



The Myasthenia Gravis Foundation
of Illinois, Inc.

Conquer

"Strength in Hope"

September 2014

275 N. York Street, Suite 401 * 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.

Practical Strategies for Living with MG

Although your MG antibodies may be beyond your control, many steps toward good health are still within reach. MGF of Illinois will host "Practical Strategies for Living with MG" on Sunday, October 19, at Palos Community Hospital in Palos Heights, Illinois. An experienced dietitian and physical therapist will discuss nutrition and exercise challenges and solutions for MG patients. For example, learn how to avoid added pounds while taking prednisone and ways to build activity into your daily routine. Don't miss this one-two punch of practical ideas to help you champion your own health. The session includes lunch. See the flyer inside for registration details.



Walk Raises MG Awareness and Funds!

Over 180 walkers and volunteers were on hand for the Second Annual Strides Against MG Walk on June 1 at Berens Park in Elmhurst, Illinois. The morning's sunny skies smiled on attendees as they enjoyed the walk, music, snacks, giveaways and raffle excitement. The event raised MG awareness and netted \$10,500 that will be used by MGF of Illinois to serve regional MG patients. We're very grateful to all walkers, teams, fundraisers, sponsors and volunteers! See inside for pictures and sponsors.

MG of IL Funds Two Research Projects

MGF of Illinois was pleased to award two research grants for 2014-15. Grants have been awarded to David P. Richman, M.D., University of California, Davis, for the study titled "Monoclonal Antibody Treatment of Anti-MuSK Myasthenia," and to Betty Soliven, M.D., University of Chicago, for a study titled "Regulatory B Cells in Myasthenia Gravis." Congratulations, Drs. Richman and Soliven!

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

They say myasthenia gravis can happen at any age. This issue offers proof with its stories of high school athlete Autumn Orm and busy retiree Alma Tallman. Autumn and Alma share something else, too – a lively spirit that keeps MG where it belongs...on the sidelines.

As I read MG news, I am excited by the amount of research taking place. Researchers worldwide are doing the legwork to establish prevalence data, understand the disease pathology and its variations, and identify new treatments. MGF of Illinois is delighted to add to that progress with its support of two pilot studies.

Speaking of support, that's what we want to offer you! Got a question or need to talk? We'll get you connected to an answer, a doctor, or a listening ear.

All the best to you!

Joan Vincentsen
Executive Director



In Memory

We regret to share that Barbara Madnick, a good friend of MGF of Illinois, passed away in March 2014. Barb led the Chicago North Suburban Support Group with Dot and Mort Goldenberg for several years. She kept in touch with MG patients, and worked selflessly to keep the group going, making sure visitors felt welcomed with coffee and snacks. In addition to her Northbrook home base, Barb loved spending winters in Arizona with her husband, Sherwin, who passed away in February. We will miss her.

We also are saddened by the news that Werner Theobald, prior leader for the Peoria support group, passed away in August. Werner offered support with a no-nonsense dose of "okay, we have MG, now let's get on with things." He emigrated to the U.S. from Germany with his family in 1959. An expert goldsmith, he operated Theobald's Gold & Silver Design in Bloomington, Illinois for many years. We will miss his kindness and wisdom.

MGF of Illinois is grateful to companies who have paid a promotional fee to post their logos and product/service description in this Conquer. However, MGF of Illinois does not guarantee or endorse the company or products, service, or claims made for these products or services.



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Teams and Fundraisers!*

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Strides Sponsors!*

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Activity Updates

Calendar Club Winners

July 2014: Kathleen Brown, Thomas Dammrich, Sandy Hasemeyer, James Schneider

June: Cynthia Klidas, Gail Olley, Mary Jo Redick, Anonymous

May: Thomas Ehmann, Jr., Anonymous (3)

April: Dr. and Mrs. David Hofrichter, Lois Johnson, G. Weber, Anonymous

March: Helen MacLeod, Mary Jo Redick, Jane Simmons, Geraldine Volpe

February: Luci Graziano, Cheryl Heldt, Mr. and Mrs. J. Scanlan, G. Weber

Side Effects of Common MG Treatments

Go to www.youtube.com and search on "MGFillinois" to see a clip from Dr. A. Barboi's "Side Effects" presentation from MGF of Illinois' Annual Meeting on May 4. Or call 1-800-888-6208 to request a DVD of the complete session for \$15 plus \$1.75 for shipping. This video was made possible through the generous sponsorship of Walgreens Specialty Infusion.

Paddling to Victory

Under Ben Maravilla's direction, the Aurora HS ROTC team paddled their "Myasthenia Gravis" canoe to first place at the Fox Valley United Way Cardboard Boat Race on August 16. Congratulations!



Walgreens Infusion Services

**are proud supporters of
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Walgreens 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

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 | 2014 DATES | TIME | LOCATION |
|--|------------------------------------|---------------------|---|
| Chicago - North / Near No. Suburban | Saturday, Nov. 15 | 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, Sept. 21 | 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. 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 | Sunday, Oct. 19 | 2:00 pm – 4:00 pm | Proctor Hospital Cafeteria, Conference room behind the cafeteria, 5409 N. Knoxville, Peoria, IL. |
| Rockford | Saturday, Oct. 11 | 1:00 pm – 3:00 pm | St. Anthony Medical Center, St. Anthony Room; 5666 E. State St., Rockford, IL. |
| Springfield | Sundays, 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 | Saturday, 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, Sept. 13, Dec. 6 | 10:00 am – 12:00 pm | Northcrest - Rose Room, 1901 Northcrest Circle, Ames, Iowa. |
| Chicago - Central | -- | -- | Contact us if you would like to start a group at a Chicago location that offers free parking. |

Got the Volunteer Itch?

Do you have skills in finance, strategic planning, fundraising, marketing, or communication?
Consider joining the MGF of IL Board or 2015 Walk Committee! Call 1-800-888-6208.

Autumn Orm Scores Points While Battling MG

Published 3/14/2014 in the high school sports page of Michigan UP's MLive.com

Reprinted with permission from author Tom Mitsos



EAST LANSING, MICHIGAN – High school junior Autumn Orm only played about three minutes in St. Ignace's Class C girls' basketball semifinal game against Grosse Pointe Woods University Liggett on Thursday at Breslin Center, but she made the most of every minute. Orm, who was diagnosed with myasthenia gravis a couple of months ago, scored four points, including a 10-foot jump shot that put St. Ignace up 30-28 late in the fourth quarter, in a 34-30 win for the Saints.

The neuromuscular disorder prevents Orm from playing for very long. She gets very tired easily, loses her breath and will collapse if she doesn't sit down.

According to the National Institute of Neurological Disorders and Stroke, myasthenia gravis is "when normal communication between the nerve and muscle is interrupted at the neuromuscular junction -- the place where nerve cells connect with the muscles they control." Her body produces extra antibodies, which end up blocking the path between the nerve and muscle.

Orm was at a loss of words to describe the feeling of playing in the game while battling this disease. "It's amazing," she said. "It's a great experience. Especially being down here so many times. It's just amazing." Orm said there is a procedure to have her thymus gland removed which could help her, but there is only a 30 percent chance of her being fully cured.

When Orm scored one of her baskets to put St. Ignace up 30-28, she said she was well overdue for a rest as she had been playing longer than anticipated. "I was needing to go out (of the game)," she said. "I was definitely really tired. I don't know, it was an open shot, so I shot it. It was more about the team, I guess."

St. Ignace coach Dorene Ingalls held back tears, noting, "All year long, she has only been able to play a total of 30 seconds at a time before she starts collapsing. We tried to get her out toward the end there, she was getting deflections, getting rebounds, getting her opportunities. ... I'm just so proud of her. The inspiration that she gives us as a team is just something you don't find on a stat sheet."

Source: Mitsos, Tom. 2014, March 14.

Retrieved from <http://hightschoolsports.mlive.com/news/article/3649710779990320655/st-ignaces-autumn-orm-scores-four-points-while-battling-myasthenia-gravis-in-class-c-girls-basketball-semifinal-win/>

Greetings from Iowa

This spring, Alma Tallman contacted MGF of Illinois for a Strides Against MG t-shirt, "to help people become aware of this CONDITION!!!" From her email:

It's a Matter of Time

We all have 24 hours.
God gave us all the same.
It doesn't even matter -
What your rank or name!

Time can't be stored -
Or hung out on a rack!
It will all be gone -
You won't get it back.

Each day is new - so -
Decide how to use it.
Invest your time wisely,
Don't wait, you'll lose it!

We weren't created equal -
With our talents, it's true.
But the 24 hours - is -
The same for Me & You!

Alma Tallman 6-15-99
With the Help of the Lord

I am now a 30-year survivor of breast cancer, a 19-year survivor of MG, and an 11-year survivor of a heart attack. The Lord still has work for me to do here. I am a Stephen Minister and just got home from my biweekly support group meeting. Then I visited five friends in a nursing home.

My church calls it my mission, but my family visited in the homes when I was 2-3 years old. I tell them I come to collect their smiles. Usually get 2-3 per person.

I promised the Lord that I wouldn't sit home and feel sorry for myself - there are too many lonely people in the world! Recently I was sitting in my recliner enjoying the rose and aqua glassware in my east window. My comment to the Lord was, I don't mean to be materialistic - but one thing I always wanted was an east window to enjoy glassware.

Fifty-six years ago I graduated from ISU as a home economics teacher. Did that for three years and then was a full time homemaker with two children. Spent nine years as a textile and clothing leader for the local 4H Club. I sold and serviced Singer sewing machines for over 25 years. I had 4Hers come to the store for seminars.

I found I had MG after I was very sick. When I got better, my voice squeaked when I did my radio show. MG is a challenge

for those of us who like to eat and talk!!! Enough of my story.

Occasionally I find a person who has MG - but I have to go clear to Ames, Iowa to a group - and that is too far. Maybe wearing this t-shirt I can find others.

I will be 80 in one and a half years. I don't feel old till I try to stand up and walk. I try not to complain and tell my friends - we didn't know what it was going to be like getting old, but so many of my friends didn't get that opportunity. So every day is a blessing.

-- Alma Tallman



National Autoimmune Disease Registry

The medical community tells us that if you have one autoimmune disease, you have an increased chance for having a second. Soon you may be able to further research on this broader topic.

The American Autoimmune Related Diseases Association (AARDA) has created the Autoimmune Registry Network with groups like MGF of IL; the groups will collaborate to support research and help those suffering from MG and other autoimmune diseases. Just as the National Cancer Registry has helped cancer research, this registry will help autoimmune diseases to get increased attention and funding.

Soon you can enroll online to be contacted when a research study is looking for patients with your condition.

Q: Will my health data be kept confidential?

A: Yes. The ARN will provide researchers with a tool that lets them determine how many participants meet their study criteria. If there are enough participants to conduct the research, the researcher will ask ARN members, including MGF of IL, to contact eligible participants.

Q: Will researchers contact me?

A: No. Participants decide for themselves if they want to contact the researcher.

Q: Can I find out what the research is going to involve?

A: Yes, with each research opportunity, we will provide you with information that describes the benefits and risks of the study. You decide whether to participate before you contact the researcher.

Q: Do I have to participate in research after I contact the researcher?

A: No. Participation in research is always voluntary; even if you start participating in a study, you can withdraw at any time. (Note that some research studies may require you to continue medications for a period of time if suddenly stopping is a health risk).

Q: Should I register if my autoimmune disease is not active?

A: Yes. Your participation will broaden the Registry's scope and effectiveness. Over time the Registry's prevalence data can shape public health policy for autoimmune disease.

Registration will open after **October 1, 2014** at www.AARDA.org



Some buffalo were grazing on the range when a tourist said, "Those are the mangiest, scroungiest beasts I have ever seen."

One buffalo turned to the other and said, "You know...I think I just heard a discouraging word."

--Mikey's Funnies

Research Updates

Targeting MG therapy. Using mice in a multi-site study, researchers were able to direct a therapeutic agent directly to where it was needed at the neuromuscular junction. This work furthers the study of complement inhibitors which have been shown to disrupt certain MG antibodies. Source: Kusner, L. L., Satija, N., Cheng, G. and Kaminski, H. J. (2014), Targeting therapy to the neuromuscular junction: Proof of concept. *Muscle Nerve*, 49: 749–756. DOI: 10.1002/mus.24057

Comorbidity and MG. “Comorbidity” is the simultaneous presence of two or more diseases in a patient. Researchers in Norway used the compulsory Norwegian Prescription Database to compare all individuals who received pyridostigmine (Mestinon®) from 2004 to 2010 to the general Norwegian population. They found MG patients more often have more than one disease (such as diabetes, thyroid disease, or psychiatric disorders), and are more often taking multiple medications. They noted that medications for one disease may be contraindicated for (that is, could worsen) the other disease(s). Source: Andersen, J.B., Owe, J.F., Engeland, A., Gilhus, N.E. (July 2014), Total drug treatment and comorbidity in myasthenia gravis: a population-based cohort study. *European Journal of Neurology*, Vol.21, Issue 7: 948-955. DOI: 10.1111/ene.12439

“Any fact becomes important
when it's connected to another.”

-- Umberto Eco, *Foucault's Pendulum*

Thymectomy approaches compared. A study conducted in China compared the clinical outcomes of two surgical approaches for removing the thymus gland. Video-assisted thoracic surgery involves several small chest incisions while conventional transsternal surgery requires splitting the breastbone to open the chest. The study of 83 patients found no obvious difference between the two approaches in terms of remission status and scores that evaluate MG weakness. However, the patients who underwent video-assisted thoracic surgery showed shorter intensive care unit (ICU) stays. Source: Chien-Ming Lo, Hung-I. Lu, Shao-Shuan Lee, Jen-Ping Chang (Published online June 25, 2014), Thymectomy for myasthenia gravis: Video-assisted versus transsternal. *Journal of the Formosan Medical Association*. DOI: <http://dx.doi.org/10.1016/j.jfma.2014.05.010>

Expanded clinical trials for eculizumab. In April, Alexion Pharmaceuticals announced that it is enrolling patients in a multinational trial of eculizumab (Soliris®); the trial will look at the drug’s safety and effectiveness for patients with generalized, refractory MG. For more information, go to www.clinicaltrials.gov, identifier NCT01997229. Source: <http://www.marketwatch.com/story/alexion-initiates-multinational-registration-trials-of-eculizumab-as-a-potential-treatment-for-patients-with-relapsing-neuromyelitis-optica-nmo-and-refractory-generalized-myasthenia-gravis-mg-2014-04-24>

MG’s pathogenic mechanism. Autoimmune disorders may share certain pathogenic mechanisms with cancer, according to a new report by George Washington University researcher Linda Kusner and colleagues. The study shows that survivin, a protein that inhibits normal cell destruction in tumors, is also expressed in lymphocytes of patients with MG, but not in normal individuals. Kusner’s laboratory will continue to work on the inhibition of survivin as a potential MG treatment. (Ed. note: This study does not say MG is cancer. Discovering this similarity in how the diseases work may lead to a new way to interrupt MG.) Source: Kusner, L., Ciesielski, M. J., Marx, A., Kaminski, H. J., Fenstermaker, R. A. (July 22, 2014) “Survivin as a Potential Mediator to Support Autoreactive Cell Survival in Myasthenia Gravis: A Human and Animal Model Study” dx.plos.org/10.1371/journal.pone.0102231

In Appreciation...

Special thanks to everyone listed who sent in a contribution from February 2014 through August 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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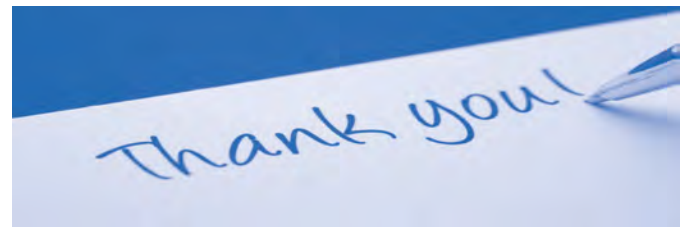
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