myasthenia gravis association
MGA
serving missouri and kansas
Celebrating 50 years

# Strength and Hope Through CONNECTIONS

**Volume 57 Issue 3** **Fall 2017**

CY'S CROWN TOWN
est. 2017
TRIVIA NIGHT
hosted by:
IOWA STATE ALUMNI OF KANSAS CITY
& THE MYASTHENIA GRAVIS ASSOCIATION

The Iowa State Alumni Association of Kansas City (ISUAA) has been volunteering for the MGA for many years. We have several alumni on our MGA Triple Crown (5k and Walk) planning committee and each year, the ISUAA chooses this event as their day of service often sending over 20 volunteers to help out! If this was not enough, in 2017, the ISUAA of Kansas City chose the MGA as its ongoing charity of choice starting this year! What does that mean? The ISU Alumni Association and the MGA partnered together to bring to Kansas City -- Cy's Crown Town Trivia Night! ('Cy' is for the ISU Cyclones).

Cy's Crown Town Trivia Night, held on Friday evening, September 29th at The Venue at Willow Creek in Kansas City, KS, attracted over 140 guests and raised over $15,000 to support the programs and services

The evening was filled with 4 rounds of Trivia, prizes and giveaways, raffles, and silent and live auctions. The winners all won a personalized engraved trophy and coasters and will have their name engraved on a plaque at Kelly's Westport Inn. This is an event you do not want to miss next year!!

## Inside This Issue

# Top Tips for Living With MG

- **Eat well, rest well** - A well-balanced diet and plenty of rest can really help. When it comes to myasthenia, the more you rest the more you can do. You may find relaxation techniques such as mindfulness and meditation can be useful as well as gentle exercise such as Tai Chi.

- **Pace yourself** - Many people learn to pace themselves and make choices about which are the important things for them to do and which are not. Plan for regular rest and spread activities throughout the day. It's better to take small steps to manage and mitigate the symptoms and improve your quality of life than it is to look for quick solutions.

- **Focus activities** at your strongest time of the day. Make telephone calls after your medication kicks in. Then you know that you can use your voice at its strongest.

- **Listen to your body** - Don't push it too far. Learning to recognize tiredness is vital because this is when symptoms are likely to be triggered. It's hard to achieve a balance between doing something and doing too much but the stability is worth the effort.

- **Keep a diary** - It is useful to write down any questions or new symptoms that come up between appointments for discussion with your neurologist. A daily record of the effects of myasthenia is also useful when applying for disability or talking to an employer.

- **A little help from your friends** - Always accept help when offered. Having somebody around to lighten the load and taking the opportunity for a rest is invaluable.

- **Accept** that with myasthenia, there will be good days and bad days.

- **Keep an eye on the weather**- Don't get too hot or too cold. Changes in temperature can have a noticeable effect on muscle function and extremes of temperature can exacerbate symptoms.

- **Keep in touch with other people affected by myasthenia** - Support groups, Facebook pages and groups, and on-line support groups mean that no one needs to feel alone with their myasthenia. This goes for caregivers, too.

- **Information is power** - Read up on your condition.

- **Carry an emergency alert card** - And wear medical ID jewelry. It is very useful to show paramedics and emergency room staff should you need emergency treatment.

- **Stay positive** - A bright outlook can really help people with myasthenia.

- **Stress** - Avoid emotional or physical stress and find ways to manage stress when it does arise.

- **If you struggle with swallowing**, eat soft foods wherever possible and, if on mestinon, take it about an hour before meals.

- **Consider adapting your home to make life that little bit easier.**

- **Surround yourself with supportive, understanding and patient people.**

- Try to keep calm

**(For help with any of these suggestions contact the MGA - 816-256-4100; mgakc@sbcglobal.net)**

*Excerpted from myaware.org, the MG organization in England, Scotland and Wales*

# A MESSAGE FROM THE MGA's EXECUTIVE DIRECTOR

**Danielle**

Caring for someone with MG can be overwhelming and leave you feeling alone. Because November is Caregivers Awareness Month, I want to share with you how the MGA helps support these unsung heroes. If you or someone you know is caring for someone with MG, we are here to help.

We offer:

**Education:** Caregiving does not come with an instruction manual. That's why we offer extensive individualized education, not only to newly diagnosed MGers, but to anyone looking for more information on understanding this disease.
**Support:** We help connect caregivers with professionals and one another. Call or email us anytime!
**Resources:** We work closely with many other helpful organizations and resources to help you cope, find support and reassurance.

MG doesn't just affect those who have the disease – it can affect the lives of everyone around them.

Many thanks to all of our MG caregivers!

This year's annual flu shot will offer protection against the H1N1 flu virus, in addition to two other influenza viruses that are expected to be in circulation this flu season. A vaccine that protects against four strains of the virus will also be available, as will a high-dose flu vaccine for adults age 65 and older. Flu shots are the most effective way to prevent influenza and its complications.

For the 2017-2018 flu season, manufacturers have indicated shipments began in August and will continue throughout October and November until all vaccine is distributed. Doctors and nurses are encouraged to begin vaccinating people as soon as the flu vaccine is available in their areas. It takes up to two weeks to build immunity after a flu shot, but you can benefit from the vaccine even if you don't get it until after the flu season starts.

It is important to get vaccinated every year because new flu vaccines are released every year to keep up with rapidly adapting flu viruses. Because flu viruses evolve so quickly, last year's vaccine may not protect you from this year's viruses.

After vaccination, your immune system produces antibodies that will protect you from the vaccine viruses. In general, though, antibody levels start to decline over time — another reason to get a flu shot every year.

The CDC notes that some groups should especially get the flu vaccine because they are at higher risk for severe complications if they get the flu. This includes those who have chronic neurological disorders (myasthenia gravis) and those who are taking immune suppressant medications (such as prednisone). It is generally believed that vaccinations (e.g. influenza) are safe in patients with MG (avoid live, attenuated vaccines like the nasal spray form of the influenza vaccine and the shingles vaccine). The evidence suggests that vaccine-related worsening of MG is rare and thus most MG specialists believe the benefits of immunization outweigh any small risk related to possible transient worsening of MG symptoms. As always, please consult your physician regarding your individual case.

With or without a flu shot, you can take steps to help protect yourself from the flu and other viruses. Good hygiene remains your primary defense against contagious illnesses.

- Wash your hands often and thoroughly with soap and water.
- Use an alcohol-based sanitizer on your hands if soap and water aren't available.
- Avoid touching your eyes, nose or mouth whenever possible.
- Avoid crowds when the flu is most prevalent in your area.
- Practice good health habits. Get plenty of sleep, exercise regularly, drink plenty of fluids, eat a nutritious diet and manage your stress.

# Home is your sanctuary.

*Home is where the heart is, but there's a world of experiences waiting for you.*

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- IV antibiotics
- And other complex conditions

ARJ is proud to be a dedicated supporter in the fight against myasthenia gravis. We continue to support MGA and the awareness it brings to the community.

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# MG Respiratory Failure Requires Specific Treatments in the ER

Myasthenic crisis is a common complication in patients with myasthenia gravis (MG), marked by exacerbation of MG symptoms and respiratory failure. But with the rarity of MG, and its similarity to a range of other neuromuscular diseases, proper detection and treatment might fail, researchers argue.

To make it easier for fellow physicians in the emergency room to handle patients who develop the condition, a research team at the University of Texas Southwestern Medical Center authored a review, presenting available data of its diagnosis and treatment.

The review, "Myasthenia Gravis and Crisis: Evaluation and Management in the Emergency Department," was published in the *Journal of Emergency Medicine*.

Up to 30 percent of patients with MG develop myasthenic crisis at some point, most often in the first two or three years after diagnosis. Nearly any form of stress, physical or emotional, can trigger the failure of muscles to adequately maintain breathing. Among the most common factors, however, is infection, which contributes to about 30 percent of cases.

Importantly, the condition can be the first sign of MG in a previously undiagnosed patient, making diagnosis and treatment even more difficult. Moreover, common MG medications — corticosteroids and cholinesterase inhibitors — can trigger the condition in patients with severe MG.

Physical examination, including examining the lungs, in combination with a review of the patient's disease and medication history, may help in diagnosing the condition. Affected patients often appear clearly distressed and use accessory muscles to maintain breathing. But the diagnosis might become difficult in some patients, as signs of breathing difficulties can be very subtle. In these cases, which often involve patients with severe MG, problems with phonation, a quiet voice, or weak neck muscles may flag respiratory distress.

Importantly, the reviewers underscored that oxygen and carbon dioxide levels often are normal until late in the crisis, and should not be used to exclude the possibility of an MG crisis. The team further underscored that noninvasive positive pressure ventilation (NIPPV) should be the first treatment choice in these patients, and may be used while physical examinations are still ongoing.

If intubation is needed, researchers underscored that emergency physicians should avoid paralytic drugs, particularly those called depolarizing paralytics, which act on the so-called motor end-plate where a motor neuron and muscle meet. Also corticosteroids and cholinesterase inhibitors should be avoided. Instead, low-dose non-depolarizing drugs should be used, they said.

The review further underscored that a range of other medications can exacerbate the condition, listing several antibiotics, anticonvulsants, antipsychotics, and heart medications among the drugs that should be avoided.

*Reprinted from myastheniagravisnews.com, 10/17/2017* -- (Read the abstract at ncbi.nlm.nih.gov/pubmed/28916122)

# Caregiver Depression: Prevention Counts

*Caregiver depression can take a toll on you and your ability to care for your loved one. Understand the signs of caregiver depression — and how to prevent it.*

Caregiving can be physically and emotionally stressful. To provide the best care possible, you might put your loved one's needs before your own. In turn, you could develop feelings of sadness, anger and loneliness, as well as guilt. Sometimes, these emotions trigger caregiver depression.

### What are the symptoms of caregiver depression?

Everyone has a bad day sometimes. However, depression is more than just a bout of the blues. It is a mood disorder that causes a persistent feeling of sadness and loss of interest. During an episode of depression, symptoms occur most of the day, nearly every day and might include:

- Feelings of sadness, tearfulness, emptiness or hopelessness
- Angry outbursts, irritability or frustration, even over small matters
- Loss of interest or pleasure in most or all normal activities, such as sex, hobbies or sports
- Sleep disturbances, including insomnia or sleeping too much
- Tiredness and a lack of energy, so even small tasks take extra effort
- Changes in appetite — often reduced appetite and weight loss, but increased cravings for food and weight gain in some people
- Anxiety, agitation or restlessness
- Slowed thinking, speaking or body movements
- Feelings of worthlessness or guilt, fixating on past failures or blaming yourself for things that aren't your responsibility
- Trouble thinking, concentrating, making decisions and remembering things
- Frequent or recurrent thoughts of death, suicidal thoughts, suicide attempts or suicide
- Unexplained physical problems, such as back pain or headaches

### What can I do if I develop caregiver depression?

If you're experiencing signs or symptoms of caregiver depression, consult your doctor or a mental health provider. Depression isn't a weakness and you can't simply "snap out" of it. It can also affect the quality of care you're able to provide for your loved one. However, most people who have depression feel better with the help of medication, psychological counseling or other treatment.

### What can I do to prevent caregiver depression?

You can take steps to prevent caregiver depression. For example:

- **Reach out for help.** Don't wait until you feel overwhelmed to ask for help caring for a loved one. If possible, get your whole family and close friends involved in planning and providing care. Seek out respite services and a caregiver support group. A support network can keep you from feeling isolated, depleted and depressed.
- **Keep up other relationships.** Caregiving can take time away from replenishing personal relationships — but showing loved ones and friends you care about them can give you strength and hope.
- **Start a journal.** Journaling can improve your mood by allowing you to express pain, anger, fear or other emotions.
- **Take time for yourself.** Participate in activities that allow you to relax and have fun. Go to a movie, watch a ballgame, or attend a birthday party or religious gathering. Regular physical activity and meditation also can help reduce stress. Aim to get plenty of sleep and eat a healthy diet.
- **Stay positive.** Caregiving allows you to give something back and make a difference in your loved one's life. Caregiving might also have spiritual meaning for you. Focus on these positive aspects of caregiving to help prevent depression.
- Remember, if you think you're depressed, seek help. Proper treatment can help you feel your best.

*By Mayo Clinic Staff. Please see page 7 for our list of suggested caregiver websites.*

# Clinical Trials

Kansas University Medical Center in Kansas City, KS, is participating in several clinical trials relating to myasthenia gravis (see below). If you are interested in participating in a trial or would like more information, go to clinicaltrials.gov, and enter the NCT number related to the specific trial. You can also call KU directly and talk to Laura Herbelin 913-588-5095.

1. Open Label Study of Subcutaneous Immunoglobulin (SCIg) in Myasthenia Gravis - #NCT02100969
2. Efficacy and Safety of IGIV-C in Corticosteroid Dependent Patients With Generalized Myasthenia Gravis - NCT02473965
3. Characterization of Agrin/LRP4 Antibody Positive Myasthenia Gravis. Visit http://www.augusta.edu/research/studies/view.php?study=713470 for more information on this study.

## 2017 MGA Board Members & Staff

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**Program Coordinator:**
Anne Strader

## Useful Caregiver Websites

**Turning Point, The Center for Hope and Healing**
913-574-0900 turningpointkc.org
They have a Caregiver Support Group.

**Well Spouse Association**
800-838-0879 wellspouse.org

**National Alliance for Caregiving**
301-718-8444 caregiving.org

**AARP Caregiving Resource Center**
877-333-5885
aarp.org/home-family/caregiving/

**Caregiver Action Network**
202-454-3970 caregiveraction.org

**Handbook for Long Distance Caregivers**
800-445-8106
caregiver.org/caregiver/jsp/content/pdfs/op_2003_long_distance_handbook.pdf

**Caring from a Distance**
cfad.org

**CaringBridge**
Start a free, personal website to share health information with family & friends
caringbridge.org/

**Eldercare Locater—Caregiver Page**
800-677-1116
eldercare.gov/Eldercare.NET/public/resources/topic/caregiver.aspx

**Family Caregiver Alliance**
800-445-8106 caregiver.org

**Area Agencies on Aging—Caregiver List**
312-669-8821
caregiverlist.com/StateInformation.aspx/Area-Agencies-on-Aging

**“Neurology Now” magazine**
This is a free, bi-monthly magazine that has a “caregiver” article in each issue. Neurologynow.com

**Caring**
800-973-1540 caring.com/caregiving-resources

# mg support groups *

| Area | Dates | Time | Location |
|---|---|---|---|
| **Kansas City, MO** | Nov. 18th—<br>Annual Mtg starts at 9am<br>Dec. 9th<br>Feb. 3rd | 11am-1:00pm | **St. Joseph Medical Center ~ Community Center**<br>1000 Carondelet Drive, KCMO 64114<br>RSVP mgakc@sbcglobal.net or (816) 256-4100 |
| **KC Northland** | Next Meeting in 2018 | noon-1:30pm | **Primrose Retirement Communities**<br>8559 N Line Creek Pkwy, KCMO 64151<br>RSVP mgakc@sbcglobal.net or (816) 256-4100 |
| **Columbia, MO** | TBD | TBD | **Daniel Boone Regional Library**<br>100 W Broadway (Room B), Columbia, MO 65203<br>RSVP mgakc@sbcglobal.net or (816) 256-4100 |
| **Springfield, MO** | Next Meeting in 2018 | 6pm-7:30pm | **The Library Center**<br>4653 S. Campbell Ave. (Story Room)<br>Springfield, MO 65810<br>RSVP mgakc@sbcglobal.net or (816) 256-4100 |
| **St. Louis** | Nov. 4th | 10am - 11:30am | **Glendale Presbyterian Church**<br>500 N. Sappington Rd. Kirkwood, MO 63122<br>RSVP mgakc@sbcglobal.net or (816) 256-4100 |
| **Wichita, KS** | Oct 28th<br>Dec. 9th | 1-3pm | **Via Christi Medical Center**<br>Saint Francis Campus 929 N St Francis St<br>Wichita, KS 67214<br>Contact: Dana or Larry Paxson for more info or to RSVP<br>dkptiffany@gmail.com or (316) 269-9120 |
| **Manhattan, KS** | TBD | TBD | **Manhattan Public Library—Friends Room**<br>629 Poyntz Ave. Manhattan, KS 66502<br>RSVP mgakc@sbcglobal.net or (816) 256-4100 |
| **Omaha, NE** | Nov. 11th<br>Dec. 9th | 10am-noon | **Calvary Lutheran Church**<br>2941 N 80th St, Omaha, NE 68134<br>Contact: Dianna McCarty for info or to RSVP<br>dmccarty@abbnebraska.com or (402)426-8006 or<br>Kathy Cassidy - cassidykathryn@yahoo.com or<br>402-719-5861 |
| **Northwest, AR**<br>**Note new location** | Nov. 12th | 2:30-4:00pm | **Schmieding Center for Senior Health and Education**<br>2422 N. Thompson (Hwy 71 North) - Springdale<br>Contact: Roger Huff for more info or to RSVP<br>jrhuff1@cox.net or (479) 790-3022 |

*** Please check with coordinator to insure date & location have not changed**

# Research ROUND UP

## Researchers Find ONX-0914 Halts Progression of Myasthenia Gravis in Animal Study

Chinese researchers have found that the drug ONX-0914 halts disease progression in an animal model of myasthenia gravis by altering immune responses. They looked specifically at autoantibody production and antibody affinity for the acetylcholine receptor (AChR), which underlies myasthenia gravis. They found that ONX-0914 improved the severity of ongoing MG by reducing the autoantibody affinity. Additionally, the drug also decreased the follicular helper T (Tfh) cells, special cells that stimulate the production of high-affinity antibody by another class of immune cells called B-cells, and antigen presenting cells (vital cells that help start the body's immune response). Another subtype of T-cells – the Th17 cells – involved in the development of many autoimmune diseases was also reduced. To read the full press release go to: https://myastheniagravisnews.com/2017/10/10/researchers-find-onx-0914-halts-progression-of-myasthenia-gravis-in-animal-study/

## Researchers Gain Insight Into How Myasthenia Gravis Antibodies Destroy Receptor Vital to Movement

University of Southern California researchers have gained insight into how antibodies connected with myasthenia gravis destroy a receptor crucial to movement. The study, "Structural insights into the molecular mechanisms of myasthenia gravis and their therapeutic implications" was published in the journal *eLife*. Many researchers have gained insight into how receptors work in healthy people and in those with a disease by making a crystal structure of the receptor, which is a kind of protein. Such a structure is a snapshot of how a protein looks at a given moment. The USC researchers were able to obtain a snapshot of the nicotinic acetylcholine receptor at the very time that autoantibodies bound to it. The snapshot showed that many of the antibodies bind in the same way. What the team learned about how the antibodies interacted with the receptor could lead to the development of drugs that block the binding. The researchers were also able to observe mechanisms that the antibodies use to destroy the receptor — and this could lead to scientists developing therapies that interfere at various stages of the disease. Read the article with link to the abstract at: https://myastheniagravisnews.com/2017/07/12/myasthenia-gravis-study-sheds-light-on-how-antibodies-destroy-muscle-receptor/

## We May Have Finally Discovered the Trigger That Starts Autoimmune Diseases

Scientists at Boston Children's Hospital and Aarhus University in Denmark have identified a chain reaction that explains why our own bodies can turn against healthy cells. The study focused on B cells gone rogue. Ordinarily these cells produce antibodies and program the immune cells to attack unwanted antigens, but scientists found an 'override switch' in mouse B cells that distorted this behavior and caused autoimmune attacks. These B-cells-gone-awry could in turn explain the biological phenomenon known as epitope spreading, where our bodies start to hunt down different antigens that shouldn't be on the immune system's 'kill list'. When B cells sense a foreign body – or something healthy that appears to be a foreign body – they swing into action in clusters called germinal centres. B cell clones actually battle each other out inside these centres so the body can determine which antibody is best suited to fight the threat. The problem comes when the body incorrectly identifies a normal protein as a threat. When that happens, the B cell selection process produces what are known as autoantibodies that prove very effective at harming our own bodies . Over time, the B cells that initially produce the 'winning' autoantibodies begin to recruit other B cells to produce additional damaging autoantibodies – just as ripples spread out when a single pebble is dropped into water. Eventually, blocking the germinal centres in some way could put a break in the vicious cycle that autoimmune diseases create. It would effectively block the immune system's short term memory, but that kind of treatment is still a long way off. Read the article at: http://www.sciencealert.com/we-may-have-found-how-runaway-train-autoimmune-diseases-get-started

## *In Memoriam*

**Mike Oliver**
Lawrence, KS

**Ed Spangler**
Excelsior Springs, MO

**Wayne Knaus**
Garnett, KS

**Pat Sego**
Independence, MO

**Bill Chadd**
Olathe, KS

# Contraindicated Medications and Infections Common Triggers of Exacerbations

Researchers at the University of Missouri presented two abstracts at the recent American Association of Neuromuscular & Electrodiagnostic Medicine annual meeting in Phoenix. Both retrospective studies were based on a chart review of 127 MG patients seen at the University of Missouri Hospital in Columbia from 2011 to 2016.

The first review looked at the impact of taking certain medications that are contraindicated in MG using the MGFA's list on myasthenic exacerbation. The 127 patients had experienced 212 exacerbations with 106 requiring visits to the ER, and 141 requiring admission with an average of 6.2 days. Of the exacerbations, contraindicated medications played a part in the plurality at 19%. Patients who were prescribed contraindicated medications also had a significantly higher number of exacerbations, with an average of 2.1, than patients not prescribed contraindicated medications, who had an average of 0.79. Beta-blockers, specifically, were found to have a significant association with a higher number of exacerbations. Their conclusion: "Certain medications (some more than others) are common triggers of MG exacerbations. It is important to increase awareness among patients and physicians about these medications and subsequent risk for patients."

The second review of the same patient charts assessed the impact of infections on MG and its exacerbations. The researchers looked at all acquired infections: vaccine preventable infections (VPI's) including pneumonia and seasonal influenza; and vaccine non-preventable infections (VNPI's) including opportunistic infections. Infections were noted for each patient, compared to their immunization records, and analyzed for their significance in MG exacerbation. In the 212 exacerbations, 106 ER visits, and 141 hospitalizations (cited above), infections were responsible for 34% of all exacerbations, 44% of ER visits, 40% of admissions, as well as the second longest average duration of hospital stay (about 7 days at a cost of $11,000-14,000). VPI's were the most common reason for exacerbation needing ER visit and hospitalization (60%), whereas only 20% of those with VNPI'S needed an ER visit and admission. Common VPI's included pneumonia (16.5%) and influenza (11%). All but two of the patients were not immunized. The most common VNPI was an upper respiratory infection (20%). Older patients were at an increased risk factor for VPI but not for a VNPI. Their conclusion: "Infections are one of the most common triggers for MG exacerbations and contribute to prolonged admissions and hospital costs."

*Abstracts #204 and #205 – see all the abstracts at: http://www.aanem.org/getmedia/25cf6de8-43d9-4ea1-b2e3-59bfb0687ca6/2017-Abstracts-web_1.pdf*

# Ralph and Dianna McCarty

*Their MG Story*

## Heartland Myasthenia Gravis Association in Omaha

Ralph is the one with Myasthenia Gravis. His symptoms began with muscle weakness in his face one hot, August day while installing new garage doors at our home in Merriam Kansas. As often is the case, his primary care physician misdiagnosed him and put him on antibiotics for a sinus infection. His left eyelid began to droop and Ralph experienced double vision. After several trips to the eye doctor and three new prescriptions for eyeglasses, Ralph went to see an ophthalmologist who specialized in children. The doctor put an ice cube on Ralph's left eye, which immediately popped open. Diagnosis - Myasthenia Gravis. Ralph had a follow-up appointment with St. Luke's neurologist, Karen Arkin, who confirmed the diagnosis after receiving the results of blood tests sent to Mayo Clinic.

In April 2000, Ralph had a thymectomy due to a tumor on his thymus gland. With prednisone and mestinon prescribed under Dr. Arkin's care, Ralph's symptoms recessed until the summer of 2001, when a bicycle accident exacerbated the MG symptoms. Back on mestinon and prednisone, an accidental high dosage of prednisone (60mg/day instead of 20mg/day) caused an MG crisis and he was hospitalized in ICU.

Later, Dr. Arkin referred Ralph to Dr. Richard Barohn, head of Neurology at Kansas University Medical Center. Under Dr. Barohn's treatment and a maintenance program of IVIG's, Ralph's health improved. He could function normally at work and home. Yay!

Retirement in 2004 brought us back to Nebraska and closer to family. The search began again for a qualified neurologist. It took a few tries and miss-steps, but we found Dr. Pamela Santamaria, who worked with Ralph and put him back on IVIG maintenance.

We also searched for a support group. We had been to Kansas City's MGA annual meeting and knew the importance of connecting with those who shared the same disease. We joined the Heartland MGA in 2004, then led by Donn Bieber. When Donn's health began to fail and he could no longer attend our meetings, he turned all his informational materials over to us. So, in 17 years, we went from knowing nothing about MG to knowing way more than we ever thought we would know and sharing responsibility for our support group.

The Heartland MGA has 70 people on our membership list – mostly in Nebraska and Iowa. Our mission is to improve the quality of life for those who are affected by this autoimmune, neuromuscular disease through awareness, education and member services. Though sometimes we have as few as 5 or 6 attending our meetings, we're always here to provide the opportunity to connect with other patients, friends and family members in the area.

# Special facebook Groups for MG

| | |
|---|---|
| **Lambert Eaton Myasthenic Syndrome (LEMS):** | www.facebook.com/groups/1666194810327716/<br>www.facebook.com/groups/24507873315/ |
| **Congenital Myasthenic Syndrome(CMS):** | www.facebook.com/groupsCongenitalMyastheniaSyndrome/ |
| **MuSK Antibody MG:** | www.facebook.com/groups/469220543197805/ |
| **IVIG/SCIG:** | www.facebook.com/groups/157968477614/ |

And don't forget to follow the MGA's page for timely, important MG information and organization news and events - https://www.facebook.com/mgakc/

## Donna Whittaker's Book Brings Hope and Understanding

Donna Whittaker, our longtime friend, supporter, former board member and support group leader, and herself a MGer since 1957, has taken her passion for helping those with MG to a new level. She has interviewed people who have had MG for over 25 years and compiled their stories of living with MG in her new eBook, Hope – For Living a Long Full Life with Myasthenia Gravis. Her purpose in creating this collection of myasthenia gravis life stories, websites, and day-to-day living strategies is to give the hope to newly diagnosed patients and those going through tough times that they can live life to the fullest. We highly recommend Donna's book – read the personal accounts, use the many links and resources, have fun with the MG trivia she's included. For a free copy, email Donna at: Hope4MGliving@gmail.com

## The Short-Term Benefits of Fruits and Vegetables

by Neil Peterson

It's easy to think of eating healthy as a long game. Sure, it's more work *now*, but it'll pay off years down the road. But a new study published in *PLoS One* is suggesting that if you eat your broccoli and have an apple a day, you could see psychological benefits in less than two weeks. Researchers from New Zealand decided to investigate the short-term benefits of fruit and vegetable consumption by recruiting 171 young adults, who they then divided into three groups:

- A group who continued their diet as normal.
- A group who received vouchers to purchase fruits and vegetables as well as text-message reminders to eat fruits and vegetables
- A group who was given two additional servings of fruits and vegetables a day

The first thing to note is that there ended up being no real differences between the first two groups – the normal diet group and the voucher group. This suggests that encouraging people to eat more fruits and vegetables is no easy task. Apparently, you have to actually physically give them fruits and vegetables every day.

Once people do up their fruit and vegetable consumption, though, a number of psychological benefits might be waiting for them. After 14 days, the third group (who actually did eat more fruits and vegetables) reported several positive changes in their lives: they scored higher on vitality, on flourishing, and on overall motivation.

Now, the study didn't look at *why* fruits and vegetables had this effect on people. But for those who are a little impatient, there's no doubt that the result is good news: eating healthy doesn't have to be an exercise in delayed gratification. It may be that upping fruit and vegetable consumption can make you feel more vital, motivated and ready to take on life right away.

From http://blog.allpsych.com - February 6, 2017

# 57th Annual Meeting

November 18th from 9am - 1pm

St. Joseph Medical Center's Community Center

## Consensus Guidance for Management of MG

### *Keynote: Donald B. Sanders, MD*

Dr. Donald Sanders is Professor of Neurology and Director of Neuromuscular Research at Duke University Medical Center, where he founded, and for 25 years directed, the Myasthenia Gravis Clinic. His major clinical and research interest is the diagnosis and treatment of neuromuscular diseases. He is a graduate of Harvard Medical School and trained in neurology at the University of Virginia. Dr. Sanders has authored more than 200 peer-reviewed papers and book chapters, and lectures extensively on the topic of neuromuscular diseases. He has been a member of the MGFA for 40 years, was named its Doctor of the Year in 1992 and received the Chairman's Award in 2014. He was President of the MGFA Medical/Scientific Advisory Board from 1993-1995, and was Chair of the MGFA Task Force on MG Clinical Trial Design from 2010-2012 and the MGFA Task Force on MG Treatment Guidelines, which recently published the International Consensus Guidance Statement for the Management of Myasthenia Gravis.

Dr. Sanders will be joined by Mamatha Pasnoor, MD and Constantine Farmakidis, MD, both from KU, for the Q&A.

## Agenda:

9:00 Registration & Light Breakfast
9:30 Annual Business Meeting & Awards
10:00 Keynote: Consensus Guidance for Management of MG
11:00 Physician Panel (Q&A)
12:00 Luncheon and Raffle

## Location:

St. Joseph Medical Center's Community Center
1000 Carondelet Dr. (I-435 and State Line) – Follow signs for "Community Center". It is past the emergency room
Kansas City, MO 64114

## RSVP:

By November 6th to 816-256-4100 or mgakc@sbcglobal.net

# MGA CONNECTIONS

Are you newly diagnosed and looking for support and answers? Have you lived with MG for years and want to share your experiences? For anyone looking to talk to others who have MG, we have MGA Connections! Give us a call and we will send you the full list or help make suggestions of people you may benefit connecting with by email or phone.

Our friends at the National Myasthenia Gravis Foundation of America have announced that their next Annual Conference will take place **April 15th to 17th** in our beautiful city, **Kansas City, MO** at the Intercontinental Kansas City at the Plaza. ***Mark your calendars*** for a fun and educational experience, that rare occasion when you can meet so many others in the MG Community both patient and professional. More information will be forthcoming soon.

## Holiday Party!

**Please join us in celebrating the holidays!**

Saturday, December 9th at 11:00 am
St. Joseph Medical Center's Community Center
1000 Carondelet Dr., Kansas City, MO

BINGO, Prizes, Lunch, Raffles & Friends. Bring the kids and grandkids!
Please RSVP by December 1st to 816.256.4100 or mgakc@sbcglobal.net

## FDA Approves Soliris® (Eculizumab) for the Treatment of Patients with Refractory Generalized Myasthenia Gravis

Breakthrough news in treating MG was announced Oct. 23rd by Alexion Pharmaceuticals. The first targeted therapy for MG since Mestinon in 1955 has been approved by the FDA for patients with anti-AChR antibody-positive generalized MG who have previously failed immunosuppressive therapy and continued to suffer from significant unresolved symptoms. To read the press release with video reactions from Nancy Law, CEO of the MGFA, and Richard Nowak, MD, researcher and head of the Yale Myasthenia Gravis Clinic, as well as a video discussion by the lead investigator, James Howard, MD, Dept. of Neurology at the University of North Carolina School of Medicine, go to: businesswire.com/news/home/20171023006539/en/FDA-Approves-Soliris®-Eculizumab-Treatment-Patients-Generalized

# 2017 membership/fundraising drive

*Celebrating over 50 years*

**October**
**YTD Totals:**
**$3,708**
**Memberships**

2017
TARGET
GOAL:
$10,000

Please keep the MGA on your list as you make your year-end charitable donations. The MGA's annual membership drive benefits those with MG and their families and caregivers through our referrals, newsletters, support groups, clinics, new patient packets, and one-on-one consultations.

Thank you to those who have become members since our last newsletter!

Ronald Boeve
Angela & Raymond Hankins
Betty & Doug Harper
D. Maddox
Kerri & Gerald Mertens
Winston Seeman
Sue & Robert Strickler
Marvin Suthers
Diana Wilmoth

## Please become a 2017 member & receive a tax deduction!

PLEASE PRINT **Cut & enclose in envelope & mail to: ➔**

MGA
2340 E. Meyer Blvd.
Bldg.1, Suite 300A
KCMO 64132

Name ____________________________________________

Address_______________________City_____________State____ Zip_____

Phone_________________________ Email _____________________________

**I want to help support the MGA by becoming a 2017 member or making a contribution:**

☐ $ 25 Basic Membership
☐ $ 57 *57th Anniversary Membership*
☐ $ 100 Sustaining Membership
☐ $ 500 Patron Membership
☐ $ 1,000 Lifetime Membership
☐ $ _____ In Memory of:
☐ $ _____ In Honor of:

**PLEASE CHECK:**
☐ **MG Patient**
☐ **Relative**
☐ **Friend**

# Thank You!

*Make checks payable to the Myasthenia Gravis Association: ALL CONTRIBUTIONS ARE TAX-DEDUCTIBLE*

DONATE NOW

If you'd rather pay with a credit card, visit www.firstgiving.com/mgakc/membershipdrive2017

## Strength and Hope through Connections

myasthenia gravis association
MGA
serving missouri & kansas
Celebrating 50 years

United Way
United Way of
Greater Kansas City

Check us out
on the Web:
www.mgakc.org

If you would like to be
removed from
or added to our mailing list,
or if you have or will have an
address change,
please send a note to:
Myasthenia Gravis Association
2340 E. Meyer Blvd.
Building 1, Suite 300A
Kansas City, MO 64132
~ Or ~
Call us at: (816) 256-4100

## The Mission of the MGA

The Myasthenia Gravis Association (MGA) is dedicated to improving the quality of life for those who are affected by this autoimmune, neuromuscular disease, through awareness, education and patient services.

Myasthenia Gravis Association
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