

Strength and Hope Through CONNECTIONS

Volume 58 Issue 3 Fall 2018

Sold out success for the 2nd Annual Cy's Crown Town Trivia

200 participants packed the Muehlebach Suite at Boulevard Brewing Company on Friday September 28, 2018 for the 2nd Annual Cy's Crown Town Trivia Night. Held in conjunction with hosts from the Kansas City Iowa State Alumni Club, the group shared the mission of raising funds for the Myasthenia Gravis Association. Funds they raised, \$35,000! It was a fantastic evening of food provided by the Russell, 4 rounds of exhilarating trivia, silent and live auctions, and brews plus wine by Boulevard. The MGA is so grateful for all who participated, sponsored, donated, purchased tables and raffles to make this night a success. We are especially grateful to our sponsors, Kelly's Westport Inn, Up Down, ARJ Infusion Services, Craig & Barb Foss, Chicken N Pickle, Penske Truck Leasing, Team Cocktail, McFaddens, Premiere Lighting and Controls, KU Neurology, MD Electrodiagnosis, Russell Hampton, Superior Biologics and Cable Dahmer. Susan Bauer Creative captured some amazing shots and you can find an entire album on our Facebook page. (www.facebook.com/mgakc) We are blown away by the generosity and support this event received. We cannot wait for next year. So get your thinking caps ready for 2019!



	Snowflake Shufflers Raise \$3500!	2	Retirement & Chronic Illness	8
his	Meet Tanya Renner	2	Research Round- Up	10
— a	NW Arkansas Conference	3	Gratitude & Giving~ Yoga & Meditation	11
le Su	Clinical Trials	5	Save the Date- MGA Triple Crown	12
Inside I Issu	New MGA Board Member Annual Meeting 11/17/18 Support Group Calendar	5 6 7	On the Bookshelf	13
			Power Ports	14
			In Memoriam	15

Snowflake shufflers raise \$3500 for the MGA

On a cold and blustery fall day at Ol Watson Park in Wichita, 69 registered participants celebrated the opportunity to shuffle for some BBQ and raffles at the MGA Snowflake Shuffle 0.1K. Due to the weather, no official 0.1K took place. However most who gathered were there for the fellowship and friendship with their MG family. A huge thank you to Wichita Support Group coordinators Larry and Dana Paxson who planned the event from the start to finish and who were still smiling even after the wind took the balloon arch down. See you next year!



Welcome Tanya Renner, Program Coordinator

Tanya Renner has joined the Myasthenia Gravis Association as the Program Coordinator. Tanya previously worked as a Pharmacy Technician and took some time off to spend at home raising her family. Tanya resides in Roeland Park with her husband Mike and three children Cohen (11yrs), Abigail (5yrs) and the newest addition to the family Jax (4 months). She is very involved in her Church and volunteering at her kid's school. If you haven't already met Tanya, be on the look out for her at clinic, support groups and other MGA events. Tanya is looking forward to this new opportunity, learning more about MG and meeting new people.



A MESSAGE FROM THE MGA'S EXECUTIVE DIRECTOR

As we enter the final quarter of 2018, I can't help but smile when I think of all the MGA has accomplished so far this year. 68 new patient packets have been sent out to those newly diagnosed across the Heartland, 29 support group meetings held across 7 cities, nearly 7,000 followers on Facebook, almost 200 Instagram followers to our new Instagram page and \$35,000 raised at Cy's Crown Town Trivia Night, When I stepped into my role, I dreamed of the day people would associate teal with MG like pink is to breast cancer. That's no easy feat, and I do love pink, but I am confident with each person we talk to, each person we encounter, we are doing our job of raising awareness. The more awareness we raise the better patients can be served and families assisted. Thanks for your continued support in this journey.

Alison Foss, Executive Director



Dr. Richard Barohn speaks at the NW Arkansas Annual Conference

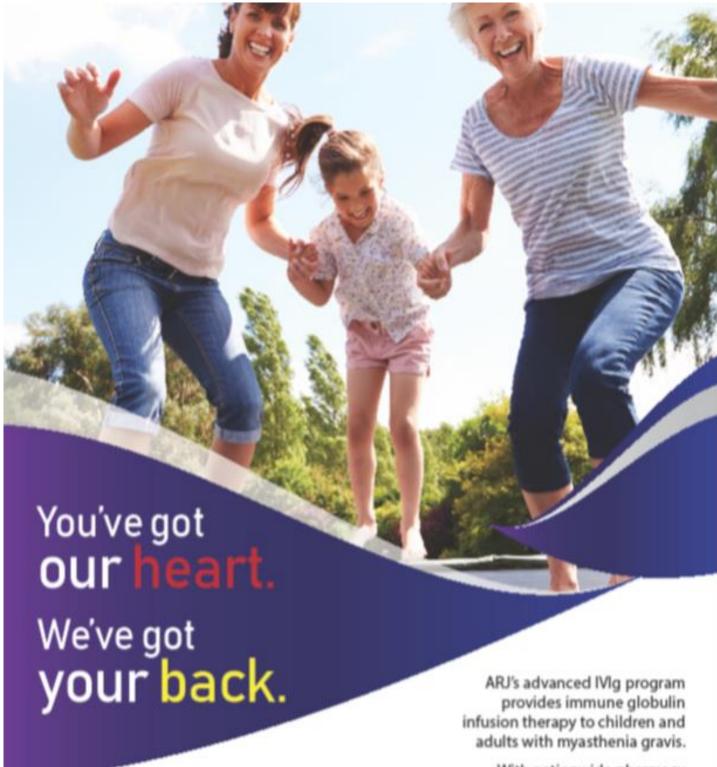
Roger and Jan Huff, NW Arkansas Support Group Coordinators invited Richard Barohn, MD, Professor of Neurology, Vice Chancellor for Research and President of Research Institute, Department of Neurology at of the University of Kansas to provide an update on Myasthenia Gravis, diagnosis and treatment to their group. With approximately 30 participants in attendance individuals received up to the date information as well as the opportunity to ask questions on diagnosis, treatments and research. A huge thank you to Dr. Barohn for speaking and to Roger and Jan for coordinating such an informative conference. The NW Arkansas Support Group meets every other month on on Sundays from 2:30-4:30 at the Schmieding Center for Senior Health and Education in Springdale. For more information on the group you can contact Roger Huff at jrhuff1@cox.net.



Black Friday. Cyber Monday.



November 27, 2018



We W making our patients

Learn how ARJ's life-changing IVIg treatments help people across Kansas City.

arjinfusion.com/journey 866-451-8804 With nationwide pharmacy coverage and 24/7 clinical support, we're on a mission to transform our patients' lives one unique journey at a time.



Clinical Trials

The University of Missouri, Columbia has studies available for MG participants. For more information and to enroll contact Dr. Raghav Govindarajan at 573-882-1515.



Wanted: Your clinical trial stories to feature in upcoming editions of Connections. Contact the MGA to share. 816-256-4100 or allisonfoss@mgakc.org

Kansas University Medical Center in Kansas City, KS, is participating in clinical trials relating to myasthenia gravis (see below). If you are interested in participating in a trial or would like more information, go to <u>clinicaltrials.gov</u>, 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. A Randomized, Placebo-Controlled, Parallel Group Study to Evaluate the Effect of Amifampridine Phosphate in Patients with MuSK Antibody Positive Myasthenia Gravis, and a Sample of AChR Antibody Positive Myasthenia Gravis Patients NCT03579966
- 2. 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



2018 MGA Board Members & Staff

President: Brett Henson
Vice President: LaDonna Diller
Secretary: John Sand, MD
Treasurer: Derek Haverkamp

Joe Bant
Brodie Beck
Stephanie Hubers
Ray Olsen
Lisa Sackuvich, RN
Nancy Vinsant
John Wilkinson

Executive Director:
Allison Foss
Program Coordinator:
Tanya Renner

Welcome Nancy Vinsant to the Board of Directors

Nancy Vinsant has joined the MGA Board of Directors. Nancy was diagnosed with MG 15 years ago. She is currently the Manager of the Village Cooperative of Verona Hills, a maintenance provided community for active seniors. Event planning and volunteer recruitment are skills Nancy hopes to transfer from the Boy Scouts of America to the MGA. Ron, Ivor (21) and Aris (19) round out the Vinsant home team.



As our newsletter was set to go to press, we learned of the passing of Jacob McGuire, DDS, who you may recall joined our Medical Advisory Committee in January 2018. Not only was Jake serving on the Committee as a Dentist, but also as a patient. Jake leaves behind wife, Bethany, children, Luke, Ethan and Julia. His parents, Richard and Jan are active members of our Springfield Support Group. Our deepest sympathies to the McGuire Family.

You're Invited to the 58th Annual Meeting of the MGA

Join us as we welcome Alexion Pharmaceuticals to hear about the October 2017 FDA approved product for myasthenia gravis. You'll hear information from Dr. Raghav Govindarajan of the University of Missouri and a patient. You won't want to miss out on this educational

Saturday November 17, 2018 Agenda:

presentation.

9:00 Registration and Light Breakfast
9:30 MGA 2017 Review and Awards
10:00 Keynote Speaker
11:30 Wrap Up
12:00 Lunch and Raffles
1:00 Annual Meeting Concludes

Please RSVP to Tanya Renner tanyarenner@mgakc.org or 816-256-4100. In your RSVP please indicate if you plan to join us for lunch.

Location:
St. Joseph Medical Center
Community Center
1000 Carondelet Dr.
Kansas City, MO
(I-435 & State Line)
Follow signs past the emergency room.

Lodging: We have a hotel block at the Holiday Inn off 435 and Nall in Leawood/ Overland Park. Book your room here. Room rates start at \$92/night under our block.

Call the Holiday Inn directly at 913-312-0900 and ask for the Myasthenia Gravis Association group block rate.

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 or send us an email and we will send you the full list or help make suggestions of people with whom you may benefit by connecting via email or phone.



mg support groups *

Area	Dates	Time	Location
Kansas City, MO	December 8th	11am- 1:00pm	St. Joseph Medical Center ~ Community Center 1000 Carondelet Drive, KCMO 64114 RSVP tanyarenner@mgakc.org or (816) 256-4100 HOLIDAY PARTY
KC Northland	See you in 2019!	noon- 1:30pm	Primrose Retirement Communities 8559 N Line Creek Pkwy, KCMO 64151 RSVP tanyarenner@mgakc.org or (816) 256-4100
Columbia, MO	TBD	TBD	Location TBD
Springfield, MO	TBD	6-8pm	The Library Center 4653 S. Campbell Springfield, MO 65810 RSVP tanyarenner@mgakc.org or (816) 256-4100
St. Louis	December Ist	10am - 11:30am	Glendale City Hall 424 Sappington Road St. Louis, MO 63122 tanyarenner@mgakc.org or 816-256-4100 HOLIDAY PARTY
Wichita, KS	November I 0th	II-Ipm	Golden Corral 616 N. Ridge Road-Wichita Wichita, KS 67214 Contact: Dana or Larry Paxson for more info or to RSVP dkptiffany@gmail.com or (316) 269-9120
Young Persons with MG Group	December 4th	6рт	Dave and Busters 1843 Village West Parkway Kansas City, KS 66109 RSVP tanyarenner@mgakc.org or (816) 256-4100
Omaha, NE		10am-noon	Calvary Lutheran Church 2941 N 80th St, Omaha, NE 68134 Contact: Dianna McCarty for info or to RSVP dmccarty@abbnebraska.com or (402)426-8006 or Kathy Cassidy - cassidykathryn@yahoo.com or 402-719-5861
Northwest, AR	November IIth	2:30- 4:30pm	Schmieding Center for Senior Health and Education 2422 N. Thompson (Hwy 71 North) - Springdale Contact: Roger Huff for more info or to RSVP jrhuff1@cox.net or (479) 790-3022

Chronic Illness and Retirement

IF YOU ARE like many Americans, you may not be preparing for retirement. A survey conducted by Money magazine in 2016 found one out of every three Americans has no savings, and 23 percent have less than \$10,000 saved. This figure is particularly alarming since retirement is one of the biggest life expenses, even without a chronic illness.

Many expenses get in the way of saving money such as credit card debt, student loans, low wages and children. But, for those with a chronic illness, saving for retirement is even harder since a large part of your income goes to cover expensive insurance plans, doctor visits, medicines and medical supplies. Furthermore, if you are unable to work or can't work full time due to your illness, there often isn't enough money to save.

Actually, the population dealing with chronic illness and its expenses is larger than most people realize. According to statistics, 133 million Americans have at least one chronic illness. And, it is estimated by 2025, that number will have grown to 164 million people or nearly half the population. But, that doesn't mean those with chronic illness can't prepare for retirement. Following are some steps to getting started in the right direction.

Steps to Prepare for Retirement 1. Talk to your doctor.

Your doctor can advise you on the likely progression of your disease and whether you will need special medical services, equipment or food. For example, if you have a neuromuscular illness, this may mean planning to make your home handicap-accessible in the future. Your doctor

can also advise if you might have to reduce your work hours in the future or retire early due to your illness. This information is vital for helping you set a budget to plan for projected costs.

2. Determine how much retirement money you will need.

After you have learned as much as possible about the expected progression of your disease, it's time to determine how much money you will need for retirement. While this may sound obvious, it isn't. According to a study conducted by Age Wave and Merrill Lynch, 81 percent of Americans say they don't know what they will need to fund their retirement.

3. Start saving.

Next is to determine how you are going to reach your goal. According to Martin Shenkman, a CPA, attorney and author of Estate Planning for People with a Chronic Condition or Disability, patients should "simplify all of their finances by consolidating everything they can." This means getting rid of unneeded bank accounts, setting bills to be automatically paid and uploading important documents. If all your information is consolidated in one place, it will be easier for you or your financial planner to manage. By making these simple changes, you can empower yourself to plan for the future and free up valuable time to concentrate on your health.



Continued from page 8

4. Stay the course.

Consistently, save money even if it is a small amount. While it may not seem much at the time, the balance will build up. Trust me, your future self will thank you for every dollar you are able to save today. Two ways you can accomplish this are by prioritizing your spending and paying down long-term debt. The less you owe, the less interest you will pay. Those interest payments can instead go toward savings!

5. Review your insurance.

derstanding insurance coverage becomes vital to your financial success. Not only do you need to be sure you are selecting the best healthcare plan to reduce out-ofpocket expenses and maximize treatments, you also need to understand disability, life and long-term care insurance. To gain a better understanding of your needs, it's a good idea to speak with an impaired-risk specialist who knows which policies would be best suited for you and to help find the right coverage.

6. Consider a financial planner.

Because of the complicated nature of retirement planning with chronic illness, you may feel your best option is to seek the help of a professional financial planner. If you choose to use a planner, finding the best one doesn't necessarily mean finding one who specializes in clients with chronic illness. Shenkman advises finding a professional who has integrity and is willing to think outside the box. After you have chosen a planner, it's up to you to provide details about your illness and what your

future needs will be.

7. Plan your estate.

Estate planning is one of the foundations of a good financial plan for a couple of reasons. First, it ensures your affairs are in order at the time of your death. More importantly, an estate plan can help manage your finances and healthcare if you become incapacitated. Two important parts of a good plan include a living will and a durable power of attorney. A living will (also known as an advanced directive) is a legal directive that states your wishes in writing about your medical and end-of-life care if you are unable to do so. With a du-When diagnosed with a chronic illness, un-rable power of attorney, you can authorize someone to handle your finances, pay bills and taxes if you become debilitated.





MG Patients Are at Greater Risk for Other Autoimmune Diseases, Study Suggests As reprinted from Myasthenia Gravis News, September 2018

Myasthenia gravis patients have a greater risk of having autoimmune rheumatic diseases, especially those who underwent a thymectomy, according to researchers in Taiwan.

Their study, "Thymectomy in patients with myasthenia gravis increases the risk of autoimmune rheumatic diseases: a nationwide cohort study," was published in the journal *Rheumatology*.

Patients with myasthenia gravis (MG), an autoimmune disease, are reported to have a higher incidence of other autoimmune diseases. The co-occurrence of other autoimmune diseases in addition to MG can suggest that a patient has systemic immune impairments that could be associated with a less favorable outcome.

Most of these reports, however, are based on single cases or clinical studies, highlighting the need to further investigate this association.

Researchers at Taipei Medical University in Taiwan set out to estimate the frequency of autoimmune rheumatic diseases (ARDs) in a large group of residents using medical data from Taiwan's Registry of Catastrophic Illness.

ARDs refer to autoimmune diseases that mainly, but not exclusively, affect the joints and muscles. These can include rheumatoid arthritis (RA), systemic lupus erythematosus (SLE), Sjogren's syndrome, progressive systemic sclerosis (pSSc), diabetes, and many other conditions.

Researchers studied 6,478 patients with myasthenia gravis and 25,912 age- and sex-matched controls.

Results indicated that the risk of total ARDs was 6.25 times higher in patients with MG compared to patients in the non-MG group after adjusting for age and sex. "Therefore, we postulate that MG increases the risk of ARDs," the researchers wrote.

When looking at specific diseases, patients in the MG group were found to have a 15.84 times greater risk of pSSc, an 11.32 times higher risk of SLE, and a 4.07 times greater risk of other ARD types.

Researchers also investigated the role of plasmapheresis (a process that filters the blood and removes harmful antibodies) and thymectomy (removal of the thymus) in the occurrence of ARDs in patients with MG.

While plasmapheresis did not have any effect on risk of ARDs in patients with myasthenia gravis, patients with MG who underwent a thymectomy had a 23.68-fold higher risk of SLE, a 15.06 times greater risk of pSSc, and a 4.41-fold higher risk of RA.

Results from this study highlight an association between myasthenia gravis and incident ARDs, particularly pSSc and SLE. Moreover, patients with myasthenia gravis who underwent a thymectomy had an increased risk of RA, pSSc, and SLE.

"Future studies are needed to elucidate the underlying [disease development] and to translate this into clinical therapeutic options," the researchers wrote.

We're excited to announce our upcoming Gratitude & Giving ~ Yoga & Meditation Donation based class which will benefit the MGA programs and services. Join Yoga Instructor Sarah Uchytil and our friends at Athleta Leawood– Town Center for the class. You must register online and select a donation level to participate. Space is limited. You can register through our website~ www.mgakc.org and click the Yoga picture. Thanks in advance and we hope to see you there!



Ways to Support the MGA





Got an idea for a fundraiser in your community?

Contact us today! allisonfoss@mgakc.org

Your financial support enables us to continue reaching

patients across the heartland.

In Memoriam

Margaret Foiles

Overland Park, KS

Virginia Miller The Woolston Family

Rose & Alan Grimes Lynne Greseth
Diane Synder Roberta Dering

Eric & Donna Vestal Stacy & Clayton O'Connor Susan Driscoll Raymond & Melissa Stolhand

Kurt and Lisa Kuhnke The Woolston Family Gary Burns Rogersville, MO





You may have gotten this newsletter via email when you previously had gotten it via US Mail. If we had your email address and it was not otherwise noted, we switched your newsletter subscription to electronic. This is due in part to helping the MGA go green, save a tree and save a little money. If you prefer to receive a hard copy of the newsletter please contact us at 816-256-4100 or allisonfoss@mgakc.org







Reunion in the Making

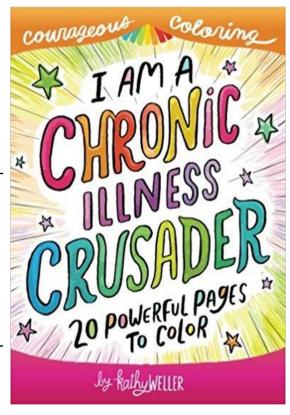
A simple conversation between the neuromuscular team at the University of Kansas and Allison Foss, Executive Director of the MGA, in the spring of 2018 about who diagnosed Allison turned into a reunion between medical student, medical professor and patient recently in Iowa City, IA. Mazen Dimachkie, M.D. Professor and Executive Vice Chair, Neuromuscular Division Chief at KU was a student under now retired Pediatric Neurologist and Emeritus Professor, Adel Afifi in Beirut in the early 1980s. Allison was diagnosed with MG in 1984 by Dr. Afifi at the University of Iowa Hospitals and Clinics. Once this discovery was made, a quest began to reunite and connect. Dr. Dimachkie tracked down Dr. Afifi and on a very cold and blustery day in early October, the three met. Dr. Afifi shared with everyone, slides he had taken of Allison as a child which he used to teach classes about myasthenia gravis. Dr. Dimachkie and Dr. Afifi traded stories of their times together in Beirut and the Neurology world as it today. No-



body wishes a life filled with chronic illness for another but if you have to deal with a chronic illness, it is best dealt with while making connections along the way to help write your story.

On the Bookshelf

Did you know coloring can reduce stress? It's true! So if you are missing your youth, grab yourself some crayons and a coloring book. You've probably seen the updated versions of adult coloring books. Recently we discovered I Am A Chronic Illness Crusader Coloring Book on Amazon. As described on Amazon, it offers support, empathy and creative therapy for those experiencing the pain and discomfort associated with chronic illnesses of every stripe and color. The book features single-sided coloring pages with motivational, encouraging and empowering sayings and affirmations specifically for those facing the daily challenges of chronic illness. Coloring is a highly creative and meditative activity that can have powerful therapeutic anti-stress and relaxation benefits. It activates the brain's right hemisphere, reducing stress, and promoting a relaxed, meditative state by focusing the brain on the "here and now"-- the feelings of positivity and calm that we experience when we color! This book combines these benefits of coloring with the specifically chosen sayings of empowerment and encouragement for



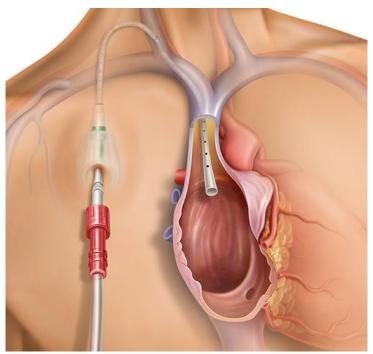
MG Impairment Index May Be Useful for Clinical Trials in Pure Ocular Disease

A new study has found the Myasthenia Gravis Impairment Index (MGII) is a sensitive tool for identifying treatment response and clinical meaningful change among patients with MG receiving prednisone, intravenous immune globulin (IVIG) and plasma exchange (PLEX). In the study, 95 patients with MG who were prescribed prednisone, IVIG or PLEX were compared with 54 control patients who received no treatment. Assessments using the MGII, Quantitative MG Score, MG Composite and MG Activities of Daily Living occurred at baseline and at three to four weeks after treatment. Those receiving prednisone, IVIG or PLEX demonstrated a significantly greater change in MGII scores. Specifically, patients receiving prednisone showed more change in the ocular domain when compared with IVIG/PLEX, and in the generalized domain, those receiving IVIG/PLEX showed greater change in scores compared with those who received prednisone. According to the researchers, the results may be useful for clinical trials in pure ocular disease.

May, B. Myasthenia Gravis Impairment Index Indicates Response to Prednisone, IVIg, PLEX. Neurology Advisor, Dec. 5, 2017. Accessed at www.neurologyadvisor.com/myasthenia-gravis-impairment-indexindicates-response-to-prednisone-ivig-plex/printarticle/711466. Reprinted from IG Living, September 2018

PowerFlow implantable apheresis IV Port now an option for patients with MG

PowerFlow is a totally implantable IV port that was designed specifically for long-term therapeutic apheresis. The PowerFlow port is totally implantable to reduce the risk of infection and enhance patient comfort. It consists of a titanium access funnel coated with a soft silicone body and a polyurethane catheter. The soft silicone body enhances patient comfort. The funnel of the port guides a 16 gauge soft IV catheter to an angled needle stop. The catheter is advanced through a silicone valve that seals the IV catheter into the port. Unlike traditional ports and central venous catheters that are accessed at 90 degrees, the PowerFlow port is accessed at 30 degrees relative to the skin surface. This enhances patient comfort and mobility. The large diameter polyurethane catheter permits high flow rates up to 118 mL per mi-



nute. The PowerFlow port has been tested to last up to 1000 accesses. The best long-term strategy is to have 2 PowerFlow ports implanted; one on left and one on right-side.

Alternatively, one PowerFlow port can be implanted in a peripheral vein can be used each time. The following video is a promotion by Bard but has good information. https://vimeo.com/216855583

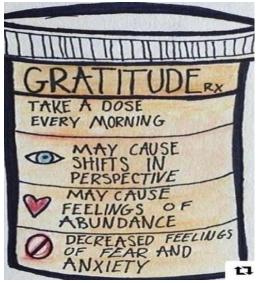
Special thanks to Fred Plapp, M.D., Clinical Professor, Medical Director, Clinical Laboratories at the University of Kansas for writing this article for us.

2018 membership/fundraising drive

YTD Totals: \$4224 Memberships 2018 Goal \$10,000 Please keep the MGA on your list as you make 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!

CC & Karen Swarens Kathleen Palmero & John Czapla Randall & Monica Duffee Bobbie Jane Gates Nancy Hupp Judith Gorsky Joan Stackhouse



The MGA can now accept donations via Venmo!

Donate via your Venmo app @MGAKC



Please become a 2018 member & receive a tax deduction!

ASE PRINT Cut & enc	lose in envelope & r	nail to: 👈	
e			MGA 2340 E. Meyer Blvd.
ress	City	State Zip_	Bldg.1, Suite 300A KCMO 64132
ne	_ Email		DI FACE CUIFOV
nt to help support the MGA by bed	PLEASE CHECK: MG Patient		
\$ 25 Basic Membership \$ 58 (<i>58th Anniversary Membership</i>) \$ 100 Sustaining Membership			☐ Relative ☐ Friend
\$ 100 Sustaining Membership \$ 500 Patron Membership \$ 1,000 Lifetime Membership \$ In Memory of: \$ In Honor of:	Thank You!		Myasthenia Gravis Association: ALL CONTRIBUTIONS ARE
			

snoitsength and Hope through Connections

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 Cravis Association 2340 E. Meyer Blvd.

Building 1, Suite 300A Building 1, Suite 300A

Call us at: (816) 256-4100







Greater Kansas City

ADM and to noissim and

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.



www.mgakc.org

Kansas City, MO 64132 Phone: (816) 256-4100 Email: mgakc@sbcglobal.net

Myasthenia Gravis Association 2340 E. Meyer Blvd. Building 1, Suite 300A