58th Annual Meeting of the MGA held in November

On Saturday November 17, 2018 patients and professionals associated with the MGA gathered to celebrate the achievements as well as learn about the new FDA approved product used for the treatment of MG, Soliris. Presenters included Raghav Govindarajan, MD of the University of Missouri and Alexion Pharmaceuticals. Recognition and awards were given to those who helped make an impact in programming for the MGA over the past year including awards for Volunteer of the Year, which went to Roger and Jan Huff of Springdale, AR. Roger and Jan are the Support Group coordinators for NW Arkansas and have held this role for over 5 years. The Stackhouse Award for exceptional service was given to Larry and Dana Paxson, Wichita Support Group coordinators who not only lead the Wichita Support Group but coordinate the MGA Snowflake Shuffle O.1K. Following the presentation participants enjoyed a potato bar lunch and raffles provided by ARJ Infusion Services. If you missed out on the meeting and would like a copy of the 2017 Annual Report and the presentation you may contact Tanya Renner at tanyarenner@mgakc.org or 816-256-4100.
Your support and participation are requested at the 9th Annual MGA Triple Crown Showdown 5K Run, Mile Mosey and Tot Trot on May 19, 2019 at Town Center Plaza in Leawood, KS. The MGA Triple Crown Showdown is the largest event of the MGA of the Heartland and raises funds to continue to provide support and services to those impacted by myasthenia gravis across Missouri, Kansas and NW Arkansas. Those living with MG can register for free using the code MGA19. Friends and family can use the code MGAFAMILY19 for 20% off. Registration is easy if you log on to www.mga5k.com and click register. Promo codes are entered at the end upon check out. Not up for running, walking or tot trotting? We will need volunteers. Volunteers can also register at www.mga5k.com. If you are traveling from out of town there is a hotel block at the nearby Holiday Inn-Overland Park Convention Center and a link to reserve is also found at www.mga5k.com. Sponsorships are also needed and start at $250. We hope to see you there!

Pictured to the right are our 2019 Race Ambassadors who are in a competition to help us spread the word and get people registered! A huge thanks to Laura Galler, Keith Asaeli, Owen Henson, Chad Harris, Kelsey Lathrop and Joey Henderson for their work as our Race Ambassadors!
A MESSAGE FROM THE MGA’S EXECUTIVE DIRECTOR

It may be winter, but we are off and running in 2019! We are very excited about the line up of programming for this year across the Heartland. That sounds a bit strange to say, excited for the programming of this rare autoimmune disease that is hard to pronounce, but we often find comfort in the commonalities we share with others. Because MG is just that, a rare disease, each and every one of you is important to us. I hope we will connect with you at support groups, gatherings or our upcoming MGA Triple Crown Showdown. Have an idea how we can better connect and partner in your community? Send me a message! I’d love to hear it.

Allison Foss, Executive Director

The MGA was pleased to be able to donate 5K to the University of Kansas for MG research in 2018. Pictured are: Richard Barohn, MD, Judy Ray, Neuromuscular LPN, Tanya Renner, MGA Program Coordinator, Allison Foss, MGA Executive Director, Mazen Dimachkie, MD, Aubrey Alsup, Neuromuscular LPN

Brenda Gagne, a member of our Wichita Support Group, recently submitted one of her House on the Lake painting to the Rare Artist Contest which is supported by the EveryLife Foundation for Rare Diseases. Brenda’s painting was one of 300 pieces submitted. Not only did Brenda win cash, but she won a stipend to travel to Washington DC for Rare Disease Week. Brenda indicates that painting has helped her stay inspired and feel productive when physical things are harder to do. You can read more about Brenda’s painting here- https://www.rareartist.org/portfolio/house-on-the-lake/
You’ve got our heart.
We’ve got your back.

ARJ’s advanced IVig program provides immune globulin infusion therapy to children and adults with myasthenia gravis.

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.

We ♥ making our patients 😊
Learn how ARJ’s life-changing IVig treatments help people across Kansas City.

arJInfusion.com/Journey
866-451-8804
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


3. A Phase 2, Multicenter, Randomized, Double-Blind, Placebo-Controlled, Study to Evaluate the Safety, Efficacy, Pharmacokinetics and Pharmacodynamics of Repeated Doses of M281 Administered to Adults with Moderate to Severe Generalized Myasthenia Gravis

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.

2019 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

Conquer MG Executive Director Joan Wincentsen and Allison Foss, MGA Executive Director met in Chicago in December. Conquer MG is the MG organization of Illinois, Indiana and Wisconsin. Like Allison, Joan also battles MG. It was a great opportunity to brainstorm, share stories and talk about how to best impact the MG community.
CycleBar with MGA is sponsoring a charity ride to raise money and awareness for Myasthenia Gravis. Event proceeds go toward programs and services for those affected by MG in the Kansas City area. For more information on MG and the MGA work in our community, please visit mgakc.org. To register and learn more about the annual 5K, please visit mgas5k.com.

**GIVING OPTIONS**


**PROCEEDS GOING TO MGA**

5053 W. 117TH STREET, LEAWOOD, KS 66211  |  913.755.9818

LEAWOOD.CYCLEBAR.COM
## mg support groups

*Ongoing and current calendar can be found at www.mgakc.org*

<table>
<thead>
<tr>
<th>Area</th>
<th>Dates</th>
<th>Time</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Kansas City, MO</strong></td>
<td>April 6th</td>
<td>10am-12:00pm</td>
<td>St. Joseph Medical Center ~ Community Center</td>
</tr>
<tr>
<td></td>
<td></td>
<td>note time</td>
<td>1000 Carondelet Drive</td>
</tr>
<tr>
<td></td>
<td></td>
<td>change</td>
<td>Kansas City, MO 64114</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>RSVP <a href="mailto:tanyarenner@mgakc.org">tanyarenner@mgakc.org</a> or (816) 256-4100</td>
</tr>
<tr>
<td><strong>KC Northland</strong></td>
<td>February 14th</td>
<td>noon-1:30pm</td>
<td>Primrose Retirement Communities</td>
</tr>
<tr>
<td></td>
<td>March 14th</td>
<td></td>
<td>8559 N Line Creek Pkwy</td>
</tr>
<tr>
<td></td>
<td>May 9th</td>
<td></td>
<td>Kansas City, MO 64151</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>RSVP <a href="mailto:tanyarenner@mgakc.org">tanyarenner@mgakc.org</a> or (816) 256-4100</td>
</tr>
<tr>
<td><strong>Columbia, MO</strong></td>
<td>February 28th</td>
<td>6:30-8pm</td>
<td>Daniel Boone Regional Library</td>
</tr>
<tr>
<td></td>
<td>June 6th</td>
<td></td>
<td>100 W. Broadway</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Columbia, MO 65203</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>RSVP to <a href="mailto:tanyarenner@mgakc.org">tanyarenner@mgakc.org</a> or (816) 256-4100</td>
</tr>
<tr>
<td><strong>Springfield, MO</strong></td>
<td>April 25th</td>
<td>6-8pm</td>
<td>The Library Center</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>4653 S. Campbell</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Springfield, MO 65810</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>RSVP <a href="mailto:tanyarenner@mgakc.org">tanyarenner@mgakc.org</a> or (816) 256-4100</td>
</tr>
<tr>
<td><strong>St. Louis</strong></td>
<td>March 2nd</td>
<td>10am -</td>
<td>Glendale City Hall</td>
</tr>
<tr>
<td></td>
<td>June 8th</td>
<td>11:30am</td>
<td>424 Sappington Road</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>St. Louis, MO 63122</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td><a href="mailto:tanyarenner@mgakc.org">tanyarenner@mgakc.org</a> or 816-256-4100</td>
</tr>
<tr>
<td><strong>Wichita, KS</strong></td>
<td>March 2nd</td>
<td>11-1pm</td>
<td>Via Christi St. Francis Hospital</td>
</tr>
<tr>
<td></td>
<td>April 6th</td>
<td></td>
<td>929 N. St. Francis St.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Wichita, KS 67214</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Contact: Dana or Larry Paxson for more info or to RSVP</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td><a href="mailto:dkptiffany@gmail.com">dkptiffany@gmail.com</a> or (316) 269-9120</td>
</tr>
<tr>
<td><strong>Young Persons</strong></td>
<td>February 12th</td>
<td>6pm</td>
<td>Minsky’s Pizza</td>
</tr>
<tr>
<td>with MG Group</td>
<td></td>
<td></td>
<td>427 Main Street</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Kansas City, MO 64105</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>RSVP <a href="mailto:allisonfoss@mgakc.org">allisonfoss@mgakc.org</a></td>
</tr>
<tr>
<td><strong>Omaha, NE</strong></td>
<td>March 9th</td>
<td>10am-noon</td>
<td>Calvary Lutheran Church</td>
</tr>
<tr>
<td></td>
<td>April 13th</td>
<td></td>
<td>2941 N 80th St, Omaha, NE 68134</td>
</tr>
<tr>
<td></td>
<td>May 11th</td>
<td></td>
<td>Contact: Dianna McCarty for info or to RSVP</td>
</tr>
<tr>
<td></td>
<td>June 8th</td>
<td></td>
<td><a href="mailto:dmccarty@abbnebraska.com">dmccarty@abbnebraska.com</a> or (402)426-8006 or Kathy Cassidy</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td><a href="mailto:cassidykathryn@yahoo.com">cassidykathryn@yahoo.com</a> or 402-719-5861</td>
</tr>
<tr>
<td><strong>Northwest, AR</strong></td>
<td>March 10th</td>
<td>2:30-4:30pm</td>
<td>Schmieding Center for Senior Health and Education</td>
</tr>
<tr>
<td></td>
<td>May 19th</td>
<td></td>
<td>2422 N. Thompson (Hwy 71 North)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Springdale, AR 72764</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Contact: Roger Huff for more info or to RSVP</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td><a href="mailto:jrhuff1@cox.net">jrhuff1@cox.net</a> or (479) 790-3022</td>
</tr>
</tbody>
</table>
Chronic Illness and Depression

For millions of people, chronic illnesses and depression are facts of life. Many people with these illnesses become depressed. In fact, depression is one of the most common complications of chronic illness. It's estimated that up to one-third of people with a serious medical condition have symptoms of depression.

It's not hard to see the cause and effect relationship between chronic illness and depression. Serious illness can cause tremendous life changes and limit your mobility and independence. A chronic illness can make it impossible to do the things you enjoy, and it can eat away at your self-confidence and a sense of hope in the future. No surprise, then, that people with chronic illness often feel despair and sadness. In some cases, the physical effects of the condition itself or the side effects of medication lead to depression, too.

Depression caused by chronic disease often makes the condition worse, especially if the illness causes pain and fatigue or it limits a person's ability to interact with others. Depression can intensify pain, as well as fatigue and sluggishness. The combination of chronic illness and depression might lead you to isolate yourself, which is likely to make the depression even worse.

Depression is treated much the same way for someone who is chronically ill as someone who isn't. Early diagnosis and treatment can ease distress along with the risk of complications and suicide. Many times, depression treatment can improve your overall medical condition, a better quality of life, and a greater likelihood of sticking to a long-term treatment plan.

When depressive symptoms are related to the physical illness or the side effects of medication, your doctor may need to adjust or change your treatment. When the depression is a separate problem, it can be treated on its own. More than 80% of people with depression can be treated successfully with medicine, psychotherapy, or a combination of both. Antidepressant drugs usually take effect within a matter of weeks. You should work closely with your doctor or psychiatrist to find the most effective medication.

Tips for Living With a Chronic Illness

Depression, disability, and chronic illness form a vicious cycle. Chronic medical conditions can bring on bouts of depression, which, in turn get in the way of successful treatment of the disease.

Living with a chronic illness is a challenge, and it's normal to feel grief and sadness as you come to grips with your condition and its implications. If these feelings don't go away, or you are having trouble sleeping or eating, or you've lost interest in the activities you normally enjoy, seek help.

To avoid depression:

- Try not to isolate yourself. Reach out to family and friends. If you don’t have a solid support system, take steps to build one. Ask your doctor or therapist about support groups and other community resources.
- Learn as much as you can about your condition. Knowledge is power when it comes to getting the best treatment available and keeping your sense of independence and control.
- Make sure that you have medical support from experts you trust and can talk to openly about your ongoing questions and concerns.
- If you suspect that your medication is bringing you down, talk to your doctor about other possible treatments.
- As much as is possible, keep doing the things you like to do. You’ll stay connected as well as boost your self-confidence and sense of community.

If you think you're depressed, don't wait to get help. Find a therapist or counselor you trust.

Excerpt taken from WebMD
Behind the Scenes: Living with MG
Written by Meridith O’Connor

Lights, camera, action! It was a pretty surreal moment, sitting across from the reporter in my apartment, interviewing me about my experience living with MG. A local TV station stumbled upon one of the articles I wrote for The Mighty, an online publication dedicated to creating awareness around disability, disease, and mental illness, and believed that my experience could have a positive impact on their viewing audience.

When I was first diagnosed, I could barely utter the words “Myasthenia Gravis” without erupting into a cry. Over the past 15 years I had to gain the strength to be my own advocate, and with that, I am now able to share my story with thousands of people. It has taken me a long time to get where I am today and I will continue to use my platform so that others who are experiencing things similar to me can feel supported and advocated for.

I know for many it is difficult to talk about having a chronic illness, and I get that. It is a vulnerable state to place yourself in, and you are risking your truth with the hope that others accept, support, and believe you. For me, I always felt alone in this disease. I was diagnosed at the age of 13 and there was really no one my age or in my community who had this rare disease. I had two choices; to hide this illness or to reveal it, and at times I did both. But then I had to ask myself, “How do I expect people to understand what I go through without letting them in?”

Surround yourself with people who are willing to support you. Trust me, I’m stubborn when it comes to asking others for help, and I’d rather push through and do things myself. I despise feeling like a burden. Yet, there are times when pushing through just simply isn’t an option, and that’s okay. The people that see you for you and not your disease are the people that you want on your side. Let them in.

Cheers to a new year filled with greater awareness, exciting opportunities, and compassionate people. Stay warm, friends!

About the Author: Meridith O’Connor is a patient in our St. Louis group who recently graduated the Brown School at Washington University in St. Louis with a Masters Degree in Social Work with a concentration in healthcare. Meridith was diagnosed with MG in 2005 and regularly writes for The Mighty.

Save the Date for the 2019 Annual Meeting 11/9/2019
Updates provided by Richard Barohn, MD at the University of Kansas

On December 10, 2018, Pharmaceutical Company Ra Pharma announced the results of their phase 2 drug study of a subcutaneous injectable complement inhibitor for MG showed effectiveness. The drug now needs to enter a final phase 3 trial phase and of the results hold up the hope is this drug will be approved by the FDA for MG patients. Additionally in 2018, Soliris was approved for MG. Soliris is an intravenous complement inhibitor that was shown in research studies to also be of benefit to MG patients. Soliris is given every two weeks through an IV. The new research drug by Ra-Pharma is self injected under the skin like an insulin injection. The University of Kansas Medical Center MG Clinic was a site for both drug studies.

A pill called Fridapse was just approved by the FDA for the treatment of a disease related to MG called the Lambert Eaton Syndrome. This is a disease somewhat similar to MG but the immune attack is in the nerve endings whereas in MG the immune attack is in the muscle the drug Fridapse was shown to improve the strength in Lambert Eaton Syndrome patients. The University of Kansas Medical Center was also a site for this research study.

Patients with MG who are male or obese more likely to experience obstructive sleep apnea

(Article taken from January 2019 edition of Myasthenia Gravis News)

Among myasthenia gravis patients (MG), males and those with a higher body mass index are at a higher risk of obstructive sleep apnea, which is similar to what has been reported in the general population, a study shows.

The study, “Characteristics of obstructive sleep apnea in myasthenia gravis patients: a single center study,” was published in the journal Neurological Sciences.

Obstructive sleep apnea is a condition that causes breathing to repeatedly stop and start during sleep due to the throat muscles intermittently relaxing and blocking the airways.

As a result, people with obstructive sleep apnea often experience daytime sleepiness, but the condition is also linked to cardiovascular problems and metabolic dysfunctions.

Recent studies have shown that, compared with the general population, MG patients have a higher prevalence of obstructive sleep apnea, estimated to affect 36-64 percent of them.

However, only a few studies have investigated the association of obstructive sleep apnea and MG.

To address this, a group of researchers in South Korea studied 18 patients diagnosed with stable MG, of whom seven had obstructive sleep apnea and 11 did not.

They looked at patients’ medical records to obtain information on several clinical parameters, namely sex, age, duration of the disease, prescribed medications, and whether they had undergone surgical removal of the thymus (thymectomy), as well as if they were positive for antibodies against the acetylcholine receptor (AChR) and muscle-specific tyrosine kinase (MuSK).

Researchers also calculated the participants’ body mass index (BMI) — a measure of body fat — and assessed their pulmonary function.

All participants underwent an overnight polysomnography test, which is used to diagnose sleep disorders.

Results showed that MG patients with obstructive sleep apnea were most often male and had an increased BMI, both of which were identified as statistically significant factors for obstructive sleep apnea.

“Several studies have reported male sex and BMI as independent risk factors for OSA in the normal population,” the researchers wrote.

Moreover, the sleep analysis revealed that the severity of the sleep apnea, measured with the Apnea-Hypopnea Under (AHI), was 11 times higher in MG patients with obstructive sleep apnea, specifically for those with supine-sleep apnea, which occurs when the person is lying face up on his or her back.

“This study showed that the occurrence of OSA [obstructive sleep apnea] in patients with MG is associated with male sex and obesity, which is in accordance with the normal population,” the researchers wrote.

“Supine dominant OSA was more frequently observed in MG with OSA,” they added, indicating that “proper treatment strategies for OSA in MG may be applied based on our results, that may eventually lead to better quality of sleep in stable MG patients.”
Please join us on February 19th at 7pm at Chicken N Pickle, North Kansas as we are a beneficiary Barstool Sessions put on by Team Cocktail. This is a Nashville style songwriters story round featuring Chad Vaughn, Chris Stewart and Noe Palma. The music and entertainment start at 7pm. A $10 donation for entry is requested. For more information you can check our website at www.mgakc or https://www.facebook.com/events/394826237957261/

2018 IMPACT

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

Support Groups
- 37 Support Groups
- In 8 different cities across MO, KS & AR
- 632 Total Attendees

The MGA reached 92% of those living with myasthenia gravis in the KC Metro in 2018.

At the MGA’s MG Clinics at KUMC and St. Luke’s

A MGA representative meets with every MG patient to:
- Let patient ask questions, receive educational materials and learn links to community resources.
- Opportunity to learn coping skills, wellness techniques and healthy lifestyle tips.

Public Awareness and Education
- Over 84 patient packets provided to those newly diagnosed.
- 82 attendees at the Annual Meeting
- 1541 MG Connections Newsletters mailed to patients, caregivers and medical professionals
- 700+ attending MGA Triple Crown Showdown 5K & MGA Snowflake Shuffle 0.1K

100% of the MGA’s programs are FREE
In Memoriam

Jacob McGuire, DDS  
Belton, MO  
Amy and Mike Brown  
Lynda and Perry Gough  
Tiffany Tavares  
Dr. Michael Moosy  
Jeffrey Dawson  
Bobbie and Linda Voris  
Melisa Ferrari  
Eileen Cox  
Lorraine Brockmann  
Kevin and Renee Kramer  
Gerry and Melanie Beck  
Pamela and Steve Overman  
Keith and Shari Clough  
Shara Dunlap  
David and Julie Hamilton  
Edward Foster  
Nita and Roger Ankrom  
Billy and Vicky Thompson  
The Scheib Family  
Craig and Nancy Whitt  
Donnie and Susie Wilson  
David Kaster

Roy Whittaker  
St. Joseph, MO  
Rick and Monica Mills  
Kansas City MG Car Club  
St. Joseph Retired Chapter MONGA  
Mary Beth and Lorin O’Daniell  
Bill Wright  
Mechela and Dan Humphreys  
Rose Wilkerson  
Joe and Ann Heil  
Doug and Cheryl Newham  
Mary Revels  
Roseanne and Nicholas Smith  
Stacy and Dustin Hung  
David Jordan  
Patricia Elder

Margaret Anderson  
Winfield, KS  
William and Dorothy Bernard  
Edward Foster

Deborah Anderson  
Kansas City, KS  
Sandra Craig  
Mary Brelsford  
Tajh Fletcher

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.

The MGA is trying to go green! You may have gotten a call recently about providing your email address or updating your email address with us! Please help us go green and call Tanya Renner, Program Coordinator back at 816-256-4100 or send her an email with your correct email address-
tanyarenner@mgakc.org

@mgakc
@myastheniakc
@mga_heartland
How sweet it is
For those of us living with myasthenia gravis, it’s safe to say we know it isn’t all truffles, bonbons and chocolates. But for Jessica Antunes, who has battled myasthenia gravis since 2003, truffles are a huge part of her life. Here’s her story.

In 1996, Jessica and her sister came to the Kansas City area from Brazil to attend school. Their parents joined them in 1998 so they could be together as a family. And for as long as she can remember, Jessica has dreamed of owning her own business.

This is where the truffles come in. A traditional artisan truffle of Brazil is called a Brigadeiro. Jessica recalls pictures of her first birthday eating Brigadeiro. While at work one day in 2014, Jessica called her mom and shared her idea to start a business making Brigadeiro. And so they embarked on an adventure and opportunity to cook up something that provides a “taste” of Brazilian culture and literally melts in your mouth.

A lot of brainstorming took place to find a name for their Brigadeiro-making business. The ultimate winner ended up being Sweet Kiss Brigadeiro because, as Jessica’s mom says, their Brigadeiro are as sweet as a good kiss!

Jessica never expected their Brigadeiro business to be what it is today. Thankfully, she has been able to keep her myasthenia gravis at bay by treating it with mestinon as needed, which is good news because busy times of year mean it’s all hands on deck for Jessica’s family to craft the Brigadeiro. From working shows, to packing boxes and shipping, you can often find Jessica’s sister, father and fiancée working alongside her and her mom to fill orders. A side business for now, they hope to continue to grow their small business and possibly have a physical location some day.

Jessica says the best part of being in the Brigadeiro business is being able to share part of Brazilian culture with customers. A fun fact about Sweet Kiss Brigadeiro is they have been providing a box of Brigadeiro to the winner of the MGA Triple Crown Showdown for the last five years! For more information or to get your hands on some of these mouthwatering tasty treats, go to http://www.sweetkissbrigadeiro.com.

Every day may not be good, but there is something good in every day
Myasthenia Gravis is one of the 6000 conditions represented on Rare Disease Day. The 12th edition of Rare Disease Day will take place on February 28, 2019. The purpose of Rare Disease Day is for better coordinated health and social care help the more than 300 million people living with a rare disease and their families to face everyday challenges. Help raise awareness of Rare Disease Day by using the #showyourrare hashtag on social media. By focusing on bridging the gap between health and social care, Rare Disease Day 2019 is an opportunity to call for the improved and continuous coordination of all health, social and community care services to ensure these services are effective, accessible and serve the best interest of rare disease patients worldwide.

The MGFA (Myasthenia Gravis Foundation of America) continues their quest to build an MG Patient Registry. Have you registered? Register today at www.mgregistry.org.

Thank you to all who attended our Gratitude and Giving Yoga Event at Athleta and helped us raise $550. Special thanks to Athleta for hosting and Sarah Uchytil for teaching Yoga!
2019 membership/fundraising drive

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!

Please become a 2019 member & receive a tax deduction!

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!

https://www.firstgiving.com/event/mgakc/2019-Membership-Drive
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
Phone: (816) 256-4100
Email: info@mgakc.org
www.mgakc.org
www.mga5k.com