



The Myasthenia Gravis Foundation
of Illinois, Inc.

Conquer

"Strength in Hope"

September, 2013

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



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Holiday Bocce Ball Party

We hope you'll join us Sunday afternoon, November 17, for a game as old as the hills of Italy...in a sparkling new venue! That's when MGF of Illinois is hosting a Holiday Bocce Ball Fundraiser Party at Pinstripes in Oak Brook, IL. You're invited whether you're an expert or you've never played (like us). A live demonstration of the game will show you how easy it is! You can sign up as a single or as a team of two. Bring your friends and family of all ages. You don't have to play to attend.

The MGF of Illinois party will have its own area with three bocce ball lanes, space to mingle and appetizers. To add some holiday spice to the event, we'll also have a split-the-pot game and award prizes to the winning teams! See the enclosed flyer for details.

All proceeds support MGF of Illinois' work to provide patient support and education. Help us help MG patients!

Stress Management and Myasthenia Gravis

Has chronic illness – either your own, or that of a loved one – affected your ability to handle school deadlines, job pressures, rebellious children or broken dishwashers? Join us for our fall educational meeting on Sunday, October 20, at Edward Hospital in Naperville. Deb Smith, M.Ed., Licensed Clinical Professional Counselor, will explain stress and how it impacts health. She'll discuss coping strategies for today's problems and ways to prevent future stressors.

Is meditation something you've been curious about? Meditation can help you refocus negative thought patterns and handle stress more effectively. Dr. Tim Fior, family practitioner and lecturer for the Naturopathic Program at National University for the Health Sciences, will offer an introduction to meditation and practice session - which requires no specific postures, nor focus on breathing or chanting - for those who are interested. Its ease and beneficial effects may surprise you. See the flyer inside for more information about these useful, enriching sessions.

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.

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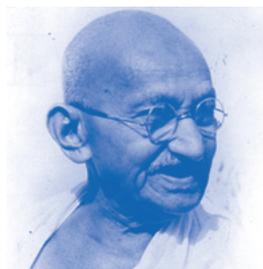
From Your Executive Director

Like many of you, I've had MG- and prednisone-related vision issues. When my vision was compromised, I learned so much about its worth. I realized it fed me information to walk down the street or pay my bills. It gave me access to Harry Potter and Jane Eyre. It helped me sort out who spoke to me in a restaurant, and helped me understand what they said...and what they meant. And of course it gave me great joy in seeing my family at the dinner table or watching sunlight play on the choppy waves of Lake Michigan. As you can imagine, I was very relieved to get my MG vision problems resolved.

This newsletter is focused (pun intended) on vision issues for MG patients. Springfield support group leader Gary Nelsen generously contributed an article about overcoming double vision with eyeglass prisms. We report on a research study on prednisone and ocular MG, and offer tips for dealing with double vision, droopy eyelids, and blurriness. I hope you find this useful.

Did you know that in addition to its Mission Statement, MGF of Illinois has a Vision Statement? It is "Eliminate Myasthenia Gravis." We'd like to see a world where MG no longer exists. That's what I wish for you: to get past your MG issues, especially those related to vision. Functioning eyesight is such a gift, and it feels so good to be connected to the world again.

Joan Wincenten

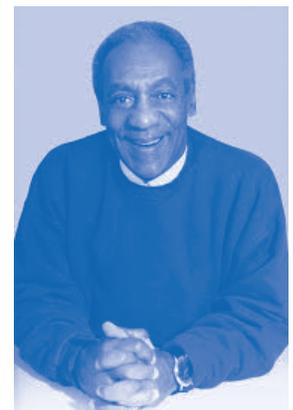


***"An eye for an eye only ends up making
the whole world blind."***

- Mahatma Gandhi

***"Every closed eye is not sleeping, and
every open eye is not seeing."***

-Bill Cosby



Activity Updates

Thanks to our Strides Against MG Sponsors

You helped make our June “Strides Against MG” walk a big success!

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Jevitz Chiropractic Clinic

Maria’s Floral Studio of LaGrange

Friends of MGF of Illinois include First Class Inc., Jewel on Schiller, and Costco (Oak Brook)

Calendar Club Winners

April – Bill Burke, Joyce Holste, Ellen Pfaffin, Anonymous (1)

May – Mr. & Mrs. Frank Menchaca, Elena Okon, Anonymous (2)

June – Cheryl Heldt, Bonnie Ostarello, Marvin Savage, Carl Stahl

July – Rosemarie Levy, Steve Malinovich, M. McGrath, Anthony Oleynichak

Board Members Needed

Do you care about MGF of Illinois’ mission to support people with MG and have skills in fundraising, finance, marketing, strategic planning, social services, legal, or communication? If so, our board would love to hear from you. A board commitment involves 5-6 board meetings in Elmhurst, IL, 1-2 educational seminars in and around Chicago, and 1-2 social fundraisers each year. If you want to make a difference in the lives of those who struggle with MG, call us at 1-800-888-6208.



A Parade and a Boat Race-Year 2

Ben Maravilla continues to spread the word about myasthenia gravis. This year he organized a group to walk in Aurora’s Puerto Rican Festival Parade on July 27. And he and his team created an MG entry for the Fox Valley United Way Cardboard Boat Race on August 17. Last year we took first prize among the nonprofits!



2013 Grant Status

Following peer review, the MGF of Illinois Medical Advisory Board was unable to recommend a research grant application for MGF of Illinois funding. We will continue to seek research funding opportunities.

2014 Call for Abstracts

A request for abstracts was issued to over 80 MG researchers in mid-August. Deadline for abstract submission is September 16, 2013. Applicants will be notified if they should submit a full application by November 1.

Ocular MG - A Prism Solution

By Gary Nelsen, Springfield Support Group Leader
and Dr. Shaun Hill, Optometrist

Double vision is often the first sign to appear for those of us who have been diagnosed with myasthenia gravis. For some, like me, that continues to be the primary symptom. I was diagnosed in 2006 and struggled with double vision, even after having tried Mestinon, Imuran, predisone and CellCept, and found little help.



Two years ago my ophthalmologist recommended that we try prisms in my eye glasses. I was not enthused because I had tried temporary prisms which can be stuck on the lenses. They had not helped at all. But my ophthalmologist wanted to have my optometrist, Dr. Shaun Hill, perform the eye exam late morning - so it would be in the middle of the day between when the double vision was the least and the worst.

The new glasses were amazing, relieving me of the double vision almost totally. When my eyes were checked a year later, the optometrist made an additional adjustment. The result—no double vision at all, tired or not. It is a Wow!

I asked my optometrist to explain what he did, in hopes it might help somebody else—though we all know about the “snowflake” aspect of MG and how things respond differently from one person to another. But it is worth a try. Here is his response.

“Myasthenia gravis is an unpredictable disease in which the muscles and nerves innervating the muscles seem randomly disconnected from a patient’s perspective. Myasthenia gravis is known to cause ptosis (drooping) of the eyelid, diplopia (double vision), and tumors of the thymus gland as well as muscle weakness even including difficulties swallowing and breathing.

“My patient (GN) has experienced ocular difficulties due to his having myasthenia gravis for over six years. He began having vertical double vision. The difficulty was that the amount of vertical prism necessary would change from one visit to the next. Every four to five months the amount of prism kept changing. With some patients this can change hourly or even after a few minutes. After approximately four years, the vertical prism stabilized and with a slight horizontal prism included, GN’s diplopia has stabilized for the last ten months.



Gary Nelsen and optometrist Dr. Shaun Hill

“The hidden pearl is that the patient’s best visual acuity (clearness and sharpness of vision) should be maximized and expect fluctuation. GN had cataract surgery to improve his overall quality of vision.

continued on page 5

“Best visual acuity is very important. Some patients may need cataract surgery and strabismic surgery to allow proper fusion of a patient’s vision from both eyes.

“Fluctuation is normal with myasthenia gravis. Best visual acuity is necessary to allow best binocular function. There are extra-ocular muscles, lid muscles and Orbicularis oculi muscles which can all be weakened by myasthenia gravis and can cause diplopia, ptosis and ocular symptoms. Much like driving a car with loose steering, the eye requires precise cooperation of the ocular muscles to keep single binocular vision intact and without the precision diplopia can and will occur. Also, because of myasthenia gravis’ fluctuating nature, the amount of diplopia is constantly changing with the fatigue of the individual. When patients get the appropriate medical treatment (medicine and glasses), the patient can improve dramatically and often achieve fusion.



“As long as the deviations of direction of the eyes are consistent, the patient can have a satisfying relief of diplopia. GN was a fairly straightforward presentation. We still changed his glasses six times during the four-year experience. Persistence by both patient and doctor often can alleviate symptoms and allow patients to enjoy single binocular vision.”



***“I never questioned the integrity of an umpire. Their eyesight, yes.”
– Leo Durocher***

Study of Prednisone and Ocular MG

A study to determine the effectiveness of prednisone for treating ocular myasthenia is underway. Spearheaded by Dr. Michael Benatar of the University of Miami, the study is recruiting participants in a number of locations including Florida, Kansas City, New York, and North Carolina (no Illinois or Indiana sites are included). According to www.clinicaltrials.gov, the study “aims to learn whether or not prednisone is effective in improving the symptoms of double vision and drooping eyes that are experienced by patients with ocular myasthenia.” The study also aims to “find a dose of prednisone that is well tolerated and safe” that also is “effective in improving the symptoms of ocular myasthenia.”

Doctor: Nurse, how is that little girl doing who swallowed ten quarters last night?

Nurse: No change yet.



Prednisone Side Effects and Vision

Prednisone has long been recognized as an effective treatment for myasthenia gravis symptoms. However, its side effects can cause a number of vision problems, including glaucoma and cataracts.

Glaucoma is a complicated disease in which damage to the optic nerve results in vision loss. The website www.mayoclinic.org notes “using corticosteroid medications ...for a long period of time may increase your risk of developing secondary glaucoma.” When prednisone triggers weight gain or diabetes, these illnesses increase one’s risk for glaucoma, too. Other risk factors for glaucoma include age, being African American and family history.

Nature and books belong to the eyes that see them.
– ***Ralph Waldo Emerson***



Untreated glaucoma can lead to permanent damage of the optic nerve and over time can progress to blindness. The most common type of glaucoma doesn’t cause symptoms or pain, so it’s important to get regular eye checkups to monitor eye pressure. Vision loss is often preventable if caught early. (Source: www.glaucoma.org)

A July 20, 2012 Johns Hopkins Health Alert titled “Six Common Causes of Cataracts” notes “Long-term use of corticosteroids, especially at high doses, is the most common drug-related cause of cataracts. In a study of individuals taking oral prednisone for one to two years, cataracts developed in 11 percent of those taking less than 10 mg a day, 30 percent of those taking 10 to 15 mg a day and 80 percent of those taking more than 15 mg a day.”



A December 14, 2012 Johns Hopkins Health Alert explains, “A cataract clouds the lens of the eye, interfering with clear vision. The resulting opacity scatters the light entering the eye, so that the light reaching the retina is diffuse rather than focused and precise.” Depending on the extent of the cataract, you might not notice a vision problem, or you could experience “blurred vision, double vision and sensitivity to light and glare.”

If you’ve passed the driver’s license vision test but have cataracts, should you drive at night? A May 10, 2013 Johns Hopkins Health Alert responds, “Even with moderately compromised vision, you’re sacrificing safety if you elect to drive at night. That’s the implication of a recent study, which found that drivers’ ability to see and respond to pedestrians after dark is degraded by modestly blurred vision (caused by failure to wear optimal corrective lenses) and by cataracts. The danger applies even when drivers have passed the required vision test.”

Health Insurance

Many people who never or rarely had health care coverage before will soon be able to get it. Visit USA.gov's Health Insurance page to learn about the new Health Insurance Marketplace and other types of health coverage. Many states, including Illinois, have in-person counselors to help you.

Starting October 1, 2013, you can fill out an application for health insurance through the Health Insurance Marketplace. You'll be able to compare your options side-by-side and enroll in a plan that fits your budget and meets your needs. Coverage takes effect as early as January 1, 2014.

Living with Low Vision

With drooping eyelids, double vision, blurriness and other eye-sight concerns, MG patients sometimes have "low vision." Low vision means there may be problems doing daily, routine things even if using glasses or contact lenses.



Glare can make it difficult to see various shades of a color. It may be difficult to see in bright light, or you may be sensitive to extreme sunlight. Dimmer lighting and evening darkness can make it difficult to pick out detail, and you may want to add lighting where possible and limit your night driving. (Source: www.glaucoma.org)

More suggestions:

- Get your eyes checked regularly.
- A variety of products and resources are available to help people who have low vision. Examples include magnifiers, colored lenses, computer text enlargers and special lighting (such as Ottilite products).
- To ease double vision, use an eye patch while reading or watching TV. Alternate the eye patch from one eye to the other to avoid eyestrain.
- Tinted lenses, sunglasses and sun visors can help with glare and sensitivity to light.
- Your local library may be able to offer books on CD, print enlargement machines and computers with text enlargers.



These websites offer great ideas to help you manage vision problems:

- The American Foundation for the Blind - www.afb.org
- Vision Aware - www.visionaware.org
- Glaucoma Research Foundation - www.glaucoma.org
- National Library Service for the Blind and Physically Handicapped - Talking Book Center www.loc.gov/nls loans books and magazines on tape. Books, playback equipment, headphones and other aids are delivered by mail, postage free, to your home. Thousands of titles are available.
- Bureau of Blind Services, Illinois Department of Human Services <http://www.dhs.state.il.us/page.aspx?item=32305> has programs which help individuals adjust to vision loss. You can call 800.843.6154 (TTY: 800.447.6404) to learn about the department's services and office locations.

News on MG Triggers

In the July/August 2013 issue of Journal of Pharmacy Technology (J Pharm Technol 2013;29:191-3), Nicole Seymour, Tejal Patel and Heather Dixon report a case in which the patient's myasthenia gravis symptoms worsened when he took the medication gabapentin for essential tremor. Noting three other similar cases related to treatment of various neuropathies, the authors suggested "gabapentin should be used with caution in patients with MG."

At the 23rd Meeting of the European Neurological Society in July 2013, Arturo Leis, MD, reported that West Nile virus infection (WNV) has been linked to the development of myasthenia gravis in several patients some months after being infected with WNV. Source: <http://www.medscape.com/viewarticle/807230>

IVIg Boxed Warning

Due to medical history, age and other factors, some patients are at risk for complications when IVIg is used. Starting June 2013, the FDA is requiring that all intravenous immune globulin (IVIg) products carry a boxed warning about an association between IVIg use and increased risk of blood clots. The warning states:

FDA has analyzed recent data that has strengthened the association between the use of intravenous, subcutaneous and intramuscular human immune globulin products and the risk of thrombosis. Additional caution regarding the use of these products is warranted.

If you are receiving IVIg treatment and have questions or concerns about blood clots, be sure to discuss this with your neurologist.

Prostigmin Not Available

Prostigmin (neostigmine bromide) is a medication that sometimes is prescribed for MG patients who cannot tolerate pyridostigmine bromide (Mestinon). The drug manufacturer, Valeant Pharmaceuticals, has put this item on back order and it currently is not being distributed. If you take this medication, please contact your doctor for an alternative.

Illinois Yellow Dot Program

In December we reported on the new Illinois Yellow Dot program sponsored by the Illinois Department of Transportation. This program gives first responders – police, firefighters and emergency medical technicians – critical medical information when caring for people involved in car crashes. Yellow Dot participants get a simple bright yellow decal for the back window of their vehicle.

The yellow dot tells first responders there is a yellow folder in the glove compartment containing medical information about the motorist, including participant's name, close-up photo, emergency contact information, doctor contact information, and notes about medical conditions, allergies and current medications. Yellow Dot packets are available at various police, fire and public health departments throughout the state. A complete list is at www.yellowdotillinois.org.

Because Yellow Dot is new, you might want to follow MG patient Vicky Benyr's example. She got program details through her county health department and shared it with her local police station.

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 - Central	Saturday, Nov 9 -CANCELLED-	-N/A-	Due to low attendance, this meeting at Rush University Medical Center is cancelled. An alternative location is being considered for 2014.
Chicago - North / Near No. Suburban	Saturday, Oct 26	1:00 pm – 3:00 pm	Glenbrook Hospital, Conference rooms B&C, 2100 Pflingsten Road, Glenview, IL Use center entrance and adjacent parking
Chicago - South Suburban	Sunday, Oct 27	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	Sunday, Nov 10	1:00 pm – 3:00 pm	Central DuPage Hospital, 25 N. Winfield Road, Winfield, IL. Meet in Conference Rooms 1 & 2 on first floor. Enter at NW entrance, Women & Children's Pavilion. Valet parking is available plus additional parking in Visitor Lot 3.
Peoria	Spring 2014	2:00 pm – 4:00 pm	Proctor Hospital Cafeteria, Conference room behind the cafeteria, 5409 N. Knoxville, Peoria, IL
Rockford	Saturday, Oct 12	1:00 pm – 3:00 pm	St. Anthony Medical Center, St. Anthony Room; 5666 E. State St., Rockford, IL.
Springfield	Sundays, Sept 15, Oct 20, Nov 17	3:00 pm – 5:00 pm	Parkway Christian Church, 2700 Lindbergh Blvd in Springfield, just east of the Parkway Point Shopping Mall.
NW Indiana	Saturday, Oct 12	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)	Saturday, Sept 14 Oct 12, Dec 7	10:00 am – 12:00 pm	Northcrest - Rose Room, 1901 Northcrest Circle, Ames, Iowa

Emergency Alert Wallet Card

The Myasthenia Gravis Foundation of America has published a new 2-part Emergency Alert Wallet Card to replace their old wallet card. It is free and can be downloaded or ordered from their website, www.myasthenia.org (click on "Living with MG", then "Informational Materials"). Or you can call us for copies at 800-888-6208. These cards offer a useful explanation of MG and a list of drugs for MG patients to avoid.

In Appreciation...

Special thanks to everyone listed who sent in a contribution from April 2013 through July 2013. 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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Strides Against MG Walk

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The Myasthenia Gravis Foundation of Illinois, Inc.
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Elmhurst, IL 60126



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Address: _____

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