

## 60th Annual Meeting of the MGA Goes Virtual

While we are sad we cannot gather in person, we are excited to announce we will be offering our 60th Annual Meeting virtually! Join us from the comfort of your own homes on Saturday, November 7th, 2020, from 8:30 am-12:00 pm as we come together and learn about all the latest updates regarding MG. If you've never had the chance to attend our Annual Meeting before, we invite you to take this opportunity to receive education on all things MG and receive an update on our organization. As disappointed as we are about not being able to hold this significant event in person, the silver lining is that we are able to extend this meeting to a wider audience across Kansas, Missouri and NW Arkansas.



In tune with 2020, the keynote for the meeting will be a presentation titled, "Calm Through the Storm" by Sally King, Licensed Clinical Social Worker in the field of community and emergency mental health needs with adults. Sally has provided outreach, education, and project management on behalf of the KU Alzheimer's Disease Center and Landon Center on Aging, and specializes in older adult mental health, end of life social work, and lifestyle intervention coaching to decrease risk for depression at any age.

This year's meeting will also include an update on COVID-19. We feel it is appropriate and necessary to provide this information to our stakeholders and believe it is our duty to keep our MG community informed. The MGA is fortunate to have this report presented by Constantine Farmakidis, MD, Assistant Professor of Neurology at the University of Kansas Medical Center. Dr. Farmakidis will share his knowledge and expertise on where we are today with COVID-19 and how it factors into MG. This will be a useful session not only for patients but for family members and providers as well.



These educational sessions are free to attend thanks to the generosity of many sponsors including Argenx, ARJ Infusion Services, Catalyst, Alexion, Momenta, UCB and Immunovant. This year continues to be a lively time with drug development for the treatment of MG, therefore we will also hear from our sponsors on their latest research in the MG space.

If you would like to attend the Annual Meeting you will need to RSVP to Tanya Renner (tanyarenner@mgakc.org) or 816-256-4100. Zoom links and instructions will be sent prior to the meeting. If you are unfamiliar with Zoom, Tanya is able to set aside some time with you to walk you through the process. All attendees will also receive their Annual Meeting packet in advance of the meeting so you are able to follow along with a booklet in front of you!



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## A MESSAGE FROM THE MGA'S EXECUTIVE DIRECTOR

How you doin'? Remember that famous line from Joey in *Friends* in the late 90s? How many times a day do we ask somebody how they are doing? Do you wait for a response or are your ears on auto-pilot? Do you give an honest answer when somebody asks you that or do you have a common phrase you let roll out?

Today and every day at the MGA, we truly want to know, how ARE you doing? 2020 came in like a lion and it's still out there roaring around, displacing things. We know this year has not been easy for many. Add in MG and other chronic illnesses and the answer to "how are you doing?" can cause a lump in your throat and tears welling around your eyes. While we haven't been able to gather as much in person and offer our support and hand, we are still here and we want to support you as best we can. You'll notice we are starting to bring back small in-person groups and if you are comfortable and able, we hope you'll join us. If you are somebody who prefers to remain virtually connected, we hope you'll join us online. If neither is a comfortable option for you with all you've got on your plate, feel free to email us, message us, call us, text us (816-408-3000) for support.

The mission of the MGA is to work to improve the lives of those who are impacted by myasthenia gravis. We want to hear how you are doing. Drop us a line. We are listening. How you doin'?

Allison Foss, Executive Director  
allisonfoss@mgakc.org



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## MGA Mourns the Loss of One of its Own

Ray Olsen was a staple at MGA support groups and events over the past several decades. Ray served on the MGA Board of Directors for over 15 years during his retirement in addition to serving on the board of Crosslines in Kansas City, KS, all while he courageously battled MG and Parkinson's disease.



On August 19th, Ray succumbed to his battle at the KC Hospice House. Ray was instrumental in sharing his worldly experiences and welcoming new patients. The MGA is grateful for Ray's service and support and is thinking of his family during this difficult time.

### Ways to Support the MGA



## COVID-19 and Myasthenia Gravis: What have we learned so far in 2020?

*Written by Constantine Farmakidis, MD, Assistant Professor of Neurology at the University of Kansas Medical Center*



First a local update from our group: thus far we have not seen COVID-19 have a disproportionate negative impact in the myasthenia gravis patients followed in our university neuromuscular practice. In fact, as part of a different project I have reviewed our charts from the pandemic period and I don't believe we have had a case of COVID-19 in our myasthenia patient population. Of course, the size of our group of patients is not large enough to draw conclusions, but I cite this information to provide a frame of reference to local leaders.

So, what have we learned so far about MG and COVID-19 in 2020? Specifically, what have we learned beyond expert opinion published in the spring that was not yet based on clinical experience. The main source of information thus far is published cases in medical journals. Let's review some of these cases together and see what we can glean from them? Then I will answer some Frequently Asked Questions about COVID-19 and MG and finally invite you to join us for the annual Myasthenia Gravis Association meeting on November 7<sup>th</sup>, 2020 where I look forward to talking about and answering questions on this very topic.

### Case Report 1

Dr. Elif Aksoy of Istanbul, Turkey and colleagues published a case report in August 2020 in the journal *Case Reports in Infectious Diseases*. The authors reported a 46-year-old woman with acetylcholine-receptor antibody positive MG (also known as the AChR antibody). After a thymectomy in 2016, the patient had excellent disease control and was just on pyridostigmine (a cholinesterase inhibitor used to treat symptoms in myasthenia but that is not strong enough to reduce disease activity in the way that prednisone, plasma exchange and azathioprine can do).

This patient presented with fatigue, fever and a rapid heart rate. After the examination and imaging of the chest the patient was found to have pneumonia and ultimately had a positive COVID-19 test. The patient's pneumonia worsened and oxygen levels in the blood declined. She was admitted in the intensive care unit for close monitoring but did not need to be intubated. Throughout her course there were no findings such as droopy eyelids or eye movement abnormalities to indicate the myasthenia was made worse. She recovered and at day 22 and was discharged to home.

What can we conclude from this case? That if you have well controlled myasthenia at baseline, are on no immunosuppression and are young, a severe case of COVID-19 pneumonia will not necessarily worsen myasthenia or lead to a crisis. Stated simply, myasthenia here appears to have been a stable background problem to a severe COVID-19 infection.

### Case Report 2

What about if you have very active myasthenia gravis that requires significant doses of prednisone and even regular plasma exchange? Our colleagues Dr. Ramaswamy and Dr. Govindarajan from the University of Missouri, Columbia reported a relevant case in the *Journal of Neuromuscular Diseases* in June 2020.

This was a 42-year-old woman recently diagnosed with AChR positive myasthenia gravis with a suspected thymoma (a mass in the chest seen in about 10-15% of patients with AChR myasthenia). She required prednisone 30 mg daily, mycophenolate mofetil 1000 mg twice daily (another immunosuppressant medication) and schedule plasma exchange every 4 weeks. Shortly after the myasthenia diagnosis the patient presented with fever, chills, cough, shortness of breath with exertion and poor appetite. A chest x-ray showed findings consistent with pneumonia and the diagnostic workup showed a positive COVID-19 test. The patient was given a diagnosis of mild COVID-19 and was discharged to home with instructions for quarantine and further infection prevention. Her myasthenia gravis treatment regimen was left unchanged.

What we can conclude here is that even with very active myasthenia gravis and (continued page 5)

significant immunosuppression 1) that does not necessarily mean that the patient will have a severe presentation of COVID-19 and 2) again this does not necessarily mean that a COVID-19 infection will cause a patient with treatment-resistant myasthenia to have a myasthenic worsening or exacerbation.

### **Case Series from Switzerland**

A series of 4 patients with myasthenia gravis and COVID-19 was published by Dr. Hubers et al. in the *Journal of Neurology, Neurosurgery and Psychiatry* in July 2020. One younger woman with generalized myasthenia gravis showed some worsening of myasthenia symptoms shortly after getting diagnosed with a mild COVID-19 infection. She was treated with an intravenous immunoglobulin G (IVIG) course and was discharged to home after 10 days. Another young woman had active myasthenia that required both prednisone and immunoglobulin G therapy to treat still active neurologic symptoms. She had a mild COVID-19 infection, but her course was complicated by shortness of breath lasting 2 months, although this was never found conclusively to be due to myasthenia gravis worsening. A 55-year-old man with mild generalized myasthenia on pyridostigmine presented with a mild COVID-19 infection. He did not have any neurologic worsening and he recovered from the viral illness in 4 weeks. Finally, a 25-year-old obese man (BMI>50) with myasthenia presented initially with a mild COVID-19 infection. He was discharged to home, but 3 days later returned with very severe respiratory symptoms an abnormal chest x-ray indicating severe pneumonia and had to be intubated. The reason for the initial respiratory failure was felt to be due to a severe COVID-19 pneumonia and not myasthenia. This is due to the notably abnormal chest imaging findings. However, the patient developed pharyngeal weakness and remained intubated for >14 days and required a tracheostomy (a surgically made opening in the neck that makes breathing easier) for 9 weeks. Both obesity and myasthenia could be considered as contributors to the patient's severe clinical course.

What is striking about this case series is how variable each patient's clinical course was with COVID19. In each case baseline myasthenia severity as well as comorbidities such as obesity seemed to affect the clinical course.

### **Case Series from Italy**

This is perhaps the most thought-provoking series of patients. Dr. Restivo published a series of 3 patients in the *Annals of Internal Medicine* in August 2020. These 3 patients were not known to have any neurologic symptoms previously but were reported to develop myasthenia gravis symptoms on days 5, 7 and 6 days respectively after onset of COVID-19 symptoms. All 3 patient's in the series were subsequently confirmed to have developed myasthenia gravis. The authors raised the question of whether COVID-19 can in fact *cause* myasthenia gravis, similar to how other infections can precede autoimmune neurologic conditions such as inflammatory neuropathy (Guillain Barre Syndrome) and inflammation of the spinal cord (transverse myelitis).

This report was met with interest and skepticism as to the idea that COVID-19 can precipitate new-onset myasthenia as a postinfectious complication. A critique is that infection may have unmasked previously occurring myasthenia gravis. Certainly, repeat observations of myasthenia following COVID-19 will be necessary before considering this idea of COVID-19 precipitating myasthenia.

### **Frequently Asked Questions**

**Is there enough evidence currently to change your myasthenia gravis medication regimen to reduce the risk of from COVID-19?**

Generally, no. There is no specific evidence at this time suggesting that being on a certain myasthenia medication including immunosuppressants can put you at additional risk for COVID-19 and severe complications. While we don't know for sure, the current experience supports the view that if you need medications to control myasthenia you should stay on them, as the risk of stopping them appears to be greater than the risk of staying on them. More research on this question will be extremely important and informative going forward.

Expert opinion on the management of myasthenia gravis during the COVID-19 pandemic explore this topic further. These guidelines were published in May 2020 when even fewer data on COVID-19 and myasthenia were available and that should be considered when reading them. This published expert opinion can be accessed here: [https://www.jns-journal.com/article/S0022-510X\(20\)30139-8/fulltext](https://www.jns-journal.com/article/S0022-510X(20)30139-8/fulltext)

#### **Any special considerations about hydroxychloroquine/chloroquine in myasthenia patients?**

In June 2020 the US FDA revoked the emergency approval granted for hydroxychloroquine/chloroquine for COVID-19. The use of these drugs is no longer recommended as the known risk outweigh any benefit. With regards to myasthenia, hydroxychloroquine is on the list of drugs that can cause an exacerbation. Thus, it should be avoided.

#### **For infusion-based therapies, are home infusions recommended over travel to an infusion center?**

Home infusions may be better during the COVID-19 pandemic. But keep in mind that infusion centers are taking steps to enact social distancing measures while at the same time home infusions also entail contact with a visiting nurse.

#### **What are the most important things I can do about myasthenia gravis during the COVID-19 pandemic?**

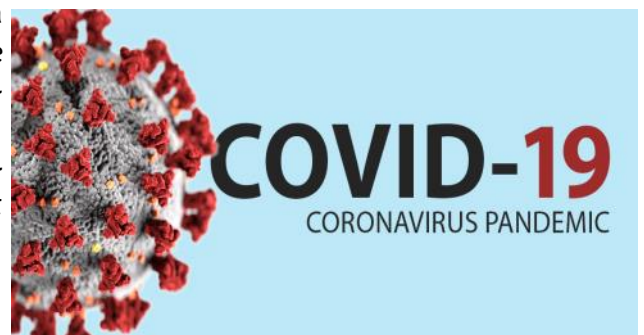
- Some things don't change: monitor your myasthenia symptoms. If there is a worsening, alert your neurologist to obtain additional advice. If you are feeling unwell, make plans to be seen or to travel to the emergency room.
  - In the time of social distancing, remaining physically active may have become harder for many. However, it is essential to make every effort to remain physically active. This is to maintain both physical and emotional health in this more stressful period. And remember every bit makes a difference such as taking the stairs when you do so safely and parking further from your destination.
  - Wash your hands after touching surfaces in public. Sixty percent alcohol is reasonable if hands are not soiled.
  - Wear a face mask when physical distancing (6 ft) is not possible. Avoid crowded events indoors and outdoors.
  - Try not to touch your face (eyes, nose, mouth). Also, the American Academy of Ophthalmology suggests not using contact lenses, as their use is associated with more touching of the eyes.
- Clean and disinfect frequently touched surfaces

#### **What is your current take on COVID-19 and MG as of September 2020?**

Myasthenia is an extremely variable condition. It can occur in children, young adults and older adults. There are at least 3 antibodies that cause myasthenia and sometimes patients have an underlying tumor (thymoma) that appears to cause the disease. And finally, disease severity and responsiveness to treatment are both highly variable. So far with COVID-19 and myasthenia we have seen similarly very diverse clinical scenarios and outcomes. And perhaps it makes sense that given the varied forms of myasthenia, the impact of COVID-19 also impacts each individual differently. Currently there is no rationale for uniform treatment recommendations and instead it seems most reasonable for patients and physicians to develop an individualized myasthenia management plan.

Finally, there is an immense need to learn more about COVID-19 occurring in myasthenia patients. Already, there is a registry designed to aggregate data from numerous cases of COVID-19 from around the world. Certainly, an analysis of a larger group of patients would be very informative.

If you have had experience with COVID-19 and myasthenia, or have questions, feel free to reach out at [cfarmakidis@kumc.edu](mailto:cfarmakidis@kumc.edu).





## KUMC & WUSTL

For Clinical Trials at the **University of Missouri:**

Raghav Govindarajan, MD at govindarajanr@health.missouri.edu

Safety & Efficacy Study of Ravulizumab in Adults with Generalized Myasthenia Gravis	A Study to Test Efficacy and Safety of Rozanolixizumab in Adult Patients with Generalized Myasthenia Gravis
<p>The primary purpose of this study is to evaluate the safety and efficacy of ravulizumab for the treatment of participants with generalized myasthenia gravis (gMG). All investigative site personnel, sponsor staff, sponsor designees, staff directly associated with the conduct of the study, and all participants will be blinded to treatment assignments. This is a randomized, control trial in which the patient will receive either the investigational drug or placebo drug through an IV infusion. After the 26-week randomized-controlled period, participants will enter the open-label extension period of the study and receive ravulizumab. Eligibility and inclusion criteria can be found in the clinical trial study record. If interested in this study, contact the appropriate study coordinator based on location and physician of interest.</p> <p><i>Alexion Pharmaceuticals // ALXN1210-MG-306</i></p> <p><b>Physicians</b></p> <p>Dr. Mazen Dimachkie (KUMC) Dr. Muhammad Al-Lozi (WUSTL)</p> <p><b>Study Coordinator(s)</b></p> <p>KUMC: Katie Jennens // kjennens2@kumc.edu WUSTL: June Smith // smith.june@wustl.edu</p>	<p>The purpose of the MycarinGstudy is to demonstrate the clinical efficacy and to assess safety and tolerability of rozanolixizumab in patients with generalized myasthenia gravis (gMG). This is a randomized, control trial in which the patient will receive either the investigational drug or placebo through subcutaneous infusion. Eligibility and inclusion criteria can be found in the clinical trial study record. If interested in this study, please contact the appropriate study coordinator based on location and physician of interest.</p> <p><i>UCB Biopharma S.P.R.L. // UCB MG0003</i></p> <p><b>Physicians</b></p> <p>Dr. Mazen Dimachkie (KUMC) Dr. Muhammad Al-Lozi (WUSTL)</p> <p><b>Study Coordinator(s)</b></p> <p>KUMC: Ali Ciersdorff // aciersdorff@kumc.edu WUSTL: June Smith // smith.june@wustl.edu</p>

## SLU & KUMC

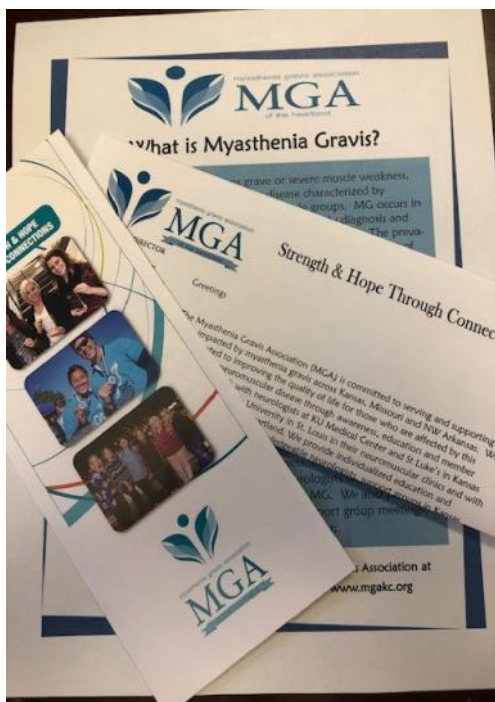
A Phase 3 Open-Label Study of Eculizumab in Pediatric Participants with Refractory Generalized Myasthenia Gravis (gMG)	Safety, Tolerability, and Efficacy of Zilucoplan in Subjects with Generalized Myasthenia Gravis
<p>The purpose of this study is to evaluate the efficacy, safety, pharmacokinetics, and pharmacodynamics of eculizumab in the treatment of pediatric refractory gMG based on change from Baseline in the Quantitative Myasthenia Gravis (QMG) score for disease severity. The study will consist of an up to 4-week Screening Period, 26-week Primary Evaluation Treatment Period, an additional (up to) to 208-week Extension Period, and an 8-week Safety Follow-up Period. Eculizumab will be administered through an intravenous (IV) infusion. Eligibility and inclusion criteria can be found in the clinical trial study record. If interested in this study, please contact the appropriate study coordinator based on location and physician.</p> <p><i>Alexion Pharmaceuticals // ECU-MG-303</i></p> <p><b>Physician</b></p> <p>Dr. Jafar Kafaie</p> <p><b>Study Coordinator</b></p> <p>SLU: Jennifer Light // jennifer.light@health.slu.edu</p>	<p>The RAISE study is a multicenter, randomized, double-blind, placebo-controlled study to confirm the efficacy, safety, and tolerability of zilucoplan in subjects with generalized myasthenia gravis. Subjects will be randomized in a 1:1 ratio to receive daily SC doses of 0.3 mg/kg zilucoplan or placebo for 12 weeks. Eligibility and inclusion criteria can be found in the clinical trial study record. If interested in this study, please contact the appropriate study coordinator based on location and physician.</p> <p><i>Ra Pharmaceuticals // RA101495-02.301</i></p> <p><b>Physician</b></p> <p>Dr. Constantine Farmakidis</p> <p><b>Study Coordinator</b></p> <p>KUMC: Samantha Colgan // scolgan@kumc.edu</p>

## Fishing for a Cure

On a beautiful, warm October day, the MGA partnered with St. Louis members Mark Macias Greta Rice and his family members John and Tina Warren to host the 2<sup>nd</sup> Annual Reel in MG Fishing Derby at their home in Troy, IL! Attendees were able to enjoy a socially distanced fishing derby and fellowship while raising awareness for myasthenia gravis.

The fish were biting, which provided constant competition, entertainment and jabs across the pond amongst participants. The biggest amusement (quite literally!), may have been the nearly 12 lb. fish caught after the contest was over!

The MGA is grateful for the continued partnership as well as for all who came out to raise awareness and fish for a cure! The MGA would like to thank our sponsors who made this day possible.



## Help Spread the Word About MG

Do you see a medical professional outside of neuromuscular medicine that doesn't know much about myasthenia gravis? Are you a newly diagnosed patient and want to share information about this disease with others such as your PCP, dentist, therapist, or child's school team?

We have gathered some materials to create an information packet that members can hand out to inform their community about MG.

Send us a message and we will be happy to supply you with this packet that you can give out. Or, if you would simply just like to have a few of these on hand to help educate others, let us know. The more people know about myasthenia gravis, the better!



## Are You Fully Hydrated?

We've all seen the slogans, "Save water, drink..." The purpose of this article, however; is to remind you to not listen to those slogans! Drinking water is key when undergoing treatments such as IVIg for myasthenia gravis. Being fully hydrated helps your body combat other side effects that may creep up during a treatment session.

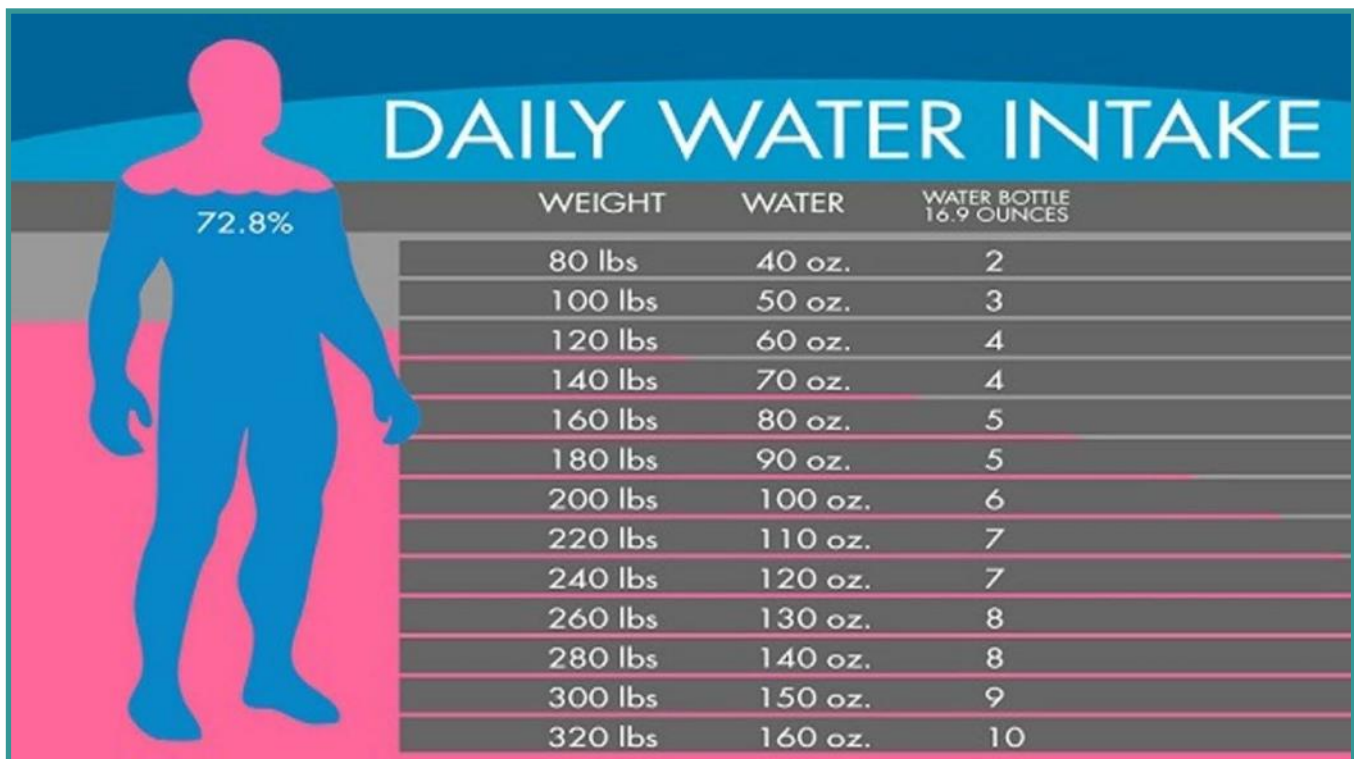
For starters: if you are fully hydrated, your veins are better prepared for IV access. An easy IV access will allow for a smoother start to a treatment.

The process of IVIg, which is infusing your immune globulin proteins into the blood, causes the fluids to shift. Proper hydration helps your body appropriately handle this shift and further prevent headaches. What's worse than coming off an IVIg treatment and battling an excruciating headache?

Additionally, experts recommend that patients begin hydrating 2-3 days before they are scheduled to receive treatment. Doing so allows the body to adjust and maintain good hydration throughout the entire treatment process.

There are lots of tools that can help with water intake including timed water bottles. Timed water bottles can be found on Amazon or if you already have a favorite water bottle, you can purchase a label on Etsy to serve as a reminder!

Check out these two graphics that provide other great tips to help you drink more water and a chart to reference what your water intake should be. Cheers!



# A Firsthand Look at Subcutaneous IG



Rewind to about a year ago when out of nowhere my eyes started drooping and seeing double like they did when I was initially diagnosed. It was evident I was having an MG exacerbation and after multiple discussions, my care team and I decided

to move forward with subcutaneous immunoglobulin (SCIg). Those living with MG may be more familiar with *intravenous* immunoglobulin (IVIg). The primary differences between the two therapies are the routes of administration and the rates in which the product is absorbed. While that may seem minor, those two factors can make a big difference. For example, I am able to administer the therapy in the comfort of my own home and am less likely to experience adverse reactions. After two months of utilizing this treatment, here are a few takeaways thus far:

## Side Effects

One of the main focal points of current MG research is the reduction of side effects. I think I can speak for all of us when I say this is a priority for MG patients as well. The data suggests SCiG has a significantly lower rate of systemic reactions in comparison to IVIG. Personally, each week is different for me. Some days I will wake up with a dull headache, and other days I will endure an intense headache that can last for days. Moreover, I would say that every week I can expect local site reactions such as redness/puffiness and to be pretty exhausted the day after my infusion. Overall, the side effects have been a bit of a seesaw for me, but they are minimal in comparison to prednisone and the ones I experienced when I underwent IVIG therapy.

## Convenience

Especially during this pandemic, the ability to infuse at home and on my own time versus at an infusion center or hospital is something I do not take for granted. For someone who has trypanophobia, an extreme fear of needles/medical procedures, this may not be the preferred choice. Sticking yourself with needles isn't the most pleasant experience, but once you start doing it, you get used to it. I myself find that it gives me a sense of control over my health and provides a certain level of accessibility that I probably wouldn't get otherwise.

## Time

As MG patients, we know time is precious. The entire infusion process takes approximately 3 hours from prep to finish. Some might say that sounds like a long time to dedicate to treatment on a weekly basis, but I don't mind it. Plus, infusing at home eliminates travel time to and from an infusion center.

MG research is also looking closely at reducing the frequency of medication intake. I take Mestinon every 4 hours or as needed. I am not bothered by this but some may find this a nuisance or even forget to take it/bring it with them. It really just boils down to personal preference.

If I could describe my experience with SCiG in one word thus far it would be fascinating. I am intrigued by the innovative technology that allows me to heal, but I'm also slightly ruffled by adjusting to this "new normal." I'm learning new skills, adapting to different circumstances, and taking each day at a time. Above all, I'm incredibly grateful for everything that allows me to live my best life with MG: medications, a healthy mindset, my family, and of course, the MGA.

*Meridith O'Connor, MSW  
MGA, St. Louis Program Coordinator*

## 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 from by connecting via email or phone.



**The MGA Digest**

Myasthenia Gravis Association

**CHECK OUT OUR NEW BLOG!**

HTTP://WWW.MGAKC.ORG  
INSIGHTS & UPDATES  
BLOG

The MGA was thrilled to be named the beneficiary for the September edition of Barstool Sessions at Chicken N Pickle in North Kansas City! Barstool Sessions is the brainchild of Nate Aholt and Lyndsey Fliehs, in which musical songwriters perform in a Nashville writer's style round. A suggested \$10.00 entry fee for attending patrons goes back to local charities. Since its inception in January 2019, Barstool Sessions has given \$25,000.00 to various charities. This is the second time the MGA has been blessed with their support.



Thank you, Barstool Sessions, Team Cocktail, and Chicken N Pickle!

If you live in Kansas City or Wichita, be sure to check out Barstool Sessions!

While physically holding our annual Trivia Night was not possible this year, the MGA successfully held a Facebook Un-Trivia Night Fundraiser which brought in over \$2,500.00 in donations! Every little bit counts and we are so grateful for the over 30 donors who contributed.

Speaking of Facebook, did you know that you can create your own fundraiser for the MGA on this platform? Host a fundraiser for your birthday or any other special event is easy and simple to set up. All you have to do is go to our home page [www.facebook.com/mgakc](https://www.facebook.com/mgakc) and click "Fundraisers" and then click "Raise Money" in the "Create a Fundraiser" box. Thank you for supporting the MGA!



On Friday, March 27, 2020 the Coronavirus Aid, Relief, and Economic Security (CARES) Act was passed into law. The CARES Act is a \$2 trillion economic stimulus package that was legislated to provide immediate relief to non-profits.

### Coronavirus Aid, Relief, and Economic Security Act

The CARES Act includes an expanded charitable giving incentive with new deduction levels available. The bill allows for new deductions for up to \$300 per taxpayer (\$600 for married couple) in annual charitable contributions. This is particularly beneficial to people who



take the standard deduction when filing their taxes. Also noted as people who do not itemize their deductions. This amount is calculated by subtracting the amount of donation from your gross income. It is an "above the line" adjustment to income that will reduce your AGI, and thereby reduce your taxable income.

To qualify, all you would need to do is give a donation to a qualified charity. If you gave after January 1<sup>st</sup> but prior to March 27<sup>th</sup> that contribution will count towards the \$300 cap. A donation to a donor-advised fund (DAF) does not qualify for this new deduction.

In addition, as part of the CARES Act there are new charitable deduction limits. Individuals and corporations that itemize can deduct much greater amounts of their contributions. Individuals can elect to deduct cash contributions, up to 100% of their 2020 AGI, on itemized 2020 tax returns. This is up from the previous limit of 60%. Corporations may deduct up to 25% of taxable income, up from the previous limit of 10%.


The new deduction amount applies for cash gifts only that go to a public charity. Donations to private foundations still follow the old deduction rules. Many organizations that manage DAF are public charities however you do not get the higher deduction for donating cash to your DAF. The new limits also do not apply to gifts of appreciated stock.

In 2020, minimum distributions will be waived for most donors until 2021. This includes distributions from a defined benefit pension plan and 457 plans. The incentive for donors to give at the new deduction levels could be hindered by this change when making contributions from a qualified charitable distribution from an IRA.

For more information you can go to <https://home.treasury.gov/policy-issues/cares> or for specific questions about your taxes and donations we recommend you consulting your Accountant or Financial Planner. As always, thank you for thinking of the MGA in your charitable giving.



LIVING WITH MG



## The CHAMPION MG STUDY

Alexion is currently recruiting patients with anti-acetylcholine antibody receptor positive generalized myasthenia gravis (MG) 18 years of age or older for a Phase 3 study of ravulizumab-cwvz, called the CHAMPION MG Study. The study will assess ravulizumab-cwvz, compared to placebo, on the improvement of MG symptoms (MG activities of daily living). Participants may continue on their current medicines\*, as long as they are stable, and after a 26-week study treatment period all participants can receive ravulizumab-cwvz for an additional follow up period of up to 2 years. For more information and to learn if you are eligible for the CHAMPION MG Study, please contact [ClinicalTrials@alexion.com](mailto:ClinicalTrials@alexion.com) or go to [MGCHAMPION.com](http://MGCHAMPION.com).

\*Except for other complement inhibitors, rituximab, chronic Plasma Exchange or Intravenous Immunoglobulin

## MG Support Groups

Area	Dates	Time	Location
Kansas City, MO	December 12th	10am-12:00pm	<b>Location- TBD</b> RSVP tanyarenner@mgakc.org or (816) 256-4100
KC Northland	January 2021	noon-1:30pm	<b>Location- TBD</b> RSVP tanyarenner@mgakc.org or (816) 256-4100
Mid-Missouri	December 3rd	6:30-8pm	<b>Location- TBD</b> RSVP tanyarenner@mgakc.org or (816) 256-4100
Springfield, MO	October 29th	6-8pm	<b>Location- TBD</b> RSVP tanyarenner@mgakc.org or (816) 256-4100
St. Louis	December 5th	10:00-11:30am	<b>Location- TBD</b> RSVP tanyarenner@mgakc.org or 816-256-4100
Wichita, KS	TBD	1-3pm	<b>Location- TBD</b> Contact: Dana or Larry Paxson for more info or to RSVP dkptiffany@gmail.com or (316) 269-9120
Young Friends of the MGA Group- Kansas City	December 1st	6pm	<b>Location- TBD</b> RSVP to Allison Foss allisonfoss@mgakc.org
Young Persons with MG Group- STL	December 3rd	6pm	<b>Location TBD</b> RSVP to Meridith O'Connor meridithoconnor@mgakc.org
Northwest, AR	January 2021	2:30-4:30pm	<b>Location TBD</b> Contact: Roger Huff for more info or to RSVP jrhuff1@cox.net or (479) 790-3022
Topeka, KS	November 19th	6-8pm	<b>Topeka &amp; Shawnee County Library</b> <b>1515 SW. 10th Ave</b> <b>Topeka, KS 66604</b> RSVP tanyarenner@mgakc.org or 816-256-4100
Eastsiders Lunch Bunch	October 21st	11am	<b>Blue Springs Park</b> <b>2204 SW South Ave,</b> <b>Blue Springs, MO 64105</b> RSVP carolhunt04@yahoo.com
Virtual Monthly Meet Up	3rd Monday of the month	6:30pm	Meets via Zoom RSVP tanyarenner@mgakc.org or 816-256-4100





**argenx is a global immunology company  
developing antibody-based medicines  
for patients suffering from severe  
autoimmune diseases, including  
Myasthenia Gravis, and cancer.**

By translating immunology breakthroughs into innovative drug candidates, argenx is building a world-class portfolio of first-in-class antibodies in both early and late clinical-stages of development.



# In Memoriam



Ray Olsen

Derek and Nina Haverkamp

Dr. Jacob McGuire

Margie Kiepert



## Membership Contributions

Lisa and Jim Sackuvich

Jimmie Harbour

Cindy Disque

Norma Thomas

Brenda Spencer

Elena Chokolova

Pamela Stucker

Richard and Deanna

Palone

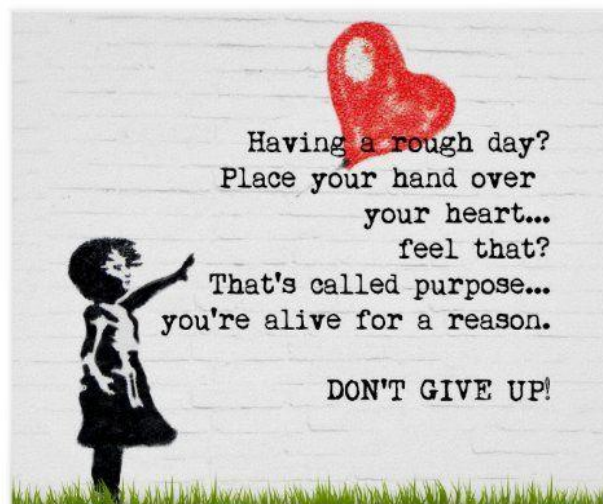
Rodney Roundtree

*thank you!*

Did you know you can VENMO the MGA?  
Venmo Handle: @MGAKC



Have an idea for a fundraiser in your community? Contact us today!  
[allisonfoss@mgakc.org](mailto:allisonfoss@mgakc.org)  
Your financial support enables us to continue reaching patients across the heartland.



**Consider becoming a 2020 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 2020 member or making a contribution:

- ☐ \$ 25 Basic Membership
- ☐ \$ 60 (60th Anniversary Membership)
- ☐ \$ 100 Sustaining Membership
- ☐ \$ 500 Patron Membership
- ☐ \$ 1,000 Lifetime Membership
- ☐ \$ \_\_\_\_\_ In Memory of:
- ☐ \$ \_\_\_\_\_ In Honor of:

DONATE NOW

# Thank You!

<https://www.firstgiving.com/event/mgakc/2020MGA>

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

PLEASE CHECK:

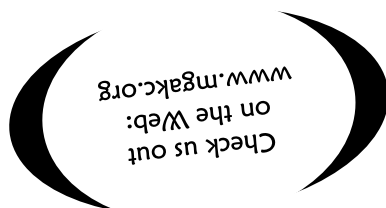
- ☐ MG Patient
- ☐ Relative
- ☐ Friend

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

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