



The Myasthenia Gravis Foundation
of Illinois, Inc.

Conquer

"Strength in Hope"

March, 2014

310 W. Lake Street, Suite 111 * Elmhurst, IL. 60126
Phone: 1-800-888-6208 * www.myastheniagravis.org

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

STRIDES Against MG



Dust off your walking shoes! This June during MG Awareness Month, MGF of Illinois will host its 2nd Annual Strides Against MG Walk. Plan to join us bright and early Sunday morning on June 1 at Berens Park in Elmhurst, Illinois for our 1-mile and 3-mile walk and kids' dash. Come on your own, bring a friend, or gather a whole team to join the fun.

We'd love to top last year's attendance of 175 walkers and volunteers. You can walk, run, or just enjoy the music and free snacks. Be part of the spirit of hope, as friends and family walk side by side with those affected by MG. "I thought it was MGF of Illinois' best event ever," stated Ashok Patel about last year's walk.

Your involvement raises vital awareness for myasthenia gravis. This year you can use our online registration tool to share your own MG journey, through story and pictures. All funds that you raise go toward MGF of Illinois' work to provide patient support and education, raise awareness among the public and among healthcare professionals, and directly fund vital medical research. *See the flyer inside to find out how you can participate!*

Side Effects of Common MG Medications

Ever wish your MG medications could specifically target your disease, without wreaking havoc on your stomach or bones or eyesight or blood sugar? If so, be sure to circle Sunday, May 4, 2014, on your calendar, and plan to attend the MGF of Illinois Spring Educational Session and Annual Business Meeting. Dr. Alexandru Barboi from Rush University Medical Center will address the side effects of common medications used to treat MG, as well as other MG hot topics. The meeting will be held at Elmhurst Memorial Hospital. See the flyer inside for registration details.

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.**
310 W. Lake Street, Suite 111
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From Your Executive Director

Working each day with MG patients and MG news, it just seemed right to choose “*Connections*” as our theme for 2014. We want to connect you to the best resources and the most up-to-date news for MG. In this Conquer issue, I’m sure some of you will connect with “juvenile MG,” “seronegative MG,” or “fixed weakness.”

We also want to connect you with other individuals struggling with the disease. I hope you can join us on June 1 for our 2nd Annual Strides Against MG Walk, so you know you are not alone in your MG journey. Last year I was so impressed with the spirit of those who walked. Determination, encouragement...you could see it in every face. What a great way to step up for MG awareness. And you know what? It was fun, too!

What do we do with walk proceeds? We are a state organization, primarily serving Illinois and northwest Indiana. **Your dollars go to support local services** like the May 4th educational session in Elmhurst covering Side Effects of Common MG Medications, our seven Illinois and Indiana support groups, and MG patient packets for doctors in Chicago, Hammond, Springfield, Peoria, and Rockford. **Your donations reach beyond the Chicago area** by helping to pay for conference videotaping, as well as the update and maintenance of www.myastheniagravis.org, our YouTube channel “MGFillinois”, our Facebook group page, and more. And your donations support research funding for pilot studies – to give innovative MG projects a starting boost.

Thank you!

Joan Wincentsen
Executive Director

Ben Maravilla Recognized



*Ben shows his volunteer awards
to director Joan Wincentsen.*

Ben Maravilla has seized upon many opportunities to spread the word about MG. Last fall, the Dominican Republic’s Montemar Project Sports Complex honored him and MGF of Illinois for Ben’s volunteer efforts.



Activity Updates

Holiday Bocce Ball Party



Despite the day's tornado gusts, experienced and first-time players alike enjoyed MGF of IL's Holiday Bocce Ball Party. Congratulations to tournament winners Mary Ann Kettell, Jeff Wincentsen, Randy Holste and Steve Kuhnhofer!

Don't Miss a Minute

Last year we emailed four issues of our latest e-publication, the "MG Minute." Don't miss out! Contact the office with your current email address (1-800-888-6208 or info@myastheniagravis.org).

MGF of IL Board

We are grateful to the MGF of Illinois Board of Trustees, who volunteer their time to guide this organization:

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If you care about MGF of IL's mission and have skills in fundraising, finance, marketing, strategic planning, or communication we'd like to hear from you!

Be a Walk Volunteer!



Want to pitch in with the Strides Against MG walk on June 1? Call the office at 1-800-888-6208 if you can direct parking, guide walkers, or help with set-up and clean-up. Let us know if your business or

employer could be a walk sponsor, or if you'd like to contribute a gift card to our Gift Card Tree raffle!

MGF of IL Research Funding

Final applications for the 2014 MGF of IL research grant were received in January and are in peer review. The grant recipient will be announced in May.

The approval process has been completed for the pilot study addressing MG and exercise (conducted by the GH School for Healthy Living and the University of Illinois Chicago), and the study is underway.

Calendar Club Winners

2014

January: Sharon Adamsheck, Elizabeth Alexander, Russell Laney, Amy Schindel

2013

Year End: Grand prize – John Sturtevant, Runner-up – Anonymous

December: Marilyn Beckman, Marita Janzen, William Prather, Chris Rickert

November: Carolyn Grebner, Cindy and Mike Klidas, Elena Okon, James Witecha

October: Glen Knudsen, Darlene Niemczura, Anonymous (2)

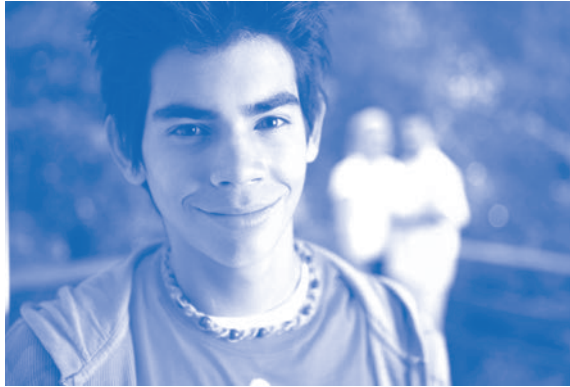
September: Bob Carna, Ken Koss, Irene Mostek, Bonita Young

August: Thomas Dammrich, Jan Schneider, Cecil Stuart, Anonymous

Juvenile Myasthenia Gravis

By Kourosh Rezaia, MD, Department of Neurology, University of Chicago

Myasthenia gravis (MG) is caused by abnormal immune reaction against components of the neuromuscular junction. The main manifestations of MG are fatigue, eyelid droopiness, double vision, swallowing



problems, nasal speech, shortness of breath, and muscle weakness. Juvenile myasthenia gravis (JMG) is applied to MG occurring between 0-19 years of age. JMG should be differentiated from neonatal MG, when antibodies from a myasthenic mother cause weakness in the baby; and from congenital myasthenia, which is caused by a genetic abnormality (mutation) in specific neuromuscular junction proteins. Congenital myasthenia usually manifests in the first year of life, but the onset of the symptoms maybe later, including adulthood.

Among Asians, MG presents by adolescence age in about 50%, most commonly between ages two and four. On the other hand, JMG accounts for only 10-15% of MG patients in the Western countries.

JMG can be diagnosed with a blood test which looks for antibodies against the acetylcholine receptors, AChR. This test is positive in 85-90% of patients who have generalized weakness, and in 50% of patients in whom the disease is limited to eyelid droopiness and/or double vision. About 30% of patients with JMG who test negative for antibodies to AChR test positively for antibodies to muscle specific tyrosine kinase (MuSK). Electromyography is often used to diagnose JMG, especially in patients who test negative to both AChR and MuSK antibodies. Cancer of the thymus (thymoma) is very rare in patients with JMG.

The treatment of JMG involves management of symptoms as well as treatment of the underlying immune disturbance. Pyridostigmine is the most commonly used medication to treat myasthenic symptoms, and may be adequate for mildly affected patients. Thymectomy (removal of thymus gland) may result in remission or reduced disease activity, and is often used in the affected adolescents. Thymectomy should probably be avoided in MuSK positive patients and very young JMG patients. Steroids (usually oral prednisone) are usually effective and are considered the first line immunomodulatory treatment in JMA. Steroid treatment - especially long term, high dose therapy - is associated with significant side effects. Therefore, immunosuppressants such as azathioprine, cyclosporine, mycophenolate, cyclophosphamide and tacrolimus are frequently used as steroid sparing agents, in order to decrease the dose of steroids or discontinue them. Long term treatment with immunosuppressants such as azathioprine is associated with increased risk of malignancy and infertility. Intravenous immunoglobulin (IVIG) and plasma exchange (PLEX) are commonly used in myasthenia exacerbations, i.e., when there is severe weakness causing respiratory failure and/or significant swallowing impairment. Less commonly, IVIG or PLEX are used on a regular basis in patients who have been intolerant or resistant to oral medications. Emerging treatments such as monoclonal antibodies provide the prospect of effective treatment of JMG with less pronounced side effects. Rituximab, which is given intravenously and is approved to be used in lymphoma and rheumatoid arthritis, has been successfully used in some patients with treatment refractory JMG.

Experience with Dry Eyes

Recently an MG patient (V.) explained that MG keeps her eyelids from fully closing at night, resulting in dry eyes. This caused discomfort and impaired her vision. She found relief when her eye doctor inserted tiny plugs in her tear ducts so that the ducts were closed. This conserves her own tears. She also applies eye ointment each night as prescribed by her doctor, and uses her own version of a medical eye mask designed to help keep the eyes closed while sleeping. (Her adapted \$3 sleep mask from Walmart is an inexpensive solution.) MayoClinic.org explains eye plugs as well as the many causes, problems and treatments associated with dry eyes at <http://www.mayoclinic.org/diseases-conditions/dry-eyes/basics/treatment/con-20024129>.

The Feel-Good Power of Music



From WebMD.com: “Researchers at the University of Maryland found that when people listened to music that made them feel good, they had better blood flow, which is good for your heart and blood vessels.” WebMD also cited a study that showed, “after a stroke, people who listened daily to their favorite music remembered more, could focus better, and were less depressed and confused than those who hadn’t.”

Affordable Care Act Deadline

Americans who have yet to purchase a health plan through their state’s health insurance marketplace have only until the end of March 2014 to decide on a plan.

The National Health Council, a nonprofit organization that provides a unified voice for people with chronic diseases and disabilities, offers valuable resources and tools through its “Putting Patients First” initiative. This special program can help health insurance consumers decide which health plan will work best for them. Visit www.puttingpatientsfirst.net.

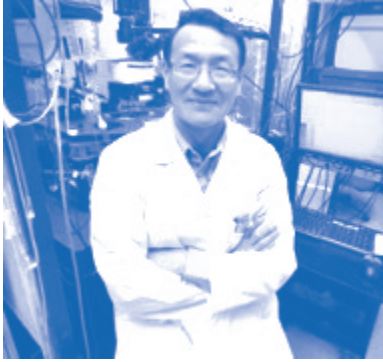
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New Cause Found for MG

Source: GRU News, online news from Georgia Regents University, Augusta Georgia. <http://news.gru.edu/archives/10267>; Posted by Toni Baker on November 11, 2013

An antibody to a protein critical to enabling the brain to talk to muscles has been identified as a cause of myasthenia gravis, researchers report.



The finding that an antibody to LRP4 is a cause of the most common disease affecting brain-muscle interaction helps explain why as many as 10 percent of patients have classic symptoms, like drooping eyelids and generalized muscle weakness, yet their blood provides no clue of the cause, said Dr. Lin Mei, Director of the Institute of Molecular Medicine and Genetics at the Medical College of Georgia at Georgia Regents University.

“You end up with patients who have no real diagnosis,” Mei said.

The finding also shows that LRP4 is important, not only to the formation of the neuromuscular junction – where the brain and muscle talk – but also maintaining this important connection, said Mei, corresponding author of the paper in *The Journal of Clinical Investigation*.

Mei and his colleagues first reported antibodies to LRP4 in the blood of myasthenia gravis patients in the *Archives of Neurology* in 2012. For the new study, they went back to animals to determine whether the antibodies were harmless or actually caused the disease. When they gave healthy mice LRP4 antibodies, they experienced classic symptoms of the disease along with clear evidence of degradation of the neuromuscular junction.

LRP4 antibodies are the third cause identified for the autoimmune disease, which affects about 20 out of 100,000 people, primarily women under 40 and men over age 60, according to the National Institutes of Health and Myasthenia Gravis Foundation of America, Inc.

An antibody to the acetylcholine receptor is causative in about 80 percent of patients, said Dr. Michael H. Rivner, MCG neurologist and Director of the Electrodiagnostic Medicine Laboratory, who follows about 250 patients with myasthenia gravis. Acetylcholine is a chemical released by neurons which act on receptors on the muscle to activate the muscle. More recently, it was found that maybe 10 percent of patients have an antibody to MuSK, an enzyme that supports the clustering of these receptors on the surface of muscle cells.

“That leaves us with only about 10 percent of patients who are double negative, which means patients lack antibodies to acetylcholine receptors and MuSK,” said Rivner, a troubling scenario for physicians and patients alike. “This is pretty exciting because it is a new form of the disease,” Rivner said of the LRP4 finding.

Continued on page 7

Currently, physicians like Rivner tell patients who lack antibody evidence that clinically they appear to have the disease. Identifying specific causes enables a more complete diagnosis for more patients in the short term and hopefully will lead to development of more targeted therapies with fewer side effects, Rivner said.

To learn more about the role of the LRP4 antibody, Mei now wants to know if there are defining characteristics of patients who have it, such as more severe disease or whether it's found more commonly in a certain age or sex. He and Rivner have teamed up to develop a network of 17 centers, like GR Medical Center, where patients are treated to get these questions answered. They are currently pursuing federal funding for studies they hope will include examining blood, physical characteristics, therapies and more.

The Journal of Clinical Investigation study was funded by the NIH and the Muscular Dystrophy Association. Mei is a Georgia Research Alliance Eminent Scholar in Neuroscience.

Is Employee Giving Available at Your Workplace?

Many Americans participate in employee giving campaigns sponsored by their employers. Employees give at work by directing a portion of their paycheck to the charities of their choice. Giving at work has great advantages for both the employees who participate and the employers who conduct a workplace giving campaign.

As a member of Community Health Charities of Illinois, MGF of Illinois depends on employee giving to fund part of our budget. We have learned that no employer is too small to implement a workplace giving campaign.

Through their no-cost employee engagement tools, Community Health Charities of Illinois can create an employee giving program for your company that reflects causes that are important to you.



If you'd like to learn more, please contact Steve Schapiro, Vice President of Corporate Development for Community Health Charities of Illinois at sschapiro@healthcharities.org or 847-804-7127.



Doctors on strike! Pharmacist called in to translate
picket signs.

- Mikey's Funnies

I don't want to brag or make anyone
jealous, but I can still fit in to the earrings
I wore in high school.

- Mikey's Funnies



Other Research News



The Journal of Cardiothoracic Surgery 2013 reported on a study that took place at the Chiba University Graduate School of Medicine, Japan. Researchers reviewed data from 1992 to 2009, comparing 70 patients who received **high-dose prednisolone before thymectomy** (surgical removal of the thymus) to 60 patients who did not get pre-operative steroids. They concluded that administering high-dose prednisolone before thymectomy “is a promising strategy for managing patients with myasthenia gravis. It may reduce the incidence of MG crisis after thymectomy while improving disease status.”

Source: Yoshito Yamada, et. al. Efficacy of perioperative high-dose prednisolone therapy during thymectomy in myasthenia gravis patients. Journal of Cardiothoracic Surgery 2013, DOI: 10.1186/1749-8090-8-226. <http://www.cardiothoracicsurgery.org/content/8/1/226>

While the hallmark of MG is fluctuating muscle weakness, a study reported in Ars Neurologica Scandinavica looked at **MG muscle weakness that is considered “fixed.”** Researchers compared muscle strength of 38 MG patients with 37 control subjects. The study found that patients with generalized MG can have signs of fixed weakness – reduced muscle strength that doesn’t vary over time or vary with repeated use. They noted the men in their study had a greater reduction in muscle force than the women, that shoulder abductor strength was most affected, and that the disease duration alone didn’t predict the loss in muscle strength.

Source: Published online October 11, 2013. Cejvanovic S, Vissing J. Muscle strength in myasthenia gravis. Acta Neurol Scand: DOI: 10.1111/ane.12193. © 2013 John Wiley & Sons A/S. Published by John Wiley & Sons Ltd.

A study supported by the Myasthenia Gravis Association, Queensland, confirmed that **balance strategy training** helped a small group of MG patients improve their balance and functional ability. Source: Published online in Muscle & Nerve, December 11, 2013. Wong, S. H., Nitz, J. C., Williams, K. and Brauer, S. G. (2013), Effects of balance strategy training in myasthenia gravis: A case study series. Muscle Nerve. doi: 10.1002/mus.24054

Trusted Health Sites



General Health: www.medlineplus.gov From the National Institutes of Health. Covers more than 900 conditions and includes a guide to thousands of drugs and supplements.



Healthy Eating: www.eatright.org Visit this site for info on nutrition; has special sections for vegetarians, athletes, and other groups; plus “get real” reviews of popular diets.



Emotional Problems: www.healthyminds.org The American Psychiatric Association offers discussions of many mental health concerns. Has sections for caregivers, teens, seniors, Latinos, and more.



Fitness. www.cdc.gov/physicalactivity Jump-start your fitness program with sample weekly workout plans from the Centers for Disease Control and Prevention. Or try www.acefitness.org With 200 workouts, this American Council on Exercise site is an alternative to going to the gym. See many exercises in action. *Be sure to get your doctor’s okay before starting an exercise program.*

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. You can find future meeting dates on our website at http://myastheniagravis.org/mgfi_support_groups.aspx.

SUPPORT GROUPS

AREA	2013 DATES	TIME	LOCATION
Chicago - North / Near No. Suburban	Saturday, May 17 Fall date tbd	1:00 pm – 3:00 pm	Glenbrook Hospital, Conference rooms B&C, 2100 Pfingsten Road, Glenview, IL Use center entrance and adjacent parking.
Chicago - South Suburban	Sunday, May 18 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, May 18, Aug. 17, Nov. 16	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	Sundays, June 29, Oct. 19	2:00 pm – 4:00 pm	Proctor Hospital Cafeteria, Conference room behind the cafeteria, 5409 N. Knoxville, Peoria, IL.
Rockford	Saturdays, April 12, July 12, Oct. 11	1:00 pm – 3:00 pm	St. Anthony Medical Center, St. Anthony Room; 5666 E. State St., Rockford, IL.
Springfield	Sundays, March 16, April 27 May 18, July 20, Aug 17, Sept 21, Oct. 19, Nov. 16	3:00 pm – 5:00 pm	Parkway Christian Church, 2700 Lindbergh Blvd in Springfield, just east of the Parkway Point Shopping Mall.
NW Indiana	Saturdays, March 29, May 31, Aug. 2, Oct. 4	10:00 am – 12:00 pm	Schererville Public Library, 1001 W. Lincoln Highway, Schererville, Indiana. Ask at the front desk for meeting room.
Ames, IA (Independent Chapter)	Saturdays, March 8, June 14, Sept. 13, Dec. 6	10:00 am – 12:00 pm	Northcrest - Rose Room, 1901 Northcrest Circle, Ames, Iowa.

Myasthenia Gravis Patient Registry

The Myasthenia Gravis Foundation of America has established an MG Patient Registry. This confidential database is a way for patients to provide information that will be useful for purposes of MG research and treatment. For more information, visit www.mgregistry.org.

In Appreciation...

Special thanks to everyone listed who sent in a contribution from August 2013 through January 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.*

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In Honor of
all Myasthenia Gravis Patients
Freida Zeidel

In Honor of Kelly Aiken
David Wiseman

In Honor of Jeremiah Campion
Mary Clark

In Honor of Peggy Cashman
Mr. and Mrs. Michael McClain

In Honor of
Harriet Catherine Daniels
Ed Daniels

In Honor of Shirley Jordan
Donald and Joyce Franklin

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Paula A. Anderson

In Honor of Their Anniversary
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In Honor of Laura Littner's birthday
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In Honor of Beverly McGovern
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Cheryl Meltzer's Birthday
Ann and Bob Neuman

In Honor of Michael P. Merchut, MD
Stuart Weis

In Honor of Melvin D. Wichter, MD
Carl Stahl Jr.

In Appreciation...(continued)

In Memory of Contributors

In Memory of Nicholas Albers

Edward Albers

In Memory of Fred Arnold

Loretta Fleming

In Memory of her beloved husband

Margrit Baerman

In Memory of David B. Cady

Geraldine O'Laughlin

In Memory of Bernard Carnivele

Gloria Carnivele

In Memory of Nora Jean Dickinson

Robert Dickinson

In Memory of Paul Frederick

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The Myasthenia Gravis Foundation of Illinois, Inc.
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Make an MG Connection!
Join us!
Annual Meeting - May 4
Strides Against MG Walk - June 1

Non-Profit Organization

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Chicago, IL

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