Additional COVID-19 updates can be found on Page 4

MGA Support Groups Go Virtual in Light of COVID-19 Concerns

If there is one thing we all know about living with MG, it’s that you have to be flexible yet prepared. As a result of COVID-19 and the stay-at-home order, the MGA came to the decision to host support groups virtually. With the use of Zoom technology, support groups will remain virtual through May and hopefully return to in-person groups sometime this summer. Our goal is to not only ensure the health and safety of our patients and families, but to remain connected in this uncertain time.

One of the great things about hosting our support groups virtually is giving our patients and families the ability to tune into any group of their liking. Each support group focuses on a different topic related to MG and guests will be offered the opportunity to “attend” support groups in other areas. Be sure to check out the support group calendar on page 13 and learn tips and tricks to utilizing Zoom on page 11. To ensure safety and security of those participating, we ask that you please RSVP to Tanya Renner. The Zoom meeting credentials will be emailed out to attendees who RSVP prior to the group.

We recognize that this is a scary time and want to remind you we are here for you and will continue to provide resources. While we have pressed pause on our clinic services at KU, St. Luke’s and St. Louis University, we look forward to the day when we can return to our regularly scheduled services. Until then, please feel free to reach out to Tanya for Kansas City tanyarenner@mgakc.org or Meridith for St. Louis meridithoconnor@mgakc.org. Stay safe and be well. We are thinking of you!

Yokota Foundation Gift

We are pleased to announce the MGA was granted a $50,000.00 donation by the Yokota Foundation! Tina and John Warren of the Yokota Foundation as well as sister and brother-in-law to MGA STL member Mark Macias, have been instrumental in the growth and development of the MGA. This gift affords an opportunity for the MGA to directly work with patients, their families, and those impacted by myasthenia gravis across the Heartland. Thank you, Yokota Foundation for making this possible; we are beyond grateful for your continued support.

*Pictured from left to right: Mark’s girlfriend, Greta Rice; STL member, Mark Macias; and Tina and John Warren of the Yokota Foundation.
ARJ INFUSION SERVICES

ULTRA RARE  MEGA CARE

ARJ’s compassionate clinicians and care specialists help manage your myasthenia gravis through nursing care, streamlined deliveries, and valuable resources.

Top Speed!

Patients rely on ARJ ReadyPack® shipments for thoughtfully organized infusion supplies and medication.

SO MEGA

We secured over $6.5 million in financial assistance and lifestyle resources for patients and families last year.

RAD!

Free ARJ Level Up Fanny Pack!

arjinfusion.com/LevelUpMGA
A MESSAGE FROM THE MGA’S EXECUTIVE DIRECTOR

I’m a planner. I get excited to buy a crisp new calendar each year and start to fill in the pages with appointments, meetings, support groups, trips and all the alike. What I didn’t plan for was wiping the slate clean of activities outside my home come 2020 due to COVID-19. What’s that they say about best-laid plans? This season of life has caused me to take a pause; to reflect and go back to the simple. It hasn’t been easy, but neither is life. I hope that I can come out of this season with a better appreciation of what’s right in front of me and what’s happening now instead of in two weeks (or even three or four). I hope I come out of this season living in the moment and not fixated on when it works in my schedule. I recognize that people reading this message come from all walks of life and come from many different situations. For some, the downtime at home hasn’t been a change of pace. For others, it has been isolating and discouraging. However, one takeaway from this season is a blatant reminder that tomorrow is never promised. I hope you enjoy today and what is surrounding you. Send us a note and let us know how you are handling COVID-19, your MG, and this pause in time. We’d love to hear from you!

Allison Foss, Executive Director
allisonfoss@mgakc.org

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Tanya Renner
Meridith O’Connor, MSW

The health and safety of our participants is our first priority. Due to developments with COVID-19, the MGA Snowflake Shuffle will not be held this year. We look forward seeing you all and celebrating in June 2021! Thank you in advance for understanding!

Ways to Support the MGA

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Follow us
Corona Virus Disease 2019 (COVID-19) is a new illness caused by a novel coronavirus, severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2). Symptoms are variable but typically include fever, cough, respiratory symptoms, diarrhea, reduction of smell and taste sensation.

Severity ranges from mild to severe and the virus may lead to pneumonia, acute respiratory distress syndrome and death, in some patients. Nearly every country in the world has been affected by this virus and is currently defined as a pandemic, by the World Health Organization. There are no known proven therapies for treating this virus and no vaccine to prevent the infection at this time.

No data currently exist on how COVID-19 affects people with myasthenia gravis (MG)/LEMS or patients with other diseases on immunosuppressive therapies. However, because most patients with MG are on immunosuppressive or immunomodulatory therapies and may also have respiratory muscle weakness, there is a theoretical concern that MG/LEMS patients may be at higher risk of contracting the infection or experiencing severe manifestations of COVID-19.

Individuals with MG and LEMS have asked for guidance on the use of therapies during the COVID-19 pandemic. There are numerous recommendations circulating that attempt to provide clarity and guidance, however, differences among the recommendations have created confusion. Immunotherapy decision making varies significantly from country to country, ranging from highly provider-directed to a collaborative decision-making model. The advice below was developed by a panel of MG experts. We recognize that peer reviewed published literature regarding COVID-19 in MG or in immunocompromised patients to date is lacking.

The MG expert panel suggests that therapy decisions should be individualized and made collaboratively between the person with MG and his/her healthcare provider. Based on their expert advice, it is suggested that:

1. People with MG should follow the corresponding national guidelines and any additional recommendations for people at risk for serious illnesses from COVID-19.

Patients on existing therapies for MG/LEMS
2. MG/LEMS patients should continue their current treatment and are advised not to stop any existing medications, unless specifically discussed and approved by their healthcare provider.
3. There is no scientific evidence to suggest that symptomatic therapies like Pyridostigmine or 3,4 Diaminopyridine increases the risk of infection and should not be discontinued unless there are other clinical reasons to do so.
4. Even though strong evidence is lacking, it is recommended that MG patients already on immunosuppressive medications should practice extra-vigilant social distancing, including avoiding public gatherings/crowds, avoiding crowded public transport and where possible use alternatives to face-to-face consultations (eg: telemedicine), if clinically appropriate.
5. When altering or stopping an existing immunosuppressive therapy that carries a potential for increased disease activity and/or MG exacerbation or crisis, people with MG and their MG healthcare providers should consider specific risks (e.g., age, comorbid health conditions, location) and benefits.

Infusion therapies, intravenous immunoglobulins and plasma exchange
6. Certain infusion therapies in MG may require travel to hospitals or infusion centers and we strongly recommend that this decision be made based on regional incidence of COVID-19 and risk/benefit of the therapy for the individual patient. The healthcare provider should be able to give region-specific advice, and where possible consider switching to home infusion.
7. There is currently no evidence to suggest that intravenous immunoglobulin (IVIG) or therapeutic plasma exchange (PLEX or TPE) carry any additional risk in catching COVID-19. However, the use of IVIG has to be based on individual patient need and indiscriminate use should be avoided. In general, PLEX and IVIG should be reserved for patients with acute exacerbations. However the panel recognize that there are some patients receiving these as maintenance therapy, who should continue these, but extra precautions may need to be taken because of the need for travel to and from a healthcare facility.
8. There is currently no evidence to support that inhibition of complement using the monoclonal antibody (mAb), eculizumab increases susceptibility to COVID infection or its outcome.

**Blood tests for existing therapies**

9. Weigh risk and benefits of routine blood monitoring at this time. Some of the MG therapies require frequent blood work monitoring and decisions regarding the ongoing need for testing, which requires patient to leave their home, should be individualized and based on regional COVID-19 incidence.

**What to consider when starting an immune therapy in patients with MG/LEMS now?**

10. Before starting a B-cell depleting therapy\(^2\) (e.g., rituximab), healthcare providers should consider the risk of worsening myasthenia or crisis and the risk of catching the viral infection. It may be advisable to delay initiation of cell depleting therapies, until the peak of the outbreak is over in their region. However, the risk of not starting the cell depleting therapy in occasional patients may outweigh the risk of severe COVID-19 infection and this has to be discussed with the patient in detail.

**Advice for patients in ongoing clinical trials**

11. Currently there are many clinical trials in progress for MG and we strongly recommend that any decision regarding ongoing need for in-person evaluations and treatments under the clinical trial be based with consideration for patients’ best interest. At present, there is no scientific evidence to suggest that complement inhibitors or neonatal Fc Receptor blockers (FcRn) may increase the risk of catching the viral infection, but the panel recommends extra precautions (as in point 4 above), to minimize the risk. In clinical trials this also has to be discussed and approved by the trial sponsor, institutional review board and medical monitor.

**Is there reasonable evidence for medications treating COVID 19?**

12. Various medications have been mentioned in the news and social media as being useful to treat COVID-19 (e.g., chloroquin, azithromycin, anti-virals etc), however, these are not proven to be effective or studied systematically at this time. Patients should be aware that some of these medications can potentially worsen MG and should avoid using these without specific medical approval. If the evidence changes and suggests there is benefit for treating COVID-19, these treatments should be used under strict medical supervision weighing the risks and benefits in an individual patient.

**Should MG or LEMS patients go for vaccinations?**

13. Vaccinations can protect for a variety of infections/pathogens. However, in the current situation it is recommended to only use dead vaccines in this patient group. For COVID-19, there is no vaccine available currently.

**What if patients have already contracted COVID-19?**

14. Most patients who develop COVID-19 have mild disease and should continue the current best practice standard of care for MG/LEMS. There might be a need to increase the dose of corticosteroids as in standard infection/stress protocol. However, if the symptoms are severe (requiring hospitalization) it may be worthwhile considering pausing current strong immunosuppression temporarily, especially if there is additional super added infections/sepsis. Immune depleting agents should not be given under such condition, milder immune-suppressive agents (azathioprine, mycophenolate) should probably be continued, since effects of dosing are longer lasting, wash out takes longer and rebuilding of effects take several months.

15. Most decisions for treatment escalation have to be individualized based on the relative severity of COVID-19 and MG.

\(^*\)These recommendations have been prepared and endorsed by a an international working group of MG experts in response to COVID-19 pandemic.

Amanda Guidon, MD  
Jeff Guptill, MD  
Michael Hehir, MD  
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Isabel Illa, MD, PhD  
Saiju Jacob, MBBS, MD, DPhil  
Renato Mantegazza, MD  
Srikanth Muppidi, MD  
Hiroyuki Murai, MD, PhD  
Richard J. Nowak, MD  
Kimiaki Utsugisawa, MD, PhD  
John Vissing, MD, PhD  
Heinz Wiendl, MD

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**MG Care and COVID-19**  
**Webinar/Zoom**  
Presented by Constantine Farmakidis, MD and  
Assistant Professor of Neurology at the University of Kansas  
Saturday May 2, 2020  
10-12pm  
RSVP to Tanya @ tanyarena@mgakc.org or 816-256-4100
What you should know about COVID-19 to protect yourself and others

Know about COVID-19
- Coronavirus (COVID-19) is an illness caused by a virus that can spread from person to person.
- The virus that causes COVID-19 is a new coronavirus that has spread throughout the world.
- COVID-19 symptoms can range from mild (or no symptoms) to severe illness.

Know how COVID-19 is spread
- You can become infected by coming into close contact (about 6 feet or two arm lengths) with a person who has COVID-19. COVID-19 is primarily spread from person to person.
- You can become infected from respiratory droplets when an infected person coughs, sneezes, or talks.
- You may also be able to get it by touching a surface or object that has the virus on it, and then by touching your mouth, nose, or eyes.

Protect yourself and others from COVID-19
- There is currently no vaccine to protect against COVID-19. The best way to protect yourself is to avoid being exposed to the virus that causes COVID-19.
- Stay home as much as possible and avoid close contact with others.
- Wear a cloth face covering that covers your nose and mouth in public settings.
- Clean and disinfect frequently touched surfaces.
- Wash your hands often with soap and water for at least 20 seconds, or use an alcohol-based hand sanitizer that contains at least 60% alcohol.

Practice social distancing
- Buy groceries and medicine, go to the doctor, and complete banking activities online when possible.
- If you must go in person, stay at least 6 feet away from others and disinfect items you must touch.
- Get deliveries and takeout, and limit in-person contact as much as possible.

Prevent the spread of COVID-19 if you are sick
- Stay home if you are sick, except to get medical care.
- Avoid public transportation, ride-sharing, or taxis.
- Separate yourself from other people and pets in your home.
- There is no specific treatment for COVID-19, but you can seek medical care to help relieve your symptoms.
- If you need medical attention, call ahead.

Know your risk for severe illness
- Everyone is at risk of getting COVID-19.
- Older adults and people of any age who have serious underlying medical conditions may be at higher risk for more severe illness.

cdc.gov/coronavirus
Stop Germs! Wash Your Hands.

When?
- After using the bathroom
- Before, during, and after preparing food
- Before eating food
- Before and after caring for someone at home who is sick with vomiting or diarrhea
- After changing diapers or cleaning up a child who has used the toilet
- After blowing your nose, coughing, or sneezing
- After touching an animal, animal feed, or animal waste
- After handling pet food or pet treats
- After touching garbage

How?
- Wet your hands with clean, running water (warm or cold), turn off the tap, and apply soap.
- Lather your hands by rubbing them together with the soap. Be sure to lather the backs of your hands, between your fingers, and under your nails.
- Scrub your hands for at least 20 seconds. Need a timer? Hum the “Happy Birthday” song from beginning to end twice.
- Rinse hands well under clean, running water.
- Dry hands using a clean towel or air dry them.

Keeping hands clean is one of the most important things we can do to stop the spread of germs and stay healthy.

www.cdc.gov/handwashing

This material was developed by CDC. The Life is Better with Clean Hands Campaign is made possible by a partnership between the CDC Foundation, GOJO, and Staples. HHS/CDC does not endorse commercial products, services, or companies.
MGA Triple Crown Showdown Goes Virtual

Due to the safety and health of all participants, the MGA Triple Crown Showdown has gone virtual for 2020. With social distancing now a common word in our vocabulary and stay-at-home orders being lifted shortly before the May 17th date, the heartbreaking decision was made to transition the annual event to a virtual platform. While there will be no in person fanfare this year, there will be plenty of opportunity of fanfare on your own. Sign up to virtually participate at www.mga5k.com! Those with myasthenia gravis are our VIPs and register for free using code MGA20. Family and friends can register for 20% off using code MGAFAMILY20. Complete a walk or a 5K run between the dates of May 17– May 24th and submit your time. Extra kudos if you submit pictures participating in an old MGA 5K t-shirt or with your kids in their capes or animals in their bandanas! Medals will be awarded to those who compete and place first and second in their age groups. For more info: watch your email, check for updates on our social media, and explore the MGA5k website (www.mga5k.com).

Presented by

Thank you to our additional sponsors
Having a rare, autoimmune disease is already overwhelming, but having a rare, autoimmune disease during a global pandemic is even more distressing. Like many of you, I take immunosuppressants to treat my MG, therefore making me immunocompromised. Being immunocompromised has its risks; infection being one of the most significant risks of all. When taking immunosuppressants such as prednisone, the body is working towards weakening the immune response in MG patients, intending to minimize the attack on the neuromuscular junction. In turn, the body becomes more susceptible to infectious diseases, making it much easier for MG patients to acquire viruses such as COVID-19. Therefore, when an infection from the coronavirus family invades countries around the world including the US, a threat is placed on the health of those living with autoimmune diseases.

So, where does that leave people like us? One might say in a pit of despair, but I am choosing to lean into a more practical mentality. Sure; some anxiety is healthy to have and can promote a more cautious approach to this virus. Yet, if we as MG patients dwell in this type of fear, we also know that stress has the potential to significantly worsen our MG symptoms. Let’s stick to what we know and what we can control. Below you will find things that I have been doing to keep a balanced mindset during this pandemic:

1) **Communicate with your healthcare provider.** In the early stages of this pandemic, the first thing I did was contact my neurologist. I reminded him of my current treatment plan as well as the concerns I had due to this virus. Moreover, I asked what steps I could take to decrease my risk of being exposed to COVID-19. As we know though, this infection seems to evolve every day, therefore, maintaining communication with your physician is vital. Don’t worry about “bothering them” or flooding their patient portal. Staying informed is a proactive approach to your health and healthcare providers appreciate that.

2) **Don’t believe everything you hear or read.** There is too much misinformation circulating social media, causing even more confusion and unnecessary anxiety. Stay informed by following credible sources, and furthermore, don’t be guilty of spreading rumors or false information to the public as well. It does more harm than good.

3) **Follow the CDC guidelines.** Wash your hands! Social distance! We know these methods work. If you are unable to social distance as a result of being an essential worker or other limitations, that is understandable. Just do your best to maintain good hygiene.

4) **Prioritize your mental health.** Now more than ever, we have a lot of free time on our hands and are expected to keep socializing at bay. Isolation and disruptions in our normal routines can cause us to feel lonely and discouraged. Explore things that bring you joy. Keep in touch virtually with friends and family. Sleep! Find small ways to be productive (my apartment is the most organized it has ever been!) All of these tactics can ease some of those negative thoughts and feelings.

5) **Do the best you can.** So many of us depend on other people to assist us in activities of daily living such as grocery shopping, preparing meals, chores around the house. With the stay-at-home order, this throws a wrench into things, but for good reason. I am utilizing Instacart, the grocery delivery service, and trying to come up with creative ways to make meals that are easy, quick, and healthy. I’m also getting my prescriptions delivered and doing chores when I have energy. Sometimes I don’t have the energy to do the dishes or make the bed, and you know what? That’s okay. The truth is, I already do most of these things. MG requires us to think outside the box, regardless of a pandemic occurring. Ironically, I find myself “thriving” in some sense during this major upheaval. Time has slowed down, and I am learning that I am probably the most prepared for something like this compared to my peers as a result of my MG. As someone who is chronically ill I am already conscious of germs and constantly educating myself appropriately about health and wellness. I also recognize the value of staying in touch with my care team, and I don’t just mean my neurologist. Staying connected with loved ones has been imperative for my wellbeing. Lastly, if anyone gets what it’s like having to adapt to change constantly, it’s people with MG. We feel the frustration daily, but for most people, adjusting to a new normal is unprecedented territory. This is a surreal time we are living in. Moments in history like these can be scary, especially for those who don’t have adequate access to resources or have been impacted by this virus directly. People have been laid off, families have been torn apart, small businesses are financially devastated, and lives have been lost. While I cannot fix the world’s problems, I can express my gratitude to all who have fought this war against COVID-19. I can do my part by staying home and offering support to those with MG and any other chronic illness warriors out there. Do your part, and we will come out of this stronger.

*The following article was composed by our St. Louis Program Coordinator, Meridith O’Connor.*
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 Phase 3, Randomized, Double-Blind, Placebo-Controlled, Multicenter Study to Evaluate the Safety and Efficacy of Ravulizumab in Complement-Inhibitor-Naïve Adult Patients With Generalized Myasthenia Gravis  NCT03920293


3. A Phase 3, Randomized, Double-Blind, Placebo-Controlled Study Evaluating Efficacy and Safety of Rozanolixizumab in Adult Patients with Generalized Myasthenia Gravis  NCT03971422

4. A Phase 3, Multicenter, Randomized, Double-Blind, Placebo-Controlled Study to Confirm the Safety, Tolerability, and Efficacy of Zilucoplan in Subjects with Generalized Myasthenia Gravis  NCT04115293

For Clinical Trials at St. Louis University contact 314-977-4900 for more information. St. Louis University is recruiting for pediatrics for the Soliris trial.

For Clinical Trials at the University of Missouri contact Raghav Govindarajan, MD at govindarajanr@health.missouri.edu

St. Louis area patients, their families and providers gathered on World Rare Disease Day, February 29, 2020 at the Courtyard by Marriott-Brentwood to discuss clinical trials and the newest FDA approved treatment for MG, Soliris. There are multiple opportunities for clinical trial participation which you can find listed above and on our website, www.mgakc.org. The group enjoyed hearing from speakers including Dr. Ghazala Hayat of St. Louis University, Angela Ponitus of Ra Pharma and Tricia Gooljarsingh of Momenta Pharmaceuticals. A huge thanks to our seminar sponsors, Optum, Momenta, Ra and ARJ Infusion Services.
Tips for using Zoom to connect with support groups

1. Download the Zoom app.
2. Open the app and click on the plus sign to create a new meeting.
3. Enter your name and select a meeting name.
4. Click the red circle with the white microphone symbol to turn on audio.
5. Check the microphone to ensure it is turned on.

Now, let's learn Zoom features & etiquette!
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 or go to MGCHAMPION.com.

*Except for other complement inhibitors, rituximab, chronic Plasma Exchange or Intravenous Immunoglobulin
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<th>Area</th>
<th>Dates</th>
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<tbody>
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<td>Kansas City, MO</td>
<td>July 11th</td>
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<td>Holy Cross Lutheran Church <em>(note new location)</em> 7851 W. 119th Street</td>
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<td>Overland Park, KS</td>
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<td>KC Northland</td>
<td>May 14th</td>
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<td>July 30th</td>
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<td>Wichita, KS</td>
<td>August 22nd</td>
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<td><a href="mailto:dkptiffany@gmail.com">dkptiffany@gmail.com</a> or (316) 269-9120</td>
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<td>Young Friends of the MGA</td>
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<td>6pm</td>
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<td>Group–Kansas City</td>
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<td><a href="mailto:jrhuff1@cox.net">jrhuff1@cox.net</a> or (479) 790-3022</td>
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<td>Topeka, KS</td>
<td>June 4th</td>
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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.
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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

Got an idea for a fundraiser in your community? Contact us today!
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Your financial support enables us to continue reaching patients across the heartland.

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