ticket or \$50 for five tickets. Entries are drawn for a weekly prize of \$25. At year end, we pick a Grand Prize Winner (\$500) and a Runner Up (\$100). Donate online at www.myastheniagravis.org > Donations > Calendar Club, or just call the office. We'll add your tickets to the drawing box.

Holiday Shopping and iGive.com



Use the iGive.com portal for your online holiday shopping and you can donate to your favorite charity (we hope it's MGF of IL) while you shop! The best part? There's no cost to you; the store makes the contribution. When you add an iGive.com button to your internet toolbar, the process is even easier. Visit iGive.com for details.

Pass the Pie for MGFI



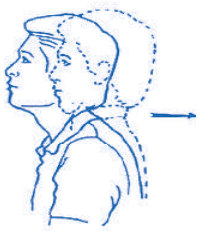
Bakers Square Sweet Returns™ cards are \$15 each and can be redeemed for a pie of your choice; a portion of your purchase helps MGF of Illinois support and educate MG patients. These cards have no end date, and make great holiday gifts. Call the office to make a credit card purchase, or mail us your request along with a check payable to MGF of Illinois.



Exercises for Posture and Breathing

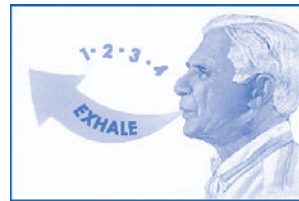
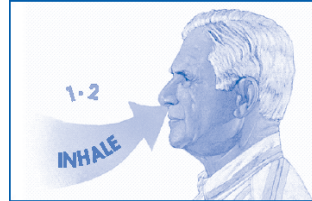
At the October session “Practical Strategies for Living with MG,” physical therapist Brittany White explained that posture exercises can help with breathing, speaking, and swallowing. Ms. White commented, “When our posture is good, many other things become easier.” She also noted the pursed lip breathing exercise below helps MG patients because it can “improve respiratory endurance.” Keep in mind that a person always should check with their doctor before beginning a new exercise regimen.

Scapular Retractions: From a seated or standing position, position your arms 90 degrees at your side. Squeeze your shoulder blades together, sticking your chest out and return to start position. Be sure your shoulders aren’t just going back, but are pushing downward. Perform 3 sets of 10 repetitions each with a 2-3 second hold on the squeeze.



Chin Tucks: Sitting in a relaxed position with head upright and shoulders back. Keeping your chin level, and eyes forward, simply draw your head back. Make sure not to dip your head down as you do this. This is strengthening your deep neck flexor muscles to help counter-balance the “forward head position” many of us have. Hold this position for about 10 seconds. Repeat 10 times.

Pursed Lip Breathing: Relax your neck and shoulders. Breathe in slowly through your nose for two counts. “Purse” (or pucker) your lips as if you were going to whistle. Breathe out slowly and gently through your pursed lips while counting to four.



“Great posture never goes out of style.”

- Cindy Ann Peterson, My Style, My Way: Top Experts Reveal How to Create Yours Today

Preparing for Flu Season

With colder weather comes flu season. The Center for Disease Control (CDC) recommends a yearly flu vaccine as the first and most important step in protecting against this serious disease.



The CDC notes that some groups should especially get the flu vaccine because they are at higher risk for severe complications if they get the flu. This includes those who have chronic neurological disorders and those who are taking immune suppressant medications. The CDC recommends that these groups avoid the nasal spray vaccine because it is made with a live virus.

MG Research Updates

Vaccine Treatment for MG. Researchers are able to induce a version of MG in laboratory rats by injecting them with the acetylcholine receptor (AChR) protein. Now researchers J. Lindstrom and J. Luo from the Perelman School of Medicine at the University of Pennsylvania have developed a fast-acting “vaccine” that can reverse the course of this MG in rats. By administering vaccine doses repeatedly over a period of time, the researchers were able to block development of the experimental MG when it was reinduced months later. Lindstrom noted the next step is to expand trials with laboratory rats, before making the step to human trials. Source: http://www.sciencecodex.com/efficacy_of_potential_therapy_for_autoimmune_disorder_of_muscle_weakness-143061, quoting the University of Pennsylvania School of Medicine

Studies Presented at AANEM Annual Meeting. MG studies were among those presented at the 2014 annual meeting of the American Association of Neuromuscular & Electrodiagnostic Medicine (AANEM) held October 31 – November 1, including the following. For details, visit <http://aanem.org/Meeting/Abstracts.aspx>



Researchers in Washington D.C. and China (Xie, H Li, Jiang, Y Li, Kaminski, and Kusner) found evidence that **Interleukin (IL)-17A plays a role in the origin and development of MG.** IL-17A is a proinflammatory cytokine produced by certain cells of the immune system. Tracking 69 MG patients over two years, they found higher levels of IL-17A associated with more severe MG symptoms, and with patients whose muscle weakness expanded from ocular to generalized.

Results from the **Phase II trial of Methotrexate in MG** were presented. The study’s goal was to determine if methotrexate is an effective therapy for MG patients who are also taking prednisone. Fifty patients at one Canadian and 14 U.S. sites were tracked for one year to see if symptoms improved more in those taking methotrexate plus prednisone compared to those taking a placebo and prednisone. While not successful on all measures, the study showed methotrexate was safe and effective for MG patients.

Azathioprine (brand name Imuran®) is one of the frontline immunosuppressant drugs used to treat MG. Possible **side effects** include liver enzyme elevation and bone marrow suppression. Researchers in London, Ontario noted that prevalence rates reported for these problems are highly variable, ranging from 5% to 25%. Based on a review of 561 MG cases, they found a relatively high percentage of these problems (14.8% for liver and 9.1% for bone marrow issues), and gathered data on severity and recovery time. They note these problems may be under-recognized, suggest more study is needed to understand severity and duration, and suggest more frequent blood work monitoring.

West Florida researchers R. Gandhi, R. Boddepalli, R. Govindarajan, and E. Salgado conducted a retrospective study to determine the prevalence of **arrhythmia in MG patients.** They found 17% of 100 MG patients in this group had cardiac arrhythmia, which might suggest an autoimmune target for both skeletal and cardiac muscles in patients.

MGF of Illinois Support Group Meetings



Our support groups are:

- A place to go for information about your particular problems.
- A group of special friends - good listeners who care about your concerns.
- A group of people like you who share a common problem or interest in acquiring information on a particular issue or need.
- A place to receive assurance, comfort, friendship and social support.

All of our support groups are important because they help MG patients and families learn about the disease, new treatments, and how to recognize and manage symptoms. If you are interested in attending any of these groups or starting a new one, contact our office at 1.800.888.6208.

*** ~ ● ~ ***

A new Chicago-Central MG Support Group begins in February 2015. Rush University Medical Center will host the group and it will be led by a licensed clinical social worker. You're welcome whether or not you're a Rush patient.

SUPPORT GROUPS

AREA	2015 DATES	TIME	LOCATION
Chicago - Central	Thursdays, Feb. 5, March 5, April 2, May 7 future dates tbd	1:00 pm - 2:00 pm	Rush University Medical Center Professional Building, Conference room 1119 (11th floor), 1725 W. Harrison St., Chicago IL. Parking garage is at SE corner of Harrison and Paulina.
Chicago - North / Near No. Suburban	Saturday, Feb. 21 Sunday, April 19, Saturday, July 18, Sunday, Nov. 15	1:00 pm – 2:30 pm	Glenbrook Hospital, Conference rooms B&C, 2100 Pfingsten Road, Glenview, IL. Use center entrance and adjacent parking.
Chicago - South Suburban	Sunday, Feb. 8 future dates tbd	1:30 pm – 3:30 pm	Metro South Hospital, private dining room in cafeteria, 12935 S. Gregory, Blue Island, IL. Use ER entrance parking garage, off Union St.
Chicago - West Suburban	Sundays, Feb. 15, May 17, Aug. 16, Nov. 15	1:00 pm – 3:00 pm	Central DuPage Hospital, 25 N. Winfield Road, Winfield, IL. Meet in Conference Room 3 on first floor. Enter at NW entrance, Women & Children's Pavilion. Valet parking is available plus additional parking in Visitor Lot 3.
Peoria	Sunday, April 19	2:00 pm – 4:00 pm	Proctor Hospital Cafeteria, conference room in the cafeteria, 5409 N. Knoxville, Peoria, IL. Use the main entrance.
Rockford	Saturdays, Jan. 10, April 11, July 11, Oct. 10	1:00 pm – 3:00 pm	St. Anthony Medical Center, St. Francis Room; 5666 E. State St., Rockford, IL. Use main entrance.
Springfield	Sundays, Jan. 18, March 15, April 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 main entrance.
NW Indiana	Saturdays, March 28, May 30, Aug. 1, Oct. 3	10:00 am – 12:00 pm	Schererville Public Library, 1001 W. Lincoln Highway, Schererville, Indiana. Ask at the front desk for meeting room.

In Appreciation...

Special thanks to everyone listed who sent in a contribution from September 2014 through October 2014. Your continuing financial support keeps our organization going! We also thank those who requested not to be listed but support our organization's mission. *Please note: deaths of those listed in the "In Memory" section are not necessarily deaths due to MG.*

Patron-Level Contributors

Neal Chadwick
Tom and Lisa Griffin
Sandy Hasemeyer
David Kelly
Larry Klong
Carl and Patricia Philips
Ed Rickert
Sharon Ruddy
Arlene Sangmeister
Deborah Volpe
Geraldine Volpe

Contributing Level Contributors

Fernando Calvarese
Peggy Greene
James Griffith
Curt McGhee
Cheryl Meltzer
Ellie Schnepf
Rosemary Sprague
Donald and Phyllis Weir

Annual Level Contributors

Margrit Baerman
Cecelia Czarnecki
Eugene Deutsch
James and Lillian Gaba
Carolyn Grebner
George and Marilyn Heinz
Cheryl Heldt
Dorothy Ippolito
Barbara Lehman
Gerald Mack
Laverne and Mildred Mousel
Chirag Pandit
Wanda Taveras
Lucile Theobald
Joan Volanti
Joan Wincentsen
Jim and Ada Witecha
Helen Wonak

In Honor of Contributors

In Honor of Anne Breuker
Janice Arrot

(Correction)

The Marriage of Neal and Mireya

Chadwick
Jo and Bradley Chadwick

In Memory of Contributors

In Memory of Nicholas Albers
Edward Albers

In Memory of Bob Ballard
Geraldine Volpe

In Memory of Rose and Al Brandt
Arlene Brandt

In Memory of Bernard Carnivele
Gloria Carnivele

In Memory of Robert Dickinson
Vernon and June Baumgart
Phyllis Cora
Dave and Marie Kuemmel

In Memory of Gert and Al Gold
Arlene Brandt

In Memory of Alexander Niemczura
Susan Alicea
Bonnie Ostarello

In Memory of Ethel Rogers
Maureen McGrath



In Memoriam

We regret to share that Lorrie Schohn, a founding member of MGF of Illinois, passed away February 9, 2013, at age 71. Lorrie helped start MGF of Illinois in 1972 and worked tirelessly as a board member for many years. Her roles included Assistant Treasurer and Patient Aid Committee Chair. With her warmth and engaging personality, she was an excellent personal contact for callers. She also wrote patient materials like the "Patient-to-Patient Memo" booklet that offered invaluable advice to those struggling with MG. She was diagnosed with MG in her mid-teens, and with the experience of two successful pregnancies was able to give hope to other young women. Our condolences are extended to Lorrie's husband, Joel Schohn, and family.

The Myasthenia Gravis Foundation of Illinois, Inc.
275 N. York Street, Suite 401
Elmhurst, IL 60126



“Strength in Hope”

Non-Profit Organization

U.S. POSTAGE PAID

Permit No. 3182

Chicago, IL

Conquer via Email reduces our expenses.

Member of:



Moving Soon? New Email? Let Us Know!

To keep our mailing list updated, we would appreciate your notifying us of any change in your contact information. Please fill out the following and mail it back to us. This will ensure you continue to receive Conquer. OR if you do not wish to receive Conquer, fill out the following and mark to be removed from our list.

PLEASE PRINT

Name: _____

Address: _____

City _____ State _____ Zip: _____

Email: _____

- ☐ Please remove my name from your mailing list.
- ☐ Please note the above change in my contact information.
- ☐ Please send Conquer via Email instead.