

February, 2013



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



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

Strides Against MG Walk

Get your walking shoes ready! This June during MG Awareness Month, MGF of Illinois will host the "Strides Against MG" walk. Plan to join us Sunday morning, June 2, at Berens Park in Elmhurst, IL for our 1-mile and 3-mile walk event. Start putting together your team – or simply walk with a friend. There's a Save the Date reminder inside to share. Call the office at 1-800-888-6208 to volunteer.

The Strides Against MG walk gives you a chance to say, "My life has been affected by this disease. I am not invisible." And your family and friends can say, "I know someone with myasthenia gravis. And I stand with him." The walk is about creating awareness and generating hope. All funds raised will support 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.

Annual Spring Meeting

Join us at our spring educational meeting on Sunday, April 21 at Embassy Suites in Deerfield. Dr. Robert Pascuzzi will speak about MG - from the history of the disease to the latest in MG research. He'll talk about related topics like depression, energy sappers and nutritional guidelines as well. Dr. Pascuzzi chairs the Department of Neurology at Indiana University of Medicine. He is involved in MG research and has published many articles on MG topics. His talk at an MGF of IL meeting in 2006 was one of our most informative sessions ever. See the enclosed flyer for details.

New Executive Director

Starting January 1, 2013, Joan Wincentsen stepped into the role of Executive Director for MGF of Illinois. She served on the board for five years and joined the staff in 2011. At the same time, MGF of Illinois extends heartfelt thanks to Kim LaBounty, our outgoing executive director. We're grateful for her strong, innovative leadership and enthusiastic patient response. See page 2 for Kim's parting words.

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 leas 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 Elmhurst, IL 60126-1531 1.800.888.6208 www.myastheniagravis.org

A Message from Kim LaBounty, Outgoing Executive Director

I'm so excited that as of January 1, Joan Wincentsen has taken on the role of Executive Director of this great organization! Joan brings a wealth of experience in a variety of capacities, from consulting to volunteering; as staff and a former board member. Joan's vision, passion and desire to take MGF of Illinois to the next level are so exciting.

I think this change also speaks well of the Board of Trustees, who recognize one way to move the organization forward in a significant fashion is to direct additional resources toward a fulltime staff presence. For the last six years, MGF of Illinois has been operating on an average of 20-25 hours per week of staff time, and there is only so much that can be done in that amount of time. MGF of Illinois not only has to ensure our own state is serviced, but we recognize other gaps that need to be filled as a result of declining organizational presence in neighboring states. We need to do more.

Joan's impact has already been felt, with increased outreach to Spanish-speaking communities, through presence at health fairs and a variety of new relationships formed. Additionally, Joan was a primary reason our 40th Anniversary event and programs last year were successful. She has great things planned for 2013, including a walk to raise awareness and funds for the organization for June – so get ready to get your team together! Joan will continue to work with our Medical Advisory Board Members in funding research, and increasing overall donations so MGF of Illinois can be of great impact.

I have appreciated the opportunity to serve as your Executive Director. It has been an honor to be part of our research funding efforts, educational programs and the opportunity to raise awareness and funds to help eliminate MG. I actually won't be far – Joan will continue working in the same office as mine and I'll be available to assist with recalling past activities, details, and offer support. Your support will be important too!

Kimberly La Bounty



Did You Get the MG Minute?

We sent out our first e-newsletter, *MG Minute*, in January with some great MG articles. Did you miss it?

Contact the office with your email address (call 1-800-888-6208 or email us at: info@myastheniagravis.org) to get the next online issue!

Calendar Club Update

Our Calendar Club fundraiser is still in progress and it's not too late to contribute and be a part of the monthly drawings. Tickets are \$12 each or \$50 for five. If you need tickets, call the office and we'll send them to you. Or donate online at our website: www.myastheniagravis.org/mgfi_calendar. aspx

January Calendar Club Winners

Arwyn Montroy Anthony Oleynihak Tom Peters JoAnn Tector

2013 MGF of IL Research Grant

Final applications for the 2013 annual MGF of IL research grant were received in January. Peer review starts in February, and the grant recipient will be announced in May.



"I don't like that man. I must get to know him better." -- Abraham Lincoln

Activity Updates

WANTED!

WALK COMMITTEE MEMBERS

Calling all MG supporters! We need about 10 people to be on our walk planning committee. An additional 20 people are needed for the week before and day of the walk. If you (or a family member) could pick up bagels, set up tables, or ask a local grocer for a snack donation, call the office at 1.800.888.6208.

BOARD & COMMITTEE MEMBERS NEEDED

We are seeking three to four additional board members to help guide this organization. We also need help at the committee level if you'd rather focus on programs, publicity, or fundraising. If you think creatively and strategically and care about those with myasthenia, call us at 1.800.888.6208. The board meets five to six times a year, and committees often "meet" by phone.

Strength in Hope

For just \$10 plus \$1.75 shipping, you can raise awareness with a durable black plastic license plate holder. Order online or call the office at 1.800.888.6208

MyastheniaGravis.org

Disabled Student Gets Support in College

Excerpted from Diane Heldt's 12/3/2012 online article. Reprinted with permission. http://thegazette.com/2012/12/03/disabled-students-getting-support-in-college/

University of Iowa (UI) graduate student Natalie Berto is sometimes so weak she can't get out of bed, or fatigue causes blurred vision. Berto doesn't "look disabled," she said, but a chronic autoimmune neuromuscular disease she was diagnosed with at 17, called myasthenia gravis, impacts her studies as a second-year master's student in social work.

She's one of more than 500 UI students this fall who receive accommodations and support through the student disability services office. Berto, a 24-year-old Ottumwa native, often gets extended



time for exams or shifts her schedule to morning events, when she has more energy. And this semester, the university converted a large textbook into digital form for Berto, so she wouldn't have to haul the heavy book around campus.

"The big thing for me is attendance, because you can only miss so many classes, and that's something I take really seriously," she said. "I have to be able to talk to my professors and say 'Hey, it's not because I've been out drinking or just partied a little too hard, it's because literally I'm too weak and I can't get out of bed.""

Knowing she has advocates in the disability services office is important, Berto said. "I think ultimately everyone wants you to succeed."

Enrollment of students with disabilities has grown more than 18 percent since 2000 at Iowa's three regent universities, according to this fall's enrollment report to the state Board of Regents. The UI, Iowa State University (ISU) and the University of Northern Iowa (UNI) serve 1,607 students with disabilities this fall, up from 1,359 students in 2000. Students this fall receive nearly 5,100 services and accommodations to help them with classes, including books on tape, note-takers and extended times and special locations for tests.

Providing accommodations to students with disabilities is mandated by federal law. The college level does differ from K-12 education, where the responsibility to identify those students lies with the schools. In college, students must self-identify and request services.

The UI, ISU and UNI follow similar processes: a student seeks help from disability services, or perhaps is referred there, then completes a request and provides documentation of a disability from a licensed professional. Once approved, each student is assigned a disability adviser. The universities aim to empower students to be their own advocates, said Mark Harris, Director of UI Student Disability Services, but the counselors are there to help and meet with students as needed.

Did You Know?

Because of the Affordable Care Act, an insurance company can no longer place lifetime limits on the amount of benefits you can receive. Starting in 2014, insurance companies cannot place annual dollar limits on your benefit coverage, and cannot deny coverage to anyone with a preexisting condition.

When celebrities get chronic illness, they go through the same mental process of denial and acceptance as the rest of us. Tennis star Venus Williams was diagnosed with Sjogren's syndrome, an energy-sapping autoimmune disease, two years ago. She made a strong tennis comeback in summer 2012. She noted at a press conference, "I feel like just this summer I've come to acceptance. It takes a long time to come to acceptance, especially when you're an athlete. You see yourself as this healthy person, that nothing can defeat you."

Quoted from Businessweek, August 29, 2012



Living with a chronic illness can be isolating and lonely. How do you find someone who can relate to your myasthenic issues? Support groups can help. If you live in a rural area or are an introvert, online chat rooms and Facebook pages can be a great resource for support and information, too. Check out these options:

- for myasthenia gravis. Instructions for joining can be found at the site. http://health.groups.yahoo.com/group/ maddysmgsupport/
- This is an electronic mail list for MG patients to discuss various issues. https://lists.asu.edu/cgi-bin/ wa?A1=ind0807C&L=OCULAR
- This is an online support group that offers a network of people sharing knowledge, experience and support. http://www.dailystrength.org/c/Myasthenia-Gravis/support-group
- This is an online community where you can post topics, communicate privately with other members, respond to polls, etc. Registration is required. http://neurotalk.psychcentral.com/forum77.html

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The Mental Game of Chronic Illness

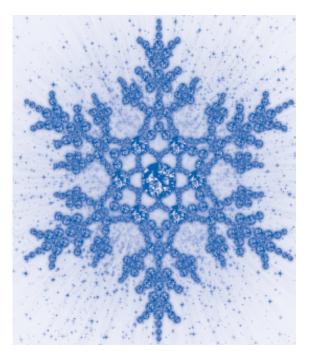


"Commitment is about what transforms a promise into reality." - Abraham Lincoln

Does Anyone Understand?

• MGF of Illinois Facebook page. Visit Facebook.com and search on "myasthenia gravis snowflake."

• This message board is a place for people to find support, encouragement, and caring friends



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How Can I Help Myself If I Am Depressed?

Chronic illness can take its toll on your mental health as well as your physical well-being. With new worries – about school, job, relationships, finances and your own sense of self – it's no wonder vour mood is affected!



If you have depression, you may feel exhausted, helpless, and hopeless. It may be extremely difficult to take any action to help yourself. But as you begin to recognize your depression and begin treatment, you will start to feel better. To help vourself:

• Do not wait too long to get evaluated or treated. There is research showing the longer one waits, the greater the impairment can be down the road. Try to see a professional as soon as possible.

- Try to be active and exercise. Go to a movie, a ballgame, or another event or activity that you once enjoyed.
- Set realistic goals for yourself.
- · Break up large tasks into small ones, set some priorities and do what you can as you can.
- Try to spend time with other people and confide in a trusted friend or relative. Try not to isolate yourself, and let others help you.
- Expect your mood to improve gradually, not immediately. Do not expect to suddenly "snap out of' your depression. Often during treatment for depression, sleep and appetite will begin to improve before your depressed mood lifts.
- Postpone important decisions, such as getting married or divorced or changing jobs, until you feel better. Discuss decisions with others who know you well and have a more objective view of your situation.
- Remember that positive thinking will replace negative thoughts as your depression responds to treatment.
- Continue to educate yourself about depression.

Source: National Institute of Mental Health. December 17. 2012; www.nimh.nih.gov/health/publications/depression/how-can-i-help-myself-if-i-am-depressed.shtml.



If a Friend is Suffering with Depression

No matter your faith, the ideas expressed in "Even prophets get the blues" (The Lutheran, February 2013) have merit. Frank Honeycutt looks at the Biblical story of Elijah and finds ways to respond compassionately to a friend's depression:

- can do is simply 'be' with another person in their pain and listen the best we can."
- hope nor dismisses what Elijah is going through as insignificant."
- and tend to the basics."

It Pays to Ask

...About sleep apnea. A 2006 study by S. Rask, M. Nicolle and colleagues showed a high prevalence of sleep apnea in a group of 100 myasthenic patients. The prevalence of obstructive sleep apnea was 36% compared to an expected prevalence of 15% to 20% in the general population.

Ask your doctor if you're at risk for sleep apnea. It could be contributing to your muscle weakness. If this is the case, your doctor may want to adjust your medication and consider other treatments.

...About antibiotics. In a recent post on dailystrength.org, a myasthenic described an ER visit for kidney stones. Even though he mentioned his MG, he was sent home with a prescription for the antibiotic Cipro[™]. Luckily he knew Cipro carries a black box warning (the sternest warning required by the FDA) stating that patients with myasthenia gravis should not take it. He didn't fill this prescription, and had a follow-up conversation with the hospital.

...About Vitamin D. On its website www.vitamindcouncil.org, The Vitamin D Council noted last June that "a group of researchers in Sweden have found that vitamin D may help myasthenia gravis patients. In this study, the investigators recruited 33 myasthenia gravis patients to participate. They found that after supplementing a sample of the patients with 800 IU/day, patients reported less fatigue." Results for this pilot study were published online June 4, 2012 in the European Journal of Neurology. Ask your doctor if you should take a Vitamin D supplement.

• Keep coming back. "Sometimes a visit to a depressed person is so uncomfortable – filled with awkward exchanges and silences – that we never return. Often the most important thing we

• Don't try to fix it. Honeycutt notes that in Elijah's story, his comforter "neither gives false

• Don't let your friend give in. Honeycutt says that "sleep is often the refuge for the depressed because depression is exhausting." Elijah's comforter, however, "insists that Elijah must rise

"I am not concerned that you have fallen - I am concerned that you arise." - Abraham Lincoln



MG Research News

Source: National Institute for Neurological Disorders and Stroke Updated December 14, 2012 www.ninds.nih.gov/disorders/myasthenia gravis/detail myasthenia gravis.htm.

Within the Federal government, the National Institute of Neurological Disorders and Stroke (NINDS), one of the National Institutes of Health (NIH), has primary responsibility for conducting and supporting research on brain and nervous system disorders, including myasthenia gravis.

Much has been learned about myasthenia gravis in recent years. Technological advances have led to more timely and accurate diagnosis, and new and enhanced therapies have improved management of the disorder. There is a greater understanding about the structure and function of the neuromuscular junction, the fundamental aspects of the thymus gland and of autoimmunity, and the disorder itself. Despite these advances, however, there is still much to learn. Researchers are seeking to learn what causes the autoimmune response in myasthenia gravis, and to better define the relationship between the thymus gland and myasthenia gravis.

"Give me six hours to chop down a tree and I will spend the first four sharpening the axe."

- Abraham Lincoln

Different drugs are being tested, either alone or in combination with existing drug therapies, to see if they are effective in treating myasthenia gravis. One study is examining the use of methotrexate therapy in individuals who develop symptoms and signs of the disease while on prednisone therapy. The drug suppresses blood cell activity that causes inflammation. Another study is investigating the use of rituximab, a monoclonal antibody against B cells which make antibodies, to see if it decreases certain antibodies that cause the immune system to attack the nervous system. Investigators are also determining if

eculizumab is safe and effective in treating individuals with generalized myasthenia gravis who also receive various immunosuppressant drugs. (Editor's note: Positive results for the rituximab and eculizumab studies have been reported in earlier issues of Conquer; the government site www. clinicaltrials.gov lists these studies as "completed.")

Another study seeks further understanding of the molecular basis of synaptic transmission in the nervous system. The objective of this study is to expand current knowledge of the function of receptors and to apply this knowledge to the treatment of myasthenia gravis.

Thymectomy is also being studied in myasthenia gravis patients who do not have thymoma to assess long-term benefit the surgical procedure may have over medical therapy alone.

One study involves blood sampling to see if the immune system is making antibodies against components of the nerves and muscle. Researchers also hope to learn if these antibodies contribute to the development or worsening of myasthenia gravis and other illnesses of the nervous system.

Investigators are also examining the safety and efficacy of autologous hematopoietic stem cell transplantation to treat refractory and severe myasthenia gravis. Participants in this study will receive several days of treatment using the immunosuppressant drugs cyclophosphamide and antithymocyte globulin before having some of their peripheral blood cells harvested and frozen. The blood cells will later be thawed and infused intravenously into the respective individuals, whose symptoms will be monitored for five years.

Other Research Notes • Working with mice, Johns Hopkins An October 10, 2012 online article from researchers say they have developed a the Annals of Neurology described an gene-based therapy to stop the rodent international study that looked at the equivalent of MG by specifically targeting genetic sources of early onset MG. The the destructive immune response the study examined the disease mechanism; results indicated that CD8+ T cells may The play a key role in disease initiation.

- disorder triggers in the body. technique, the result of more than 10 years of work, holds promise for a highly specific therapy for the disease, The May 2012 issue of the European one that avoids the need for long-term Journal of Immunology reported that immunosuppressant drugs (Ed. note: like researchers in Heilongjiang, China were able to reduce the severity of the disease in prednisone) that control the disease but may create unwanted side effects. The lab rats that had been induced with MG by next step would be to move on to clinical activating the adenosine A2A receptor. The trials in humans. Source: Neurology researchers believe they may have identified a new class of compounds to treat MG. Today Online (November 5, 2012)
- Researchers at The George Washington The Archives of Neurology recently published two studies that identified more sensitive University Medical Faculty Associates Department of Neurology in D.C. and effective testing measures to diagnose announced on October 25, 2012 that they MG (April 9, 2012 and June 11, 2012). A are conducting clinical research trials June 19, 2012 Archives of Neurology online that examine molecular biomarkers editorial put these studies in context. The in patients with MG and ocular MG. editorial said that among myasthenic patients, 85% are found to have antibodies · Biopharmaceuticals company Gliknik, to AchR (acelcholine receptors). Of the Inc. is working with the University of remaining 15% (called "seronegative") about Maryland, Baltimore to create a lab-made half have blood that reacts with MuSK alternative to IVIG. IVIG is a product (muscle-specific serum kinase). The newer derived from human blood that has studies help diagnose patients whose cases couldn't be confirmed before. been pooled from thousands of donors.



The runner replied breathlessly, "A lion has escaped from the city zoo."

"Oh no! Which way is it heading?"

"Well, you don't think we're chasing it, do you?" -- Mikey's Funnies

* MGF of Illinois - Conquer, February 2013 - p.8*





A man was walking along the street when he saw a crowd of people running toward him. He stopped one of the runners and asked, "What's happening?"

* MGF of Illinois - Conquer, August, 2012 - p.9 *

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.

SUPPORT GROUPS

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 2013 meeting dates on our website at http://myastheniagravis.org/mgfi support groups.aspx.

SUPPORT GROUPS				
AREA	2013 DATES	TIME	LOCATION	
Chicago - Central	Saturday, May 18	1:00 pm – 3:00 pm	Rush University Med. Ctr., Academic Bldg., 600 S. Paulina, Room 1094 (10th floor). Parking available in parking deck across the street.	
Chicago - North / Near No. Suburban	Sunday, May 19	1:00 pm – 3:00 pm	Glenbrook Hospital, Conference rooms B&C, 2100 Pfingsten Road, Glenview, IL	
Chicago - South Suburban	Sunday, May 5	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, May 19	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 C.	
Peoria	Sunday, April 21	2:00 pm – 4:00 pm	Proctor Hospital Cafeteria, Conference room behind the cafeteria, 5409 N. Knoxville, Peoria, IL	
Rockford	Saturday, April 13	1:00 pm – 3:00 pm	St. Anthony Medical Center, St. Anthony Room; 5666 E. State St., Rockford, IL. Topic: Home Safety	
Springfield	Sundays, March 17, April 21, May 19	3:00 pm – 5:00 pm	Location varies – call office to confirm. March and April meetings will be at Parkway Christian Church, 2700 Lindbergh Blvd in Springfield, just east of the Parkway Point Shopping Mall. Call to confirm May location.	
NW Indiana	Saturday, March 30 <i>NEW DATE</i>	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, April 13	10:00 am – 12:00 pm	Northcrest - Rose Room (As of July 2012), 1901 Northcrest Circle, Ames, Iowa	

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Cpecial thanks to everyone listed who sent in a contribution from November 2012 through January ${\cal Y}_{2013}$. 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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In Appreciation...

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