

Inaugural Reel in MG Fishing Derby nets awareness

On a sunny, crisp fall day patients, their families and providers enjoyed a day of fishing and good eats at the home of Mark Macias and Greta Rice, St. Louis Members. The Inaugural Reel in MG proved to be the perfect combination of fall festivities, fellowship and fishing. Luckily, the fish were biting for the kids derby. Tougher luck for the adults! Mark made fishing poles for the winners in each category as well as participants enjoyed raffles including an iPad Pro! A huge thanks to our sponsors, as well as the Yokota Foundation for making this event possible. Thank you Mark and Greta for hosting us as well as Tina and John Warren for their event execution! We are already looking forward to the 2nd Annual Reel in MG.



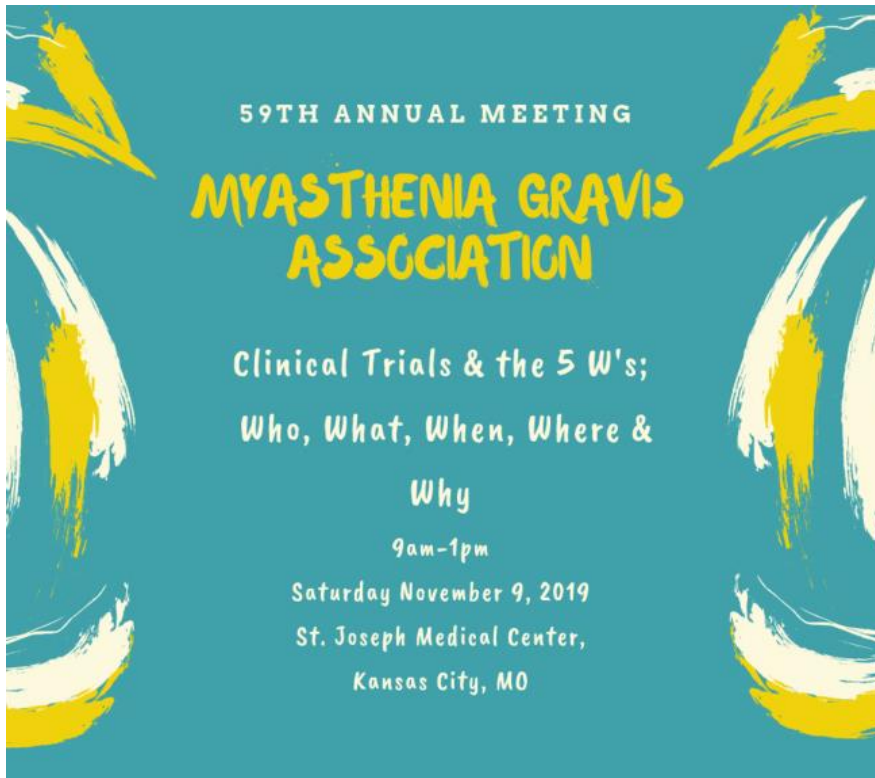
Snowflake Shufflers shuffle for a cure in Wichita

The ever so mighty Wichita support group gathered on Saturday, October 19th for their annual MGA Snowflake Shuffle 0.1K. Complete with BBQ, raffles, selfies, with walking optional. New this year, patients and their families enjoyed interacting with vendors, having kids activities and face painting! A huge thank you to our sponsors and Wichita Support Group Coordinators, Dana and Larry Paxson who have made this event possible!



THANK YOU TO OUR SPONSORS:





Panel featuring



Angela Pontius
Ra Pharma



Mamatha Pasnoor, M.D.
University of Kansas Medical
Center



Meredith Martin
Patient

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59th Annual Meeting

Saturday November 9, 2019

St. Joseph Medical Center

1000 Carondelet Drive, Kansas City,
MO 64114

Community Center, Building D

Agenda

9:00 Registration & breakfast

9:30 Opening remarks, Awards
& MGA updates

10:15 Keynote: Clinical Trials
Panel

11:15 Questions

11:45 Wrap Up

12:00 Luncheon and Raffles

RSVP to Tanya Renner

tanyarenner@mgakc.org or 816-256-
4100

by November 1st, 2019

In your RSVP please note if you will
join us for lunch.

Lodging

Lodging is available at the
Holiday Inn– Overland Park.

[www.holidayinn.com/
overlandprkks](http://www.holidayinn.com/overlandprkks) group code:

MGA

or 913-312-0900 and ask for
the

Myasthenia Gravis Association
group block rate.

A MESSAGE FROM THE MGA'S EXECUTIVE DIRECTOR

A few weeks ago, I celebrated the start of a new decade for me. In about 2 months, we will *all* enter a new decade. As the ball drops on New Year's Eve, it signifies the 60th birthday of the Myasthenia Gravis Association. We've got a whole lot of fun, storytelling and celebration in store for 2020, and we can't wait to share it with you! Be sure to mark June 18, 2020, on your calendar because we are going to be saying, "Cheers to 60 Years!" No matter the circumstances, we are glad our paths have crossed and you are in our story. New decades, new years and milestone celebrations also bare questions and bring to light a time of great reflection. What are your goals? Who do you want to be when you grow up? Are you getting the most out of your community? Are you getting the most out of your health? Are you satisfied with your life? Each decade tells a story. The real question is: what will your story be?



Allison Foss, Executive Director

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BENEFITTING THE
MYASTHENIA GRAVIS
ASSOCIATION

*Holiday Self
Care Yoga*

Sunday December 8, 2019
10:30-11:30am
Maya Yoga
215 W. 18th Street #200
Kansas City, MO 64108
To register go to www.mgakc.org
This is a donation based class.






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New bio marker for MG identified

University of Alberta researchers have identified a unique biological marker that can be used to identify the presence of the rare autoimmune disease myasthenia gravis, predict the course of the disease and identify new, personalized treatments.

In a study published in the journal *Metabolomics*, neurologist Zaeem Siddiqi, graduate student Derrick Blackmore and their team used metabolic analysis of serum (blood with all cells removed) to find a unique pattern of metabolites -- products of the body's metabolic processes such as amino acids, vitamins or antioxidants -- that is specific to myasthenia gravis.

Siddiqi and his team first compared the serum of patients with myasthenia gravis to a healthy control group. They then performed a comparison of serum from myasthenia patients to serum from rheumatoid arthritis, another autoimmune disease. After identifying more than 10,000 compounds in the serum samples, they found a unique pattern of 12 metabolites exclusive to patients with myasthenia gravis.

"This is really important because now we have a way to easily separate a patient with myasthenia gravis from someone with rheumatoid arthritis or another autoimmune disease," said Siddiqi, a member of the U of A's Women's and Children's Health Research Institute and the Neuroscience and Mental Health Institute.

"What's more, now we're able to explore how those 12 metabolites change in mild, moderate or severe cases so we can make this biomarker more robust and more effective for predicting the course of the disease and developing treatment plans."

The results highlight the potential metabolomic profiling has in identifying disease biomarkers.

"Right now we don't have the ability to manage myasthenia gravis in a more specific way; we treat all patients the same," said Siddiqi.

"Now we have a unique fingerprint or map of metabolites that can easily separate healthy individuals from those with myasthenia gravis, and a path to the discovery of more accurate and specific treatments."

Biomarkers are useful in managing diseases because they not only help in early diagnosis of a disease, but can also help outline its severity, predict the course and expected outcomes, and indicate what treatments would be the most effective.

"Biomarker discovery is an important step in individualized medicine," said Siddiqi.

According to Siddiqi, current methods for diagnosing myasthenia gravis only tell physicians whether or not a patient has the disease. There are no other biomarkers that can reliably predict the course of myasthenia gravis in a patient, or the best therapeutic response. Although there is no known cure, there are treatments for the disease that can manage the symptoms throughout the rest of the patient's life. Even so, because myasthenia gravis is so rare, treatments can be extremely expensive, hard to find and not tailored to the patient, Siddiqi said.

"Finding the antibodies is good for diagnosis, but they do not tell us how the patient will react to a specific drug or which drug will be most effective," Siddiqi said. "What we're trying to do with this biomarker discovery is develop treatments specific to the needs of the patient, to have more precise management and to be able to more accurately predict the effects of the treatments."

Siddiqi is hoping to soon expand the team's research by examining patients at different stages of the disease to get a more precise picture of how each stage affects the metabolites, and make their biomarker more robust.

Article published in the Journal of Clinical Neurology, July 2019

Registration will
open on January
1, 2020 for the
10th Annual MGA
Triple Crown
Showdown! You
won't want to
miss it!
www.mga5k.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.



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.



THANK YOU FOR HELPING US RAISE
OVER \$35,000 @ OUR 3RD ANNUAL
CY'S CROWN TOWN TRIVIA NIGHT!

Help available through Kansas City's Medicine Cabinet

Long-time residents of the Kansas City region will no doubt remember Baptist Medical Center in Brookside and Trinity Lutheran Hospital in Midtown. Although the hospitals closed in the early 2000s, Baptist-Trinity Lutheran Legacy Foundation (BTLLF) continues their tradition of meeting the region's healthcare needs.



KANSAS CITY'S
MEDICINE
CABINET

Since 2005, BTLLF has operated Kansas City's Medicine Cabinet (KCMC), a program that helps our neighbors in need to access specific healthcare services. For eligible individuals, KCMC covers the entire cost of dental emergencies (fillings and extractions), diabetic supplies, durable medical goods (including hearing aids), prescription medications, and vision exams and eyeglasses.

In 2018, KCMC provided 3,381 services totaling \$1.06 million to individual throughout our region. As a direct result, more than 3,000 uninsured and underinsured people were not forced to choose between paying rent or buying medicine. KCMC is here to help!

How does the program work?

The program partners with non-profit social services agencies that screen for eligibility and issue vouchers, which are redeemed at local vendor partners. The vendors invoice KCMC for payment, so there are no receipts for clients to send in or forms to fill out. To ensure the program is convenient and accessible to as many area residents in need as possible, the 16 partner agencies have a combined 29 intake sites in Kansas and Missouri. KCMC also serves survivors at six domestic violence shelters and clients of Cancer Action. In addition, there are nearly 100 vendor locations, with options on both sides of the state line.

Am I eligible?

Kansas City's Medicine Cabinet helps people with financial challenges fill short-term medical needs. To qualify, an individual must provide proof of household income of up to 200% of the Federal Poverty Level for the past 30 days. For someone living alone, the maximum monthly income for 2019 is \$2,082; for a two-person household the maximum is \$2,818.

Individuals seeking assistance must also provide photo identification, proof of address for the past 30 days, and a Social Security card or Individual Taxpayer Identification Number (ITIN) Card for each member of their household.

What else should I bring with me?

If you have a drug prescription or a medical order for a nutritional supplement, equipment or other item, bring it to the non-profit with you. If you think you might need glasses, you do not need to get an eye exam in advance, as the program covers the cost for a complete eye exam at a participating vendor.

What else do I need to know?

Over an individual's lifetime, KCMC can provide up to \$1,800 in assistance. While clients may get help on just one day in a 12-month period, it is possible to get multiple vouchers in a single visit. So, if you need prescriptions and an eye exam and glasses, you can get both.

How can I learn more?

To learn more about Kansas City's Medicine Cabinet or to find a convenient non-profit partner, visit www.kcmedicinecabinet.org or call (816) 276 7517.

Q & A with Kimberlee Fields

Kimberlee Fields is a new therapist with JS Therapy Group in Leavenworth, KS. She is also a patient. We caught up with Kimberlee recently to hear about her journey. To connect with Kimberlee you can reach her at Kimberlee@jstherapygroup.com

When were you diagnosed with MG?

I started experiencing my symptoms (droopy eyelids, weak smile, speech slurring) in September 2014, but I did not receive the official diagnosis until January 2015.

How has MG affected you?

My MG has completely shifted my life. Having a rare disease comes with challenges that I never thought to expect. The experiences that I have had have taught me to advocate for myself. 2015 was by far the hardest year of my life. This year I got a tattoo to represent that time. It is a reminder to myself that I am an overcomer. If I got through that, then I can do anything. My MG has made me strong.

When did you decide to become a therapist?

I have known that I wanted to be a therapist since I was in high school, but I didn't find my field until my junior year of undergrad. There are several areas that fall under "Mental Health," that it was almost overwhelming. It wasn't until my Psychology as Profession class, that I found Marriage and Family Therapy. It was kind of over from there.

Do you think your MG played any part in your career?

I would say so. In the beginning stages of my journey with MG I didn't feel like I had a voice, which lead to me feeling lost. I know what it's like to feel powerless in my own life, because of MG. My goal when it comes to being someone's therapist is to help my clients find their voice again; helping them regain their power.

What's your advice to somebody like yourself, living with a chronic illness and working full time?

My advice is to give yourself grace and practice self-care. I was pretty stubborn when it came to pushing myself passed my limits. Taking a break wasn't part of my narrative. Eventually I realized that breaks are the only way I can succeed. MG forced me to become attuned to my body. I do my best to rest when I know I need to, not get overly stressed about life, and becoming more comfortable with saying "no." I'm still working on it though :).

Anything else you'd like to add?

I don't want my answers to seem like I'm dismissing the struggles that come with MG, because this thing is hard. I've had four crises between 2015-2017, fallen more times than I can count, and have cried enough tears to fill a pool. I just want whoever reads this to know that they are stronger than they think. Having MG doesn't define us. It is simply one part of our story. It's up to us to decide what we want to do with it.



Young Persons with MG Group forming in St. Louis

Are you a young person living with myasthenia gravis in the St. Louis area? Do you like to have fun and connect with other like minded people? If this is you please join us for our Inaugural Young Persons with MG Group on Thursday December 12th at Westport Social in Maryland Heights beginning at 6pm. Dutch treat. Feel free to bring a friend or family member. Please RSVP to Allison Foss allisonfoss@mgakc.org.



MG Support Groups

Area	Dates	Time	Location
Kansas City, MO	December 7th	10am-12:00pm	St. Joseph Medical Center ~ Community Center 1000 Carondelet Drive Kansas City, MO 64114 RSVP tanyarenner@mgakc.org or (816) 256-4100
KC Northland	January 2020	noon-1:30pm	Primrose Retirement Communities 8559 N Line Creek Pkwy Kansas City, MO 64151 RSVP tanyarenner@mgakc.org or (816) 256-4100
Mid-Missouri Columbia, MO	December 5th	6:30-8pm	Services for Independent Living– note location change 1401 Hathman Place Columbia, MO 65201 RSVP to tanyarenner@mgakc.org or (816) 256-4100
Springfield, MO	January 30th 2020	6-8pm	The Library Center 4653 S. Campbell Springfield, MO 65810 RSVP tanyarenner@mgakc.org or (816) 256-4100
St. Louis	December 14th	10am - 11:30am	Glendale Lutheran Church– note location change 1365 N. Sappington Road St. Louis, MO 63122 tanyarenner@mgakc.org or 816-256-4100
Wichita, KS	December 14th	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	December 3rd	6pm	The Boardroom– Overland Park 8725 Metcalf Overland Park, KS 66212 RSVP to Allison Foss allisonfoss@mgakc.org
Young Persons with MG Group-STL	December 12th	6pm	Westport Social 910 Westport Plaza Drive Maryland Heights, MO RSVP to Allison Foss allisonfoss@mgakc.org
Northwest, AR	November 2nd Annual Conference	10am-12:00pm	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 jrhuffl@cox.net or (479) 790-3022

Northwest Arkansas Annual Conference happening soon

Join our Northwest Arkansas Support Group for their Annual Conference on Saturday November 2nd from 10-12 at the Schmieding Center for Senior Health and Education. Richard Barohn, MD, University of Kansas will speak on MG Treatments and Updates Today. Dr. Barohn has given this presentation in both St. Louis and Kansas and it's one you don't want to miss. Please RSVP to Roger and Jan Huff, jrhufl1@cox.net.

Stress, holidays and MG

Contrary to popular belief, the holidays are often not the happiest time of year. The holidays can churn up not only financial stress but family stress which can only make your MG worse. The Mayo Clinic has provided these tips for surviving the holidays!

Tips to prevent holiday stress and depression

When stress is at its peak, it's hard to stop and regroup. Try to prevent stress and depression in the first place, especially if the holidays have taken an emotional toll on you in the past.

Acknowledge your feelings. If someone close to you has recently died or you can't be with loved ones, realize that it's normal to feel sadness and grief. It's OK to take time to cry or express your feelings. You can't force yourself to be happy just because it's the holiday season.

Reach out. If you feel lonely or isolated, seek out community, religious or other social events. They can offer support and companionship. Volunteering your time to help others also is a good way to lift your spirits and broaden your friendships.

Be realistic. The holidays don't have to be perfect or just like last year. As families change and grow, traditions and rituals often change as well. Choose a few to hold on to, and be open to creating new ones. For example, if your adult children can't come to your house, find new ways to celebrate together, such as sharing pictures, emails or videos.

Set aside differences. Try to accept family members and friends as they are, even if they don't live up to all of your expectations. Set aside grievances until a more appropriate time for discussion. And be understanding if others get upset or distressed when something goes awry. Chances are they're feeling the effects of holiday stress and depression, too.

Stick to a budget. Before you go gift and food shopping, decide how much money you can afford to spend. Then stick to your budget. Don't try to buy happiness with an avalanche of gifts.

Try these alternatives:

- Donate to a charity in someone's name.
- Give homemade gifts.
- Start a family gift exchange.

Plan ahead. Set aside specific days for shopping, baking, visiting friends and other activities. Plan your menus

and then make your shopping list. That'll help prevent last-minute scrambling to buy forgotten ingredients. And make sure to line up help for party prep and cleanup.

Learn to say no. Saying yes when you should say no can leave you feeling resentful and overwhelmed. Friends and colleagues will understand if you can't participate in every project or activity. If it's not possible to say no when your boss asks you to work overtime, try to remove something else from your agenda to make up for the lost time.

Don't abandon healthy habits. Don't let the holidays become a free-for-all. Overindulgence only adds to your stress and guilt.

Try these suggestions:

Have a healthy snack before holiday parties so that you don't go overboard on sweets, cheese or drinks.

Get plenty of sleep.

Incorporate regular physical activity into each day.

Take a breather. Make some time for yourself. Spending just 15 minutes alone, without distractions, may refresh you enough to handle everything you need to do. Find something that reduces stress by clearing your mind, slowing your breathing and restoring inner calm.

Some options may include:

- Taking a walk at night and stargazing.
- Listening to soothing music.
- Getting a massage.
- Reading a book.

Seek professional help if you need it. Despite your best efforts, you may find yourself feeling persistently sad or anxious, plagued by physical complaints, unable to sleep, irritable and hopeless, and unable to face routine chores. If these feelings last for a while, talk to your doctor or a mental health professional.

Take control of the holidays

Don't let the holidays become something you dread. Instead, take steps to prevent the stress and depression that can descend during the holidays. Learn to recognize your holiday triggers, such as financial pressures or personal demands, so you can combat them before they lead to a meltdown. With a little planning and some positive thinking, you can find peace and joy during the holidays.



2019 Membership Drive

Donald and Eleanor Ferguson
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In Memoriam

Jack O'Benar



The MGA can now
accept donations via
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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

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.



Please become a 2019 member!

PLEASE PRINT

Cut & enclose in envelope & mail to: →

Name _____

Address _____ City _____ State _____ Zip _____

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

PLEASE CHECK:

- ☐ MG Patient
- ☐ Relative
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Thank You!

Make checks payable to the
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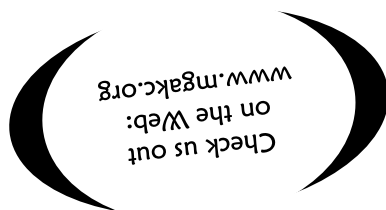
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www.mgakc.org
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The Mission of the MGA
 The Myasthenia Gravis Association (MGA) is dedicated to improving the quality of life for those who are affected by this autoimmune, neuromuscular disease, through 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
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Strength and Hope through Connections