



The Myasthenia Gravis Foundation
of Illinois, Inc.

Conquer

"Strength in Hope"

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

March 2016

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

4th Annual Strides Against MG Walk

Join us – in person or in spirit - to raise awareness about MG in June during Myasthenia Gravis Awareness Month. On Sunday, June 5, we'll host the 4th Annual Strides Against MG Walk at Berens Park in Elmhurst, Illinois. Come on your own, bring a friend, or gather a whole team!

This year, we're bumping up the fun with bubbles, bags and hula hoops. With last year's weather in mind, we even have a new and improved rain plan! We'll start with the kids' dash, then everyone is invited to walk, run, or just enjoy the music, free snacks and raffle. You can do a short turn or go for three miles or more at this untimed event.



Strides Against MG is MGF of Illinois' biggest fundraiser of the year. We invite you to be part of the spirit of hope, as friends and family walk side by side with those affected by MG. Use our online registration tool to explain your own MG journey through story and pictures – and then share it with those you know. All funds raised for the event go toward MGF of Illinois' efforts to provide patient support and education, raise awareness among the public, and directly fund vital medical research.

See the flyer inside for details.

Spring MG Patient Education Meeting

More and more, words like "inflammation," "leaky gut," and "environmental toxins" are being linked to autoimmune diseases such as myasthenia gravis. And while traditional MG medications reduce inflammation, an emerging discipline called "functional medicine" suggests we need to look at its underlying causes. Join us at the MGF of Illinois Spring MG Patient Meeting on May 1, Elmhurst Memorial Hospital in Elmhurst, Illinois. Julie Rowin, MD, will present "Functional Medicine Approach to MG: Understanding and treating the root cause of disease." *See the flyer inside for 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.**
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From Your Executive Director

I admit I'm a skeptic. When I started hearing about gluten free diets and inflammation, it was often from questionable online articles that were selling questionable supplements. But more and more I'm hearing these words from trusted sources. Upon hearing that neurologist Julie Rowin, who treated many MG patients at the Rush University and University of Illinois medical centers, was pursuing something called "functional medicine," I was intrigued. I hope you can join us for her presentation at our Spring patient meeting on May 1, when she'll discuss root causes of autoimmune disease including gut health, environmental toxins, and stealth infections. We're recording her session, so you can still see it at a later date.

In many ways, the approach of Dr. Rowin and most physicians today is very different from what Al Paveza (p. 4) encountered in the '90s. When Al asked a question, he heard, "I'm the doctor." Luckily he went on to have a productive relationship with another doctor!

I hope you can join us for our 4th Annual Strides Against MG Walk on June 5. It's an amazing opportunity for friends and families to support their loved ones struggling with myasthenia gravis. Come for the smiles! The music, games, and raffle prizes will be an added bonus.



All the best to you,

Joan Wincentsen
Executive Director

Patient Assistance Program

Launched in 2014, the MGF of Illinois Patient Assistance Program will help cover the cost of medical bills and prescription drug costs up to \$1,000 - per person per year.

You may be eligible if you are an MG patient, reside in Illinois or Indiana, and can show proof of medical hardship. Costs do not have to be MG-related. Contact us (800-888-6208 or info@myastheniagravis.org) for the application.

*To the extent funds are available



Activity Updates

Run for MG!

This year you (or a family member) can shine a light on myasthenia gravis by participating in the **Chicago Half Marathon**. Join our “Team Conquer MG” by August 28 (and get a \$10 discount on entry fees), or represent the organization as an event volunteer. While not required, any funds you raise to support MG would be a plus.

The race is September 25, 2016. It follows South Lake Shore Drive, with start and finish near the Museum of Science and Industry. Contact the office at 800-888-6208 for details and the team registration code.

St. Louis Support Group

We had a great turnout of 24 Illinois and Missouri MG patients (and surprisingly balmy weather) for the Greater St. Louis Area support group meeting in January. Registered dietitian Danielle Glesne shared many nutrition tips for MG patients’ special concerns.

You may recall that this year MGF of Illinois is taking turns with the Myasthenia Gravis Association – Missouri and Kansas to host combo presentation/support group meetings for MG patients living in and around the St. Louis area. MGA’s Danielle Walk will host the next event Saturday, April 16 (see box for details).

Trivia Night to Conquer MG

We’re planning to host a Trivia Night this summer at a Chicago area location to help spread the word about MG. Watch your emails for details.

You’re Invited! **Greater St. Louis Area MG Patient Meeting**

Guest Speaker
Julia Edgar, PhD, CCC-SLP

“Effects of MG on Speech, Swallowing and Voice”

April 16 at 10am
Glendale City Hall Auditorium
425 N. Sappington
Glendale, MO

Dr. Edgar, Assistant Professor at Truman State University, teaches courses on voice disorders, dysphagia, neurogenic motor speech disorders and culminating experiences. Dr. Edgar also supervises voice and neurogenic disorders cases in the Truman State University Speech and Hearing Clinic.

To register, call
MGF of Illinois at 800-888-6208 or
MGA at 816-256-4100

Calendar Club Winners

November 2015

Bradley Chadwick
Jim Hearn
Pat Lichtenfield
Cheryl Thompson

December 2015

Cheryl Heldt
John Davenport
Anonymous
Natalie Striegl

January 2016

Janet Goldblatt
Tom Peters
Glen Knudsen
Steve Malinovich
Cheryl Heldt

\$100 Runner Up

Dorothy Mykisen

\$500 Grand Prize

John Sturtevant

Al Paveza, MG Patient and Senior Baseball Hall-of-Famer

Al Paveza is a competitive athlete, retiree, and 6-time trustee for the village of Burr Ridge. A natural storyteller, he can make a myasthenia gravis diagnosis as compelling as a double play when the Men's Senior Baseball League National Championship is at stake.



AL: “My MG started when I was playing baseball at a [MSBL] tournament in Atlanta around 1998. I was a good ball player but I didn’t have a good tournament. The guys asked are you ok? Your eyes look like they’re closed. When I got home, my wife said the same thing. I took a good look and sure enough.

“I was one of the lucky ones. Well, I was lucky and I wasn’t. I went to the doctor and was diagnosed right away. But the neurologist I saw didn’t really understand MG. He gave me Mestinon. I got worse. And he gave me more Mestinon. I kept getting worse and he just kept giving me more of the same drug. I couldn’t eat and lost 32 pounds in a month. Keep in mind

I was in my late 50s, playing ball three times a week, exercising a lot.

“My kids researched several other drugs used to treat MG. I mentioned these to the doctor. What about this, what about that, I asked. He just looked at me and said, ‘I’m the doctor.’ He seemed offended that I brought anything up.

“My kids also told me about the Myasthenia Gravis Foundation of Illinois. I called and got names of three doctors who treat MG, and got very lucky with Dr. Michael Merchut. When I called, the receptionist said it would be three weeks before I could get in. I said I don’t know if I have three weeks. After talking with the doctor, she said to come in the next day.

“He spent 45 minutes with me. Saw how weak I was. He arranged for me to have three plasma pheresis treatments. I had a little bit of a reaction at the end of the treatment. The nurse said, I’m going to get the doctor. I’ll be right back. In the meantime, here’s a snack for you to nibble on. For the first time in a long time I could eat! I ate the whole thing and called my wife. I said, ‘We’re going out for a steak tonight!’

“Dr. Merchut explained plasma pheresis was a temporary fix. So I started a regimen of medications, at one point taking 36 pills a day. I started feeling better very gradually. At one point I went 6 months without medication. But the double vision returned, and I resumed medication. I learned that MG doesn’t just go away.

“Then I had my thymus removed. Couldn’t believe it. I had it taken out on a Thursday, full approach – chest cracked open and everything. And I was out the next Tuesday, able to walk the dog. Dr. Merchut warned me as soon as you feel tired, rest. Don’t push yourself. So I followed his regimen.

2012 World Series Hall of Fame. “A couple of years went by. By my early 60s I was back to playing ball and winning championships. I played ball for 15 years and was on seven championship teams!” Al was inducted into the Men’s Senior Baseball World Series Hall of Fame in Phoenix in 2012.

“I played second base. In one championship game it was the bottom of the 8th. We were in trouble; the other team had bases loaded with one out. A hit went right up the middle. The shortstop ran to get it. I ran to second base to wait for the throw. He picked it up with his bare hand and flipped it wide toward third. I leaned to grab the ball with my bare hand. As I was falling to the ground I whipped it to first base for the force. People couldn’t believe two 60-year old men could do that! We went on to win 3-2.”

Still Playing Ball. Although Al no longer travels for the sport, he enjoys playing in a very competitive senior league in the Chicago area. His pre-season workouts start in February. He noted, “When a friend visits...we’ll spend two hours hitting and throwing and fielding. You’ve got to stay in shape so you don’t look foolish!”

He added, “I’ve had a great time and met some great people.” Al continues to manage his MG with azathioprine and prednisone. “I would say, even though you’re extra weak, you have to push yourself to maintain what’s prescribed for you. Wanting to play ball gave me a reason to push myself to get back to a normal life.”

MG Patients Offer Ways to Cope

Ideas from our Chicago South Suburban Support Group:

Nancy Van Laten: “When exercising, build in recovery time so it’s less stressful on your body. Do reps with your arms. Stop and do repetitions with your legs. Then do an exercise with your arms and then go back to the next exercise with your legs.”

Joyce Holste: “Keep a medical diary. Note how you slept that night, if you had any trouble with medicine during the day or stomach problems. Write down if you have any problems chewing or swallowing or muscle weakness. Take that with you to the doctor because sometimes you can see something that can help with your MG.”

Jen Powers: “Use a medical bracelet.”

Mary Williams: “Don’t be afraid or ashamed to cry. You’ll be surprised how much better it’ll make you feel.”

Bob Ratzel: “Find a support group. There’s always somebody there who has symptoms that are similar to yours. Somebody who’s had similar trials in their life.”



Funny, but I can't name a business that's like show business. - Mikey's Funnies

They certainly give very strange names to diseases. - Plato

Medication Side Effects: Managing Diarrhea

Many MG patients use pyridostigmine bromide (brand name Mestinon®) to ease symptoms of muscle weakness. Like most medications, pyridostigmine bromide has side effects which affect users to varying degrees. The Mestinon® website notes diarrhea and abdominal cramps are among the most common.

Jennifer Koman, RD LDN, offers these suggestions to manage diarrhea:



- Don't take over-the-counter anti-diarrhea medications, which have their own side effects.
- Avoid fried foods and other greasy or high fat choices (for instance, doughnuts, potato chips, cheeseburgers, and milkshakes).
- Avoid spicy foods.
- Avoid insoluble fiber (this is stuff you normally should eat lots of, but need to go easy on when diarrhea hits, for example, popcorn, seeds, beans, cauliflower, greens, peas, etc.) Avoid eating these items alone on an empty stomach.
- Avoid dairy foods, except for yogurt or kefir which can sooth digestive problems.
- Take it easy on coffee and cola because caffeine can stimulate the bowel.
- What *should* you eat? Good choices include low-fat, mild foods like bananas, white rice, eggs and chicken.
- Opt for small frequent meals.
- Because diarrhea can lower potassium levels, be sure to eat foods rich in potassium such as orange juice, bananas, potatoes, avocados and apricots.
- Keep hydrated.
- Ask your doctor about medications to help with diarrhea.

*“Edible names are what drives me as a musician.
My next band will be called the Hot Dogs.”
Chad Smith, Red Hot Chili Peppers*

Orphan Drug Status

A number of medications that are used or may be used in the future to treat myasthenia gravis have “orphan drug status.” Among them are methotrexate, eculizumab (still in clinical studies), and mycophenolate mofetil (Cellcept®). Orphan drug status gives pharmaceutical developers incentives to research and bring these drugs to market. The incentives can be tax incentives, enhanced patent protection and marketing rights, or financial help with clinical research.

Orphan drug status may or may not affect whether a drug is covered by an individual’s insurance plan. In some cases, the insurance company will decline coverage if an alternate treatment exists, or if the use is not for an FDA-approved indication. In other cases the drug is covered, but the patient can’t afford the required cost-sharing. And in other cases, the medication is covered upon appeal made by the prescribing physician or patient. In any event, it helps to be persistent, and advocate on your own behalf if necessary.

Sources: R. Hyde and D. Dobrovolsky, “Orphan Drug Pricing and Payer Management in the United States: Are We Approaching the Tipping Point,” *American Health & Drug Benefits*, Jan/Feb 2010; <http://www.ahdonline.com/issues/2010/january-february-2010-vol-3-no-1/97-feature-97>

Ed Silverman, “High Prices for Orphan Drug can be Sustained, a Payer Survey Shows,” *Wall Street Journal*, Sep 29, 2014; <http://blogs.wsj.com/pharmalot/2014/09/29/high-prices-for-orphan-drug-can-be-sustained-a-payer-survey-shows/?KEYWORDS=orphan+drug>

Option Care is a proud sponsor of Myasthenia Gravis Foundation of IL

Option Care is a national leader, providing unmatched safety outcomes for home-based IG patients with autoimmune disorders, such as Myasthenia Gravis. Our patient-centered care, offering all brands of IG, focuses on education and communication.

Comprehensive support for IG therapy is provided by our expert staff of pharmacists, nurses and reimbursement specialists, who closely monitor patient’s tolerance and response to therapy.

We are there to provide IVIG therapy to MG patients, in the comfort and privacy of home.

For additional information on immunoglobulin therapy:
Phone: 877.974.4844 Fax: 877.974.4845





Identifying genetic variations in MG patients

In the December 3, 2015 issue of Journal of Human Genetics, M. Nel, J. Buys, R. Rautenbach, S. Mowla, S. Prince, and J. Heckmann report there may be a specific genetic variation associated with treatment-resistant ocular symptoms in younger MG patients with African ancestry genes. They suggest the difference may be in key genes that affect the muscle healing responses. Source: doi:10.1038/jhg.2015.146

Advances in Telemedicine Policy

Adopted or in the works for 26 states so far, the Interstate Medical Licensure Compact offers a streamlined licensing process for physicians to be licensed in multiple states. This agreement is expected to expand access to health care, especially to those in rural and underserved areas of the country, and facilitate new modes of health care delivery such as telemedicine.

Telemedicine is the use of telecommunication and information technologies to provide clinical health care at a distance. Visualize communication between patient and doctor via two-way video, email, and smart phones.

In addition, a majority of states now have telemedicine parity laws, which require private insurers to cover remote consultations the same way they cover in-person medical visits.

Sean Parker's donation for autoimmunity research

In November 2015, USA Today reported that ex-Facebook president and Napster co-founder Sean Parker donated \$10 million to establish a new research laboratory at the University of California-San Francisco Diabetes Center for autoimmunity research. BuzzFeed News reported that the new UCSF lab will be led by “an immunologist whose research has focused on the idea that therapies can reprogram the immune system to stop autoimmune diseases while maintaining its ability to fight infections. That’s in contrast to therapies that suppress abnormal immune functions, but can put patients at higher risk of developing infections.” Source: <http://www.buzzfeed.com/stephaniemlee/the-story-behind-sean-parkers-10-million-donation-to-autoimm#.objddaWEV>

New test for ocular MG diagnosis

Acetylcholine receptor antibody blood tests help diagnose a large majority of MG cases. However the blood test provides an accurate diagnosis for only 50-70% of those who have ocular MG – when symptoms are limited to the muscles of the eyes and eyelids. Researchers report that a new test may improve the accuracy of ocular MG diagnosis. The test records activity of a specific eye muscle in response to vibratory stimulation of the forehead. Source: <http://www.news-medical.net/news/20160129/Vestibular-test-may-aid-ocular-myasthenia-gravis-diagnosis.aspx>

The pharmacist asked me my birthday again today....Pretty sure she's going to get me something.



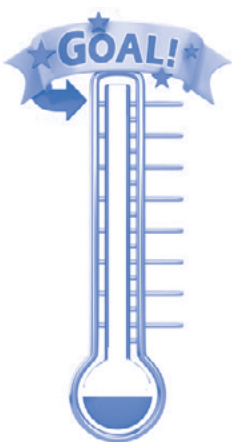
A Chance Call

In January, MGF of Illinois received a Calendar Club contribution from Susan Martino. Noticing that she had donated since 2003 (the start of our current database), we called to say thanks.

Susan laughed and noted, “I’ve been donating for a lot longer than that! My daughter is 49 now, and she developed myasthenia gravis when she was 24. I’m a nurse, and I didn’t know about the illness. My doctor and dentist didn’t know about it either. I contacted the Myasthenia Gravis Foundation of Illinois and they sent me lots of material. I ended up educating our dentist! MGF of Illinois helped me so much and I’ll be forever grateful.”

She added that her daughter went on to be a teacher and has two beautiful children. “She went to Loyola and they watched her very carefully especially when she was pregnant.” When asked how her daughter is now, Susan said, “She was able to be off [MG] medication for a few years. Her job as a teacher can be very stressful, and she’s back on meds, but doing okay.”

Susan added, “There’s more to the story! About 10 years ago my husband started having symptoms, and we knew right away what it was.” Sure enough, Susan’s husband also has MG, and it is well managed. Susan noted, “I’ve been donating to Calendar Club for years in my daughter’s name. She won \$25 a while back. But last year she was the Grand Prize winner! That \$500 came at a time when they really needed it.”



Can you help us meet our 2016 goal?

We’re excited to announce that MGF of Illinois surpassed its \$50,000 goal last year with \$56,400 in individual donations! Thank you to so many individuals who came forward to help us improve the lives of MG patients.

We’ve set the same goal for 2016. Please know your dollars support our telephone responses, seminars, newsletters, new patient packets, support groups, and online resources like our website and YouTube channel.

2016 Target: \$50,000

Amount raised to date: \$3,550

MGF of Illinois Support Groups 2016



Our 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.

SUPPORT GROUPS

AREA	2016 DATES	TIME	LOCATION
Chicago - Central	First Thursday of the month 3/3, 4/7, 5/5, 6/2, 7/7, 8/4, 9/1, 10/6, 11/3, 12/1	1:30 pm - 2:30 pm	Rush University Medical Center Tower Resource Center Conference Room (get directions at Rush information desks), 1620 W. Harrison St., Chicago, IL. Parking garage is at SE corner of Harrison and Paulina. Register with Eve Escalante at 312-942-8175. Parking vouchers for attendees available.
Chicago - North Suburban			Large and small groups meet at Glenbrook Hospital, 2100 Pfingsten Road, Glenview, IL.
Large Group	Sundays, March 5, Sept. 17	1:00 pm – 2:30 pm	Conference Rooms B&C; use center entrance and South (Blue) parking off Hospital Drive.
Small Group Breakfast Chats	Tues. 5/17, Sat. 7/16, Tues. 8/16, Sat. 11/12, Tues. 12/13*	9:30 am – 11:00 am	Atrium Café; use the entrance for the hospital's John & Carol Walter Ambulatory Care Center, turn right at the piano for the café. Park in the West (Green) lot. *December is holiday gathering
Chicago - South Suburban	Sundays, 5/15, other dates tba	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 15, Aug. 21, Nov. 20	1:00 pm – 3:00 pm	Central DuPage Hospital, Conference room 3, Women & Children's Pavilion; 25 N. Winfield Rd., Winfield, IL. Use NW entrance, park in Visitor Lot 3 or use valet parking.
Rockford	Saturdays, April 9, July 9, Oct. 8	1:00 pm – 3:00 pm	St. Anthony Medical Center, St. Francis Room; 5666 E. State St., Rockford, IL 61108. Use main entrance and adjacent parking.
Springfield	Sundays, March 20, April 17, May 15, July 17, Aug. 21, Sept. 18, Oct. 16, Nov. 20	3:00 pm – 5:00 pm	Parkway Christian Church, 2700 Lindbergh Blvd in Springfield, just east of the Parkway Point Shopping Mall. Use office entrance and adjacent parking.
Northwest Indiana	Saturdays, March 26, May 28, July 30, Oct. 1	10:00 am – 12:00 pm	Schererville Public Library, ask at desk for meeting room; 1001 W. Lincoln Hwy, Schererville, IN. Adjacent parking.
Greater St. Louis, Missouri	Saturday, April 16 other dates tba	10:00 am - 12:00 pm	Glendale City Hall Auditorium, 424 N. Sappington Road, Glendale, MO. Use main entrance and adjacent parking.

*What's in a name? That which we call a rose by any other name would
smell as sweet. – William Shakespeare*

*The first time I got a universal remote control, I thought to myself,
“This changes everything.”*

In Appreciation...

Special thanks to everyone listed who sent in a contribution from November 2015 through January 2016. 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.*

Contributors

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In Memory of Contributors

In Memory of Nicholas Albers

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In Memory of Clarence Bachar

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In Memory of George Brozauskis

John and Martha Ward

In Memory of Jeri Caulfield

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In Memory of Contributors continued

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Joel Schohn

In Memory of Mark Weinberg

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In Memory of Chester Wonak

Helen Wonak

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Join us!

St. Louis MG Patient Meeting – April 16
Chicago MG Patient Education Meeting – May 1
Strides Against MG Walk – June 5

Non-Profit Organization

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Chicago, IL

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