Yokota Foundation provides generous gift to the MGA

In March, the Yokota Foundation provided a $50,000 gift to the Myasthenia Gravis Association. The Yokota Foundation consists of John and Tina Warren whom are the sister and brother in law of St. Louis member, Mark Macias. Their generous gift allows the MGA to provide services to patients across the Heartland through support groups, education and awareness events. With heartfelt appreciation, thank you, Yokota Foundation!

Finding strength
Allison Foss

When I first met Cynthia Gray last spring, she was reeling from the death of her husband David. Shortly there after, her MG would take her down a road where she would require a hospital stay and IVIg treatments to get her a ticket home. With IVIg not quite cutting the bill, Cynthia and her medical team at the University of Kansas opted to try Soliris.

As you may recall, Soliris, given through IV Infusion, was approved by the FDA as the first in a class of new drugs for treatment for generalized MG in the fall of 2017.

Cynthia started Soliris last fall at the KU Infusion Center in South Kansas City. She takes medical assisted transit there twice a month from her home up North for her infusions. Not only does Cynthia have a smile back on her face, she has a pep in her step and she is back co-teaching exercise class three days a week at the Senior Center in Smithville.

Cynthia shared she is fortunate enough to have an upbeat personality and tries not to sweat the small stuff. Cynthia stated her MG was in remission for many years. With the help of her infusions she is back to feeling almost as she did all those years she was in remission.
Are you prepared?

If you are like me, you want to forget that our snowy winter ever existed. As it’s now spring, ‘tis the season for tornados and storms, are you prepared? Preparing for a natural disaster is one thing but preparing for a natural disaster while you battle a chronic illness is a whole other “thing.” In a recent blog post published by the University of Southern California Department of Nursing titled, “What Can Chronically Ill Patients Do To Brace For Natural Disasters,” Dr. Tracie Kirkland shares the following tips.

- Maintain a 10-day supply of all necessary medications
- Wear a bracelet that helps first responders identify an individual with a chronic condition or specific care requirement.
- Organize a supply of emergency food, battery-operated flashlights and a change of clothes.
- Have devices at home that monitor vital signs and changes in physical health.
- Ensure family members and close neighbors know how to administer care.
- Develop an evacuation plan, including identifying stable buildings in the community for shelter.
- Sign up for community warning systems for weather alerts
- Organize communication with family members in the event of lost power.
- Create an updated list of emergency phone numbers for providers and medical facilities, and keep the list somewhere accessible.

This is a great time to review your plans for emergency and natural disasters with your loved ones, care team and paramedics. Stay safe and enjoy all things spring!

See you at the 9th Annual MGA Triple Crown Showdown

On May 19, 2019, participants will take to the roads of Leawood for the 9th Annual MGA Triple Crown Showdown 5K Run, Mile Mosey and Tot Trot. 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 are our VIP’s! VIP status means you register for FREE and have your own easy check in station on the day of the event. VIP’s can register for free using the code MGA19. Friends and family of those impacted by MG 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. All promo codes expire on 5/16/19 so don’t delay! Be looking for return appearances from Corner Bakery, Half Pint Heroes, Top Golf and Smoothie King! VIP’s running and walking isn’t required. Just come hang out! We hope you join us for this very fun morning of raising awareness and meeting others impacted by myasthenia gravis.
A MESSAGE FROM THE MGA’S EXECUTIVE DIRECTOR

You might notice we have changed some things up with this edition of Connections. Do you recognize what we have changed? We become so ingrained in everyday rituals that we are often resistance to change. However, change is good! After all, we live in the Midwest where yesterday it was summer, today it is winter and tomorrow it will be fall! Living with a chronic illness means having the flexibility of getting through life one day at a time, one step at a time. It is kind of like change. Accepting what you can do today and checking out where you will land tomorrow! Keep smiling and keep putting one foot in front of the other, taking each day as they come. 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

MGA Board of Directors and Staff

President: Brett Henson
Vice President: LaDonna Diller
Secretary: John Sand, MD
Treasurer: Derek Haverkamp

Joe Bant
Brodie Beck
Michael Eagan
Stephanie Hubers
Ray Olsen
Lisa Sackuvich, RN
Nancy Vinsant
John Wilkinson

Executive Director: Allison Foss
Program Coordinator: Tanya Renner

Michael Eagan joins MGA Board of Directors

The MGA is happy to announce that Michael Eagan has joined the Board of Directors. Michael is a Senior Vice President of Operations and Marketing for the Advanced Technology Group (ATG). Prior to joining ATG, Michael worked at Deluxe Corporation and Cap Gemini Consulting, having served in multiple sales, marketing, and operational roles. He holds a Bachelor of Science degree in Marketing from Missouri State University and a Master’s degree from Webster University. Michael is active in the Kansas City community and is co-founder of the Sporting Blue Valley TEAM Soccer program, a soccer program designed for children with special needs. Michael and his wife Dorothy live in Overland Park and have 3 daughters and 1 grandson. Michael and his family were impacted by myasthenia gravis after his father battled it for many years. Welcome Michael!

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.
You've got our heart.

We've got your back.

We ❤️ making our patients 😊

Learn how ARJ's life-changing IVlg treatments help people across Kansas City.

arjInfusion.com/Journey
866-451-8804

ARJ's advanced IVlg 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.
New and emerging myasthenia gravis treatments
Mamatha Pasnoor, MD; Constantine Farmakidis, MD; Mazen M. Dimachkie, MD; Richard J. Barohn, MD

Myasthenia gravis (MG) is an autoimmune condition that has many effective treatments. In addition to anti-Acetylcholinesterase agents (e.g. Mestinon), therapeutic plasma exchange (PLEX), intravenous immunoglobulin (IVIG), thymectomy and corticosteroids, numerous other immunosuppressive and immunomodulatory therapies have become available for the treatment of MG. Some of these include azathioprine, cyclosporine, methotrexate, tacrolimus, mycophenolate mofetil and cyclophosphamide.

Complement Inhibitors:
Eculizumab (Soliris) is the recently approved medication for generalized MG. It is a recombinant humanized monoclonal antibody. It is designed to block part of the immune system called the terminal complement cascade, consisting of a series of reactions that trigger the damaging immune response seen in myasthenia gravis. Eculizumab binds to and inhibits the cleavage of protein called C5, an essential step in the start of the cascade. The benefit of this was demonstrated in a phase 3 clinical trial called REGAIN. This trial, which ended in June 2016, was a double blind placebo-controlled global study evaluating the safety and efficacy of Eculizumab in 125 generalized MG patients who failed to respond to other immunosuppressive treatments (refractory disease). The study results showed clinically meaningful reduction in disease severity in treated patients, compared to those on the placebo in the secondary outcome measures. A Phase 3 open-label extension study to assess eculizumab long-term safety and efficacy in patients who had taken part in the REGAIN study. This indicated sustained benefits after 52 weeks of additional treatment. These trials showed that the drug is safe in MG patients and patients receiving the eculizumab did better on MG-specific Activities of Daily Living (MG-ADL) and Quantitative MG scales (QMG). This has been approved by FDA in October 2017.

Life threatening and fatal meningococcal infections can occur with this treatment and therefore all patients who are planned to receive eculizumab, must be immunized with 2 types of meningococcal vaccines (Meningococcal conjugate vaccines (Menactra® or Menveo®) and Serogroup B meningococcal vaccines (Bexsero® or Trumenba®)) at least 2 weeks prior to administering the first dose. If medication needs to be started immediately prior to 2 weeks, antibacterial drug prophylaxis has to be provided for 2 weeks. The infusion is started at 900mg weekly for 4 weeks, followed by 1200mg for the 5th dose 1 week later, then 1200mg every 2 weeks. The most frequently reported side effects are musculoskeletal pain (joint pains and back pain), headache, nasopharyngitis and nausea. Patients are at increased risk of infections.

Other complement inhibitors in the investigation phase: Zilucoplan which is delivered subcutaneously (under the skin) is being currently investigated in a phase II clinical trial. Ravalizumab given intravenously, has the benefit of an extended dosing interval of 8 weeks. A phase 3, randomized, double-blind, placebo-controlled trial in MG is in the planning stage for this.

FcRn receptor antagonists
FcRn receptor antagonists are antibody fragment biologic agents. They bind the FcRn receptor and block the immunoglobulin recycling apparatus with the intent of decreasing overall IgG levels, including the levels of any disease causing IgG autoantibody. Efgartigimod is the first FcRn antagonist evaluated for safety and efficacy in patients with MG. A small study suggested fast and significant clinical improvement. A phase 3 trial of efgartigimod in MG is underway. There are also other FcRn antagonists in development for MG and other neuromuscular diseases. Rozanolixizumab has a completed phase 2 study in MG based on which the company will be initiating a confirmatory study in 2019. Another phase 2 study of agent M281 in MG is also in progress.

Subcutaneous Immunoglobulin (SCIG)
Another area of investigation of MG treatment has been subcutaneously administered pooled immunoglobulin G (SCIG). FDA approved the use of SCIG in other autoimmune neurological condition and now there are ongoing efforts underway to evaluate the suitability of SCIG in MG therapy. We have recently concluded a prospective open-label study in which MG patients on stable doses of IVIG were continued for 3 cycles on IVIG and subsequently stable patients were switched to SCIG. We found that most MG cases had no deterioration of the MG clinical status after the transition from IVIG to SCIG with good safety profile. There are other agents that are under investigation as potential treatments for other similar autoimmune conditions e.g Belimumab, Tocilizumab, Abetacept.
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 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

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.

Health Care

The MGA hosted our 3rd Annual Cyclegiving event at CycleBar Leawood in February which sold out all 48 bikes and raised $1475 for the upcoming MGA Triple Crown Showdown!

Mark Your Calendar

9.6.19
Blvd Brewing Company

10.12.19
St. Louis

The MGA hosted our 3rd Annual Cyclegiving event at CycleBar Leawood in February which sold out all 48 bikes and raised $1475 for the upcoming MGA Triple Crown Showdown!
Making a splash

In 1996, Terry Ham started working for his father in law, Jim Kraft with Kraft Pool Service, opening and closing about 70 pools and providing full service throughout the season to about 40 pools. In 2005, Terry would buy the business and rename it Ham’s Pool Service, but he would also be diagnosed with MG. However, MG has not stopped Terry from making a splash in the pool business. Ham’s Pool Service now has 7 employees and in 2018 opened and closed 240 pools as well as provided full service to 140 pools. They also have a long list of customers who count on Terry and his staff for service calls for equipment repair.

Terry has learned how to adapt and grow his business while also managing his MG. Terry stated he feels fortunate that his MG has progressed slower than other people he knows. He acknowledges that MG is so different for each person. Terry stated, “A slower progression and a great neurologist is why I think I am able to still perform my duties.” He shared that his MG does somewhat dictate his schedule. “For instance, if I am going to bid a job and will need to speak to a customer, or have a lot of phone calls I need to make, I do this in the early part of the day.” Terry’s MG seems to worsen later in the day. Terry relies a lot on email and texting for communication with customers. When Terry’s wife isn’t doing the bookkeeping, she is helping with the phone calls.

Terry loves the freedom of being self-employed and working in some of the city’s most beautiful backyards! Terry intends to continue to build on the business he bought from his father in law while managing his MG. We’ll be thinking of you on those hot Kansas days, Terry!
June is MG awareness month

Here are some ideas on how you can raise awareness.

- Share this newsletter by pressing forwarding via email, or share on Facebook and Twitter. Still getting a hard copy? Pass it along to a friend or family member!
- Explain to stranger what myasthenia gravis is.
- Use hashtags #mgakc #mgastl #mgacomo #mgawhc #mganwa #careaboutrare #rarekc #mgstrong on social media
- Invite others to “like” the MGA Facebook page (@mgakc)
- Contact the MGA office and ask for a brochure to take to your local EMT/Paramedics.
- Attend the next support group in your area or ask a friend to join you!
- Wear teal! Wear your MGA gear! Wear an awareness bracelet. Don’t have one of our awareness bracelets? Send us a message and we will get you one!
- Make a donation to the MGA in honor of June Awareness month.
- Connect with us on social media.

@mga_heartland @mgakc @myastheniakc

National Take Back Drug Day is April 27, 2019.
Check out www.takebackday.dea.gov for locations in your area for proper drug disposal.

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

HUGE THANKS TO ALL WHO CAME OUT TO BARSTOOL SESSIONS IN FEBRUARY WHICH RASIED $2000 FOR THE MGA!
### MG Support Groups

<table>
<thead>
<tr>
<th>Area</th>
<th>Dates</th>
<th>Time</th>
<th>Location</th>
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<tbody>
<tr>
<td>Kansas City, MO</td>
<td>July 13th</td>
<td>10am-12:00pm</td>
<td>St. Joseph Medical Center ~ Community Center</td>
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<td>note time change</td>
<td>1000 Carondelet Drive</td>
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<td>Kansas City, MO 64114</td>
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<td><a href="mailto:tanyarenner@mgakc.org">tanyarenner@mgakc.org</a> or (816) 256-4100</td>
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<tr>
<td>KC Northland</td>
<td>May 9th, July 11th</td>
<td>noon-1:30pm</td>
<td>Primrose Retirement Communities</td>
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<td>8559 N Line Creek Pkwy</td>
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<td>Kansas City, MO 64151</td>
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<tr>
<td>Columbia, MO</td>
<td>June 6th</td>
<td>6:30-8pm</td>
<td>Daniel Boone Regional Library</td>
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<td>100 W. Broadway</td>
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<td>Columbia, MO 65203</td>
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<tr>
<td>Springfield, MO</td>
<td>April 25th, July 25th</td>
<td>6-8pm</td>
<td>The Library Center</td>
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<td>4653 S. Campbell</td>
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<td>Springfield, MO 65810</td>
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<tr>
<td>St. Louis</td>
<td>June 8th</td>
<td>10am - 11:30am</td>
<td>Glendale City Hall</td>
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<td>424 Sappington Road</td>
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<td>St. Louis, MO 63122</td>
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<tr>
<td>Wichita, KS</td>
<td>June 22nd, July 20th</td>
<td>1-3pm</td>
<td>Via Christi St. Francis Hospital</td>
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<td>929 N. St. Francis St.</td>
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<td>Wichita, KS 67214</td>
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<td>Contact: Dana or Larry Paxson for more info or to RSVP</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 Persons</td>
<td>July 9th</td>
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<td>Chicken N Pickle</td>
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<td>1761 Burlington Street</td>
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<td>North Kansas City, MO 64116</td>
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<td>RSVP to Allison Foss <a href="mailto:allisonfoss@mgakc.org">allisonfoss@mgakc.org</a></td>
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<tr>
<td>Omaha, NE</td>
<td>May 11th, June 8th</td>
<td>10am-noon</td>
<td>Calvary Lutheran Church</td>
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<td>2941 N 80th St, Omaha, NE 68134</td>
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<td>Contact: Dianna McCarty for info or to RSVP</td>
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<td><a href="mailto:dmcarty@abbnebraska.com">dmcarty@abbnebraska.com</a> or (402)426-8006 or</td>
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<td>Kathy Cassidy - <a href="mailto:cassidykathryn@yahoo.com">cassidykathryn@yahoo.com</a> or</td>
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<td>402-719-5861</td>
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<td>Northwest, AR</td>
<td>May 19th, July 14th</td>
<td>2:30-4:30pm</td>
<td>Schmieding Center for Senior Health and Education</td>
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<td>2422 N. Thompson (Hwy 71 North)</td>
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<td>Springdale, AR 72764</td>
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<td>Contact: Roger Huff for more info or to RSVP</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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</tbody>
</table>

- Ongoing and current calendar can be found at www.mgakc.org
- Your RSVP to support group is important to support group coordinators! Please RSVP!
In Memoriam
Marilyn Lowrey
Newton, KS
Kenneth and Brenda Shipley
Carol Fieser
Norval and Dallas Harris
Jeff and Susan Guilkey
Debra Power
Kimberly Caliendo
Thomas and Dana Wurdemann
John and Julie Frisbie
B.D. and Joyce Parker
Steven and Colleen Van Gieson
Carolyn Adams
Carla and Jerry LeRoux
Glenda Burkett
Earl and Norma Compton
Bruce and Sondra Stonebraker
Philip and Judy Wacker
Ted and Debbie Hall
Marilyn Schmidt
Kirk Poe
Randy and Rosemary Jackson
Jack and Judy Casner
Carol Barnes
Kenneth and Alice Robson
Rita Parker
Bob, Barbara and Katie Parker
Mark and Renee Sinclair
J.C. Long

Margaret Anderson
Winfield, KS
Janice Bode

John Suther
Topeka, KS
Karen Suther and Family
Chuch and Virginia Schumacher
Patricia Keithley

Gene Wilmoth
Olathe, KS
Bob and Cindy Tucci, Jeff, Jeanna and Joe Wolfe
Sharon Piercey
Susan and Larry Devine
Kaye Darter
Daniel and Nancy Richart
Anne Strader
Joyce and Michael Orlovski
Timothy and Lila Strubhar

2019 Membership Drive
Ron Crumpler
Brodie Beck
Jacque and Brett Henson
Stephanie and Jeremy Hubers
Derek and Nina Haverkamp
Allison Foss
Jay Hurt
Richard and Janice McGuire, in memory of Jacob McGuire
Anita and Everett Jenkins
Arthur and LaQuita King
Harry and Beulah Paxson
Daniel and Denise Cogan
Marilyn and Don Sisson
Michael and Dorothy Eagan
Richard DeGeorge
Anne Strader

On the Bookshelf
The Port by E.H. Sonny
(Summary taken from I.G. Living 2019)

When a boy becomes sick, the Masked Ones steal him from his happy graveyard home and place a port in his chest so they can summon him at will. Raw and poignant illustrations reveal the boy’s conflicted relationship with the port and a medical system that heals his body but damages his spirit. In a story both cathartic and hopeful. The Port speaks to the importance of patient empowerment at all ages, especially when managing a chronic illness and/or enduring repeated hospitalizations.

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.
Cooling Vest Option for MG

As most know heat can play a role in myasthenia symptoms. There appear to be more cooling vest options on the market for those with neuromuscular diseases. An article titled, “The Effect of Whole Body Cooling in Patients with Myasthenia Gravis” summarized the following.

Local muscle cooling has been shown to reduce symptoms in some neuromuscular diseases. To determine whether lowering body temperature using a cooling vest would result in improvement in muscle strength, subjective perceptions of weakness and fatigue, and pulmonary function in patients with generalized myasthenia gravis (MG). Patients (five female, one male) with generalized MG, aged 29-58, were studied when mean body temperature was lowered (34.9 +/- 0.62 degrees C) using a cooling vest (CT) and at normal body temperature (35.8 +/- 0.58 degrees C) (NT). Isokinetic and isometric muscle strength and isokinetic endurance were measured using upper body muscle groups. The myasthenic muscle score (MMS) was performed to assess muscle impairment specific to MG patients. Pulmonary function measurements included forced vital capacity (FVC), maximal inspiratory pressure (MIP), and maximal expiratory pressure (MEP). The fatigue impact scale (FIS) was used to track subjective perceptions of fatigue. Core body and skin temperatures were measured throughout each NT and CT trial. Mean body temperature was reduced significantly following 30-45 min of cooling. The MMS and MIP increased significantly with cooling. Although all other variables were not statistically different between temperature conditions, individual results for grip strength of the right hand, fatigue ratio for wrist extensors and shoulder internal and external rotators, FVC, and MEP showed improvement for the majority of the subjects. Cooling in patients with MG shows promise to decrease symptoms of weakness and fatigue, thus allowing increased muscle strength and endurance in some patients. Body cooling vests are available online and through durable medical supply companies with prices ranging from $39 to $250. Let us know if you turn to a cooling vest this summer and how you fare.

Please become a 2019 member!

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<tr>
<th>PLEASE PRINT</th>
<th>Cut &amp; enclose in envelope &amp; mail to:</th>
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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
☐ $ 500 Patron Membership
☐ $ 1,000 Lifetime Membership
☐ $ ____ In Memory of:
☐ $ ____ In Honor of:

Thank You!

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

https://www.firstgiving.com/event/mgakc/2019-Membership-Drive
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.

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