



Strength and Hope Through CONNECTIONS

Volume 59 Issue 3

Summer 2019

9th Annual MGA Triple Crown Showdown a success!

As daylight broke on Sunday May 19, 2019, volunteers and committee members for the MGA Triple Crown Showdown were on pins and needles. Was it going to rain or was the sun going to peek through? After all 464 participants had registered for the 9th Annual MGA Triple Crown Showdown and surely a monsoon wouldn't happen two years in a row. It was a tad windy, maybe a few sprinkles mixed in with over-cast skies, but the event commenced without a hitch and \$45,000 was raised for the Myasthenia Gravis Association! Participants enjoyed mingling with 20 vendors, petting therapeutic mini ponies and grabbing a cup of joe from Corner Bakery. We were delighted to have 36 VIP (individuals with MG) as participants and volunteers this year. That nearly doubled our number from last year. 120 people enjoyed brunch at Pig and Finch following the race where they had triple crown themed drink specials and a yummy breakfast buffet where \$5 from each ticket sold went back to the MGA. 2020 marks year number 10 for the MGA Triple Crown Showdown. Be sure to get 5.17.20 on your calendar now! More details to come. Thank you to all who participated, volunteered, supported and donated to the MGA Triple Crown Showdown. To view this year's video and see additional pictures please go to www.mga5k.com



THANK YOU TO OUR AWESOME SPONSORS!

Take 5 to Care



A New Look

As you may recall, in 2017, the MGA rebranded it's logo. We are excited to announce that we have finally rebranded our New Patient Packets, our MGA Brochure and our Legacy Brochure! Special thanks to Jeanine Davis with Nine Creations for helping us with these. We hope you enjoy our new look!



3rd Annual Cy's Crown Town Trivia Night nearly sold out! Get your tickets ASAP!

The 3rd Annual Cy's Crown Town Trivia Night is set for Friday September 6, 2019 at Boulevard Brewing Company in Kansas City, MO. At press time there are only 25 tickets left before we sell out! The MGA is thrilled to have the assistance of the Kansas City Iowa State Alumni Club again this year as they help play host and plan the event as the MGA being their charity of choice. Funds raised at this event benefit the MGA with the KC Iowa State Alumni Club recouping any expenses they incur. If you want to attend you can purchase your tickets online at www.mgakc.org or by contacting Allison Foss at allisonfoss@mgakc.org to get your tickets. Individual tickets are \$75 and a table of 10 can be purchased for \$600. Participants will enjoy beer and wine from Boulevard as well as pasta, salad, breadsticks and dessert from Waldo Pizza accompanied by 3 rounds of trivia, live and silent auctions. We hope to see you there!



Needy Meds provides assistance

Needy Meds is a national non profit that is working to educate and empower those to find affordable healthcare. Their website contains an updated database of patient assistance programs to over 4,000 drugs. Their website is user friendly and allows you to search by drug to locate resources available. You can find them at www.needymeds.org.



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.

A MESSAGE FROM THE MGA'S EXECUTIVE DIRECTOR

You probably have seen that MG is known as the “snowflake” disease because each person is different and can be impacted differently, just like a snowflake. As you read these updates and look through this issue, know that you and your doctor know what is best for your case and scenario. In the world of social media, it’s easy to live life and go off advice or mimic the exact thing somebody else is doing or trying. There are times when it is nice not to have to reinvent the wheel, but when it comes to your medical decisions, especially MG related, it’s always important to catch up with your Neurologist to gather input. The MGA strives to put forth the most current recommendations and articles on all of our social media channels with the disclaimer to talk to your team for their input. It’s an exciting time in the MG world because of all the research and advancements, but there is also a lot of misinformation. So educate yourself and work with YOUR team to find what works for YOU! In the words of Dr. Seuss, “Today **you are you**, that is truer than true. There is no one alive who is youer than **you**.” So go forth, snowflakes, be YOU!



Allison Foss, Executive Director

MGA Board of Directors and Staff

President:	Joe Bant	Executive Director:
Brett Henson	Brodie Beck	Allison Foss
Vice President:	Michael Eagan	Program Coordinator:
LaDonna Diller	Stephanie Hubers	Tanya Renner
Secretary:	Ray Olsen	
John Sand, MD	Lisa Sackuvich, RN	
Treasurer:	Nancy Vinsant	
Derek Haverkamp	John Wilkinson	

In This Issue

Behind the lens	5
Clinical trials	6
Reel in MG	6
Snowflake Shuffle	6
Research Update from Ra Pharma	7 & 8
Support Group Calendar	9
Memorials & Memberships	10
Tips for swallowing	11

59TH ANNUAL MEETING

MYASTHENIA GRAVIS ASSOCIATION

Clinical Trials and the 5 W's
Who, What, Why, Where and When
Panel featuring Neurologists from University of Kansas, Pharmacy Representatives and a Patient
 9am-1pm
 Saturday November 9, 2019
 St. Joseph Medical Center,
 Kansas City, MO
 More info to come!

Specialty Pharmacy & Home Infusion

ARJ ReadyPack[®]

We thoughtfully organize each ReadyPack[®] with patients and caregivers in mind.



Benefits

- Supplies for every infusion
- Easy-to-read labels
- Travel-friendly packaging

The ARJ Advantage

Our pharmacists are happy to expedite medication right to your home or doctor's office.

24/7 Nationwide Care

866-451-8804

arjinfusion.com



ARJ Infusion
SERVICES

Behind the Lens

If you were aware of Liz Davenport behind the camera at the 9th Annual MGA Triple Crown Showdown, you probably not aware that in December 2016, her myasthenia gravis took a turn in which she was hospitalized at the University of Kansas Medical Center on a ventilator and with a feeding tube. Fast forward to today, Liz and her husband are raising two young kids and she is either behind the lens of the camera or using her creative juices at her graphics design business.

Diagnosed in 2003, Liz recalls that much of the early years of diagnosis with MG were easy. Her treatment started out with the removal of her thymus gland. Then there were times when her speech was slurred but she lived an otherwise normal life. Some 10 years later after she married and began having children, the stress of sleepless nights and having little ones at home sent her MG into overdrive. She struggled with her speech, swallowing and breathing. It was nearly impossible for her to lift her kids or even verbally communicate with them. As Christmas of 2016 approached, Liz was preparing to receive ongoing plasmapheresis treatments when her fistula was infected and treatments were stalled when she fell into crisis. Liz did not accept the news that she could be on a ventilator and feeding tube for the rest of her life. She had kids to tend to, a husband to grow old with and pictures to take!

Overtime she has recovered; can eat, speak, enjoy her family and even work out. All amongst the time she spends running, Sunshine and Shadows, her photography business as well as her graphic design business. Liz is not a smile at the camera type of photographer. Liz captures people living their lives, interacting with others, being playful and exploring. Living life with MG has given Liz a unique perspective, because she has been on the cusp of losing what she so enjoys capturing of her clients, living. Liz truly understands the need to appreciate each breath, each simple step, and her pictures capture just that. For more information on Sunshine and Shadows you can check Liz out at

www.sunshineandshadowsphotography.com



6 Clinical Trials

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 clinicaltrials.gov, and enter the NCT number related to the specific trial. You can also call KU directly and talk to Andrew Heim at 913-945-9926



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

3. *A Randomized, Double-Blind, Placebo-Controlled, Multicenter Phase 3 Trial to Evaluate the Efficacy, Safety and Tolerability of ARGX-113 in Patients with Myasthenia Gravis Having Generalized Muscle Weakness*
NCT03669588

4. *A Phase 2, Multicenter, Randomized, Double-Blind, Placebo-Controlled Study to Evaluate the Safety, Tolerability, Efficacy, Pharmacokinetics and Pharmacodynamics of M281 Administered to Adults with Generalized Myasthenia Gravis*
NCT03772587

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.



Reel in MG set for October 12, 2019 in Lebanon, IL

The inaugural Reel in MG event has been set for October 12, 2019 from 11-3pm at the home of St. Louis Member, Mark Macias and his family. We hope you will consider joining us for a day of raising awareness, fishing, food trucks, raffles and silent auctions. There is no admission fee to come to this event but we do request that you register in advance at www.mgakc.org and click the Reel in MG picture.



2nd Annual MGA Snowflake Shuffle 0.1K in Wichita on October 19, 2019

Wichita and Southern Kansas friends, don't forget to join us for the 2nd Annual MGA Snowflake Shuffle 0.1K at the Linwood Recreation Center on Saturday October 19, 2019 from 10:30-1:30pm. Registration is \$25 and includes a t-shirt. Not to worry, no walking or running required! Just come out for a fun day of mingling with others with MG, BBQ, raffles and new this year vendors and silent auction items! Head on over to www.mgakc.org and send in your registration to ensure you get a t-shirt!



Ra Pharmaceuticals Announces Positive gMG Phase 2 and Open-Label, Long-Term Extension Data at the 2019 AAN Annual Meeting

Open-label, long-term extension data show durability of zilucoplan treatment effect, with sustained improvements observed in primary and secondary endpoints at 24 weeks

Cambridge, MA—May 7, 2019 – Ra Pharmaceuticals, Inc. (Nasdaq:RARX) today announced the presentation of data from the Company's Phase 2 clinical trial evaluating zilucoplan for the treatment of generalized myasthenia gravis (gMG), including data from the open-label, long-term extension study, at the 2019 American Academy of Neurology (AAN) Annual Meeting, in Philadelphia, PA, from May 4-10, 2019.

"Zilucoplan achieved rapid, clinically meaningful, and statistically significant reductions in primary and secondary endpoints in this Phase 2 study, with a durable and sustained treatment effect observed at 24 weeks for patients in the long-term extension," said James F. Howard, M.D., Distinguished Professor of Neuromuscular Disease and Chief of the Neuromuscular Disorders Section, Department of Neurology, University of North Carolina School of Medicine. "These data provide continued support for the role of this convenient, subcutaneously (SC) self-administered C5 inhibitor as a potential treatment option for a broad range of patients with gMG."

Base Study Results

- The 0.3 mg/kg dose of zilucoplan consistently achieved rapid, sustained, and near-complete complement inhibition. The 0.1 mg/kg dose of zilucoplan achieved rapid, sustained, but submaximal complement inhibition. Based on the pharmacokinetic, pharmacodynamic, and efficacy results, the 0.3 mg/kg dose of zilucoplan was selected for evaluation in the upcoming pivotal Phase 3 trial.

- As previously reported, the pre-specified primary efficacy endpoint of change from baseline to week 12 in Quantitative Myasthenia Gravis (QMG) score was met with zilucoplan dosed at 0.3 mg/kg SC daily, resulting in a clinically meaningful and statistically significant improvement over placebo (QMG reduction from baseline at week 12 = -6.0; placebo-corrected change in QMG at week 12 = -2.8; $p=0.05$). The key secondary efficacy endpoint of change from baseline to week 12 in the MG Activities of Daily Living (MG-ADL) score was met with zilucoplan dosed at 0.3 mg/kg SC daily, resulting in a clinically

meaningful and statistically significant improvement over placebo (MG-ADL reduction from baseline at week 12 = -3.4; placebo-corrected change in MG-ADL at week 12 = -2.3; $p=0.04$).

- The 0.3 mg/kg dose of zilucoplan led to rapid, statistically significant, and clinically meaningful reductions in additional pre-specified secondary endpoints, the MG Composite (MG-COMP) and the 15-item MG Quality of Life revised scale (MG-QoL15r), versus placebo at week 12 (MG-COMP reduction from baseline at week 12 = -7.4; placebo-corrected change at week 12 = -4.1; $p=0.04$); MG-QoL15r reduction from baseline at week 12 = -5.9; placebo-corrected change at week 12 = -3.7; $p=0.06$).

- Rescue therapy with intravenous immunoglobulin or plasma exchange was required by 3/15 (20%) patients in the placebo arm, 1/15 (7%) patients in the 0.1 mg/kg zilucoplan arm, and in zero (0%) patients in the 0.3 mg/kg zilucoplan arm.

- Treatment with zilucoplan had a favorable safety and tolerability profile in the study, consistent with previously-completed Phase 1 and Phase 2 studies. The majority of adverse events (AEs) reported were mild and were not considered by the investigators to be related to study drug. There were no serious AEs observed related to treatment with zilucoplan.

Open-Label, Long-Term Extension Results

- Sustained responses were observed for all four efficacy endpoints after 24 weeks at the 0.3 mg/kg dose of zilucoplan, with changes from baseline to week 24 as follows:

- o QMG = -8.7, $p<0.0001$
- o MG-ADL = -4.5, $p<0.0001$
- o MG-COMP = -10.2, $p<0.0001$
- o MG-QoL15r = -7.5, $p=0.0006$

- Placebo subjects crossing over to the 0.3 mg/kg dose of zilucoplan after 12 weeks experienced rapid, clinically meaningful, and statistically significant improvements for all four efficacy endpoints from weeks 12 to 24, with changes from week 12 to week 24 as follows:

- o QMG = -3.1, $p=0.01$
- o MG-ADL = -3.6, $p=0.0004$
- o MG-COMP = -5.5, $p=0.004$
- o MG-QoL15r = -4.0, $p=0.04$

continued next page



Continued....

Based on feedback provided by the U.S. Food and Drug Administration (FDA), Ra Pharma plans to initiate a single, 12-week, pivotal, Phase 3, randomized, double-blind, placebo-controlled trial evaluating the efficacy of a once-daily, SC self-administered dose of 0.3 mg/kg of zilucoplan versus placebo. The trial is expected to enroll approximately 130 patients with gMG who are acetylcholine receptor (AChR)-antibodypositive, regardless of their prior therapies. The primary endpoint will be the change in the MG-ADL score from baseline to week 12. Following completion of the Phase 3 clinical trial, patients will have the option to enroll into an open-label, long-term extension study.

"These Phase 2 data support the competitive profile of zilucoplan in gMG, and as a convenient, SC self administered therapy, we believe zilucoplan has the potential to bring complement inhibition to the forefront of treatment in this disease," said Doug Treco, Ph.D., President and Chief Executive Officer of Ra Pharma. "We look forward to initiating our pivotal Phase 3 trial in MG in the second half of this year, as part of our mission of expanding patient access to convenient and accessible therapies."

Details of the presentation are as follows:

The presentation and poster from the 2019 AAN Annual Meeting can be accessed by visiting the "Presentations and Publications" section of the Ra Pharma website: www.rapharma.com.

About Zilucoplan Phase 2 gMG Clinical Trial

The Phase 2, multi-center, randomized, double-blind, placebo-controlled trial was designed to evaluate the safety, tolerability, and preliminary efficacy of zilucoplan in patients with generalized myasthenia gravis (gMG), regardless of prior therapies, who had an MGFA Disease Class of II-IVa at screening and a Quantitative Myasthenia Gravis (QMG) score, a physician-administered assessment of MG-related muscle weakness, of ≥ 12 at screening and randomization. The trial enrolled 44 patients in the U.S. and Canada.

At the outset of the 12-week treatment period, patients were randomized in a 1:1:1 ratio to receive daily, subcutaneous (SC) doses of 0.1 mg/kg of zilucoplan, 0.3 mg/kg of zilucoplan, or matching placebo. The pre-specified primary efficacy endpoint was the change in QMG score from baseline to week 12. The key secondary efficacy endpoint was the change in MG Activities of Daily Living (MG-ADL) score, a patient reported outcome measure, from baseline to week 12. Significance testing was pre-specified at a 1-sided alpha of 0.1. All 44 patients completed the 12-week study and, of these, 42 (95%) entered a long-term ex-

tension to receive active study drug.

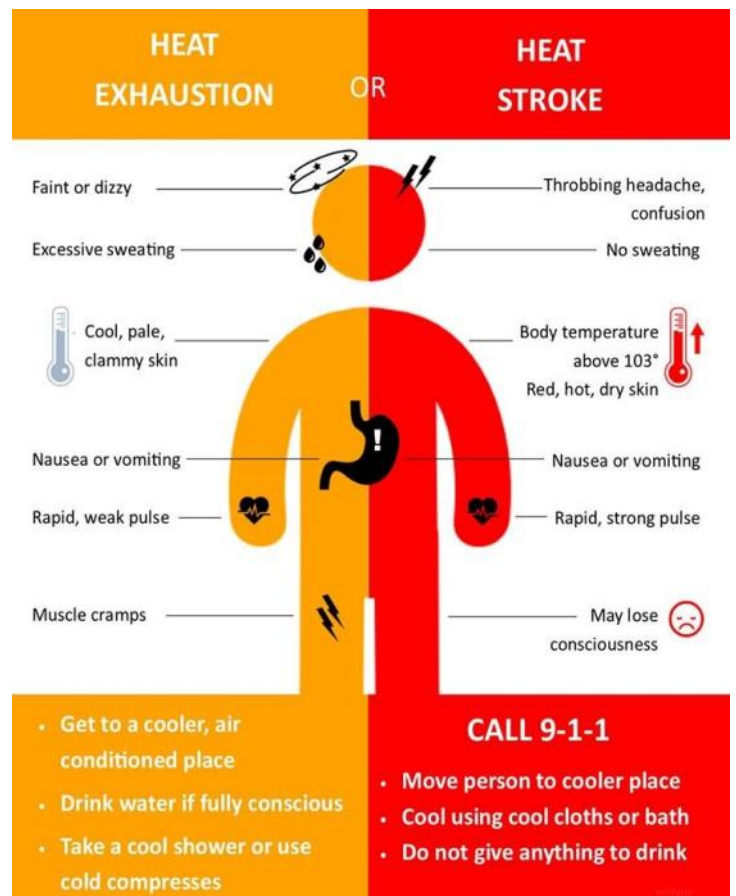
About Zilucoplan

Ra Pharma is developing zilucoplan for generalized myasthenia gravis (gMG) and other tissue-based, complement-mediated disorders with high unmet medical need. The product candidate is designed for convenient, once-daily, subcutaneous (SC) self-administration. Zilucoplan is an investigational, synthetic, macrocyclic peptide discovered using Ra Pharma's powerful proprietary drug discovery technology. The peptide is designed to bind to complement component 5 (C5) with sub-nanomolar affinity and allosterically inhibit its cleavage into C5a and C5b upon activation of the classical, alternative, or lectin pathways.



Be Weather Aware!

The dog days of summer have arrived. While each person is different be aware of how temperature affects your body and your MG.



MG Support Groups

Area	Dates	Time	Location
Kansas City, MO	October 12th	10am-12:00pm note time change	St. Joseph Medical Center ~ Community Center 1000 Carondelet Drive Kansas City, MO 64114 RSVP tanyarenner@mgakc.org or (816) 256-4100
KC Northland	September 12th	noon-1:30pm	Primrose Retirement Communities 8559 N Line Creek Pkwy Kansas City, MO 64151 RSVP tanyarenner@mgakc.org or (816) 256-4100
Columbia, MO	September 5th	6:30-8pm	Daniel Boone Regional Library 100 W. Broadway Columbia, MO 65203 RSVP to tanyarenner@mgakc.org or (816) 256-4100
Springfield, MO	October 24th	6-8pm	The Library Center 4653 S. Campbell Springfield, MO 65810 RSVP tanyarenner@mgakc.org or (816) 256-4100
St. Louis	September 14th	10am - 11:30am	Glendale City Hall 424 Sappington Road St. Louis, MO 63122 tanyarenner@mgakc.org or 816-256-4100
Wichita, KS	August 17th September 7th	1-3pm	Via Christi St. Francis Hospital 929 N. St. Francis St. 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	October 1st	6pm	TBD RSVP to Allison Foss allisonfoss@mgakc.org
Omaha, NE	September 14th	10am-noon	Calvary Lighthouse Church Church 2941 N 80 th 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	September 15th	2:30-4:30pm	Schmieding Center for Senior Health and Education 2422 N. Thompson (Hwy 71 North) Springdale, AR 72764 Contact: Roger Huff for more info or to RSVP jruff1@cox.net or (479) 790-3022

- Ongoing and current calendar can be found at www.mgakc.org
- Your RSVP to support group is important to support group coordinators! Please RSVP!

In Memoriam

Gene Wilmoth

Olathe, KS

Theodore Folkert

Barbara Ragsdale

Ronald and Joyce Slayden

Scott and Margaret Walker

Karen Swofford

Mary Durst

Matthew and Joann Weger

Shelly Weatherford

Christine Schlomann

Charles and Loralu Droegemueller

Ruth Ronfeldt

Thomas Jones

Patricia Peth

Dianna Smith

Contributions

Marilyn Lowrey

Newton, KS

Lori Harris

Terry Davidson, DDS

Lorraine Boyd

Jim Hakenwerth

Blue Grass, MO

Kelly Hakenwerth

Mike and Kim Pafford

2019 Membership

Drive

Lorraine Boyd

Lee's Summit Medical Center

Cindy Disque

Lisa and Jim Sackovich

Lynda Hireskorn in memory of Sheldon

Hollub

The MGA can now
accept donations via
Venmo! Donate via
your Venmo app
@MGA KC



Webinar coming in September!

Please be sure to watch your email and social media for more information on a webinar with Argenx on a Phase 3 Clinical Trial for myasthenia gravis. There will be opportunities to participate the evening of September 23rd and during the day on September 24th. All from the comfort of your own home! Questions? Contact Allison Foss allisonfoss@mgakc.org



Save the Date!

NW Arkansas Annual Conference

Saturday November 2, 2019

10am-12

Schmieding Center for Senior Health and Education

Contact: Roger Huff for more info
jrhuff1@cox.net or (479) 790-3022

Share with us!

We want to see your wins, your celebrations, your victories, big or small, what you are up to! Send us your pictures and any stories you may have about your life with MG. We are sprucing up our social media and our website and looking for items to share. You can send any to allisonfoss@mgakc.org



SCORE ONE FOR THE MGA!
GRAB YOUR CHIEFS TICKETS USING
CODE MGA KC @
WWW.CHIEFS.COM/TICKETFUNDRAISER
A PORTION FROM EACH TICKET WILL
BENEFIT THE MGA.



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.



Tips for swallowing assistance

- If your doctor has prescribed Mestinon, eat 30 to 45 minutes after taking it.
- Rest before meals and avoid talking.
- Watch for difficulty when eating including: coughing, clearing your throat, food sticking in your throat.
- Stop and take a rest break if you notice more difficulty when eating. Try eating later when you feel well rested.
- Try eating six smaller meals during the day if eating three full meals is tiring.
- Swallow or take a sip of liquid to help clear food if you feel it sticking in your mouth or throat. Cough up any food if you need to.
 - Avoid chewing gum. This can tire your muscles for swallowing.
- You may need to change food textures (how the food feels in your mouth) if you have difficulty swallowing. You may need to eat:
 - Pureed (blended) foods
 - Minced (finely chopped) foods. Food with two textures (for example: cereal & milk or some soups) needs more swallowing control. They may be harder to eat.
- Eat food from all food groups even if you are changing your food textures. For example, don't avoid meat because it is difficult to chew. Finely chop or blend the meat. You will have to do less chewing to eat it.
- Watch your weight and tell your doctor if you lose 5 pounds or more.
- Be aware of changes in your swallowing. If the above tips don't help, ask for a swallowing assessment by a Speech-Language Pathologist.
- See your doctor right away if:
 - you get a chest infection
 - a fever
 - your MG gets worse



Taken from Toronto General University Health Network

Please become a 2019 member!

PLEASE PRINT

Cut & enclose in envelope & mail to: ➔

Name _____

Address _____ City _____ State _____ Zip _____

Phone _____ Email _____

I want to help support the MGA by becoming a 2018 member or making a contribution:

- ☐ \$ 25 Basic Membership
- ☐ \$ 59 (59th Anniversary Membership)
- ☐ \$ 100 Sustaining Membership
- ☐ \$ 500 Patron Membership
- ☐ \$ 1,000 Lifetime Membership
- ☐ \$ _____ In Memory of:
- ☐ \$ _____ In Honor of:

Thank You!

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

PLEASE CHECK:

- ☐ MG Patient
- ☐ Relative
- ☐ Friend

*Make checks payable to the
Myasthenia Gravis Association:
CONTRIBUTIONS may be tax
deductible*

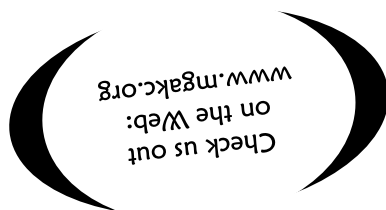
**DONATE
NOW**

<https://www.firstgiving.com/event/mgac/2019-Membership-Drive>

Myasthenia Gravis Association
 2340 E. Meyer Blvd.
 Building 1, Suite 300A
 Kansas City, MO 64132
 Phone: (816) 256-4100
 Email: info@mgakc.org
www.mgakc.org
www.mga5k.com

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.

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



Strength and Hope through Connections