

MGFA LAUNCHES STRATEGIC PLANNING PROCESS FOR 2021-2023 AND BEYOND

How does an organization go to the next level in ensuring relevance to those it serves? Staff and volunteers need to first understand the needs and interests of their key constituents. Only then can they set about developing a plan that has the right goals, and pathways to achieve them. An organization's strategic plan is its roadmap, and getting it right is essential in ensuring that leadership allocates resources for the greatest possible impact.

To ensure the best results, we asked new MGFA Board member, Brian Gladden, to lead the process. He not only agreed, but has also brought talent and resources from his business associates to guide the process. Brian is currently an operating partner for Bain Capital, and has

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2020 MG Walks

- FEB 8 Coconut Creek, FL
- FEB 22 St. Petersburg, FL
- FEB 29 Tallahassee, FL
- MAR 14 Atlanta, GA
- MAR 14 New Orleans, LA

NATIONAL WALK

- APR 4 Ft. Worth, TX
- MAY 9 Green Bay, WI
- MAY 17 Charlotte, NC
- MAY 30 San Francisco, CA

MORE WALK DATES COMING SOON!
Please go to mgwalk.org for more information on a walk near you!

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MG Community "LIGHTS THE MAP TEAL" in over half the nation for June Awareness Month!

What began in the beginning of June as a blank United States map transcended to 26 states illuminated teal nationwide, thanks to the tremendous and impressive work by our MG community. Volunteers, support group leaders and members all raised awareness efforts within their cities, parishes, and states to make June #MGStrong.

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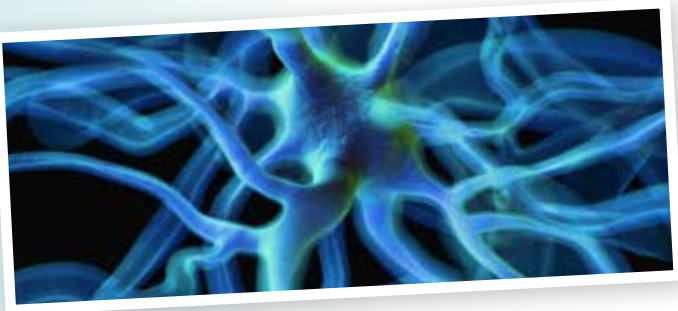
CEO'S LETTER



Dear MG Community Colleagues,

WE HAVE AMAZING NEWS TO SHARE!

In October, the National Institutes of Health (NIH) announced a \$7.8 million award to establish a rare disease network for myasthenia gravis!



Please see the press release on page 4 for details of the project. We owe huge thanks to members of our Medical and Scientific Advisory Board who comprise the executive committee for this project, called MG Net. Led by Dr. Henry Kaminski and Dr. Linda Kusner of George Washington University, this group has hit the ground running—already issuing a request for applications for pilot grants and fellowships for young investigators. The funding will also ensure that the serum bank that was started by Dr. Jeffrey Guptill at Duke University with a \$275,000 three-year transformative grant will continue—providing samples for MG research that will lead to greater understanding of the disease. Dr. Guptill is already seeking support to add more sites to the project.

MG Net has been in the works for more than a year, and to demonstrate the commitment of the MG Community to support MG Net, MGFA pledged \$250,000 over the five-year period to support the work. We know that our commitment, and a matching one from Illinois-based Conquer

MG, were instrumental in demonstrating the engagement of the MG community in supporting research.

MGFA will play a major role in supporting the project, with a position on the Executive Committee, and participation in the Council of Patient Advocacy Groups for the Rare Disease Clinical Research Network (RDCRN). I am excited to be our organization's representative and took part in the initial meeting on November 20, 2019. I look forward to sharing what I learn from the other disease groups. There are only 25 disease networks at any given time who are a part of this network. It is really very special to see MG included in this way. I am sure we will have a feature on this project at our National Conference too.

And speaking of that, **we hope to see many of you at the beautiful Omni Hotel in Fort Worth for that National Conference and our National Walk.** Our National MG Walk will be just outside the hotel doors of the spectacular Ft. Worth Water Garden. Search "Ft. Worth Water Garden" online and see some of the amazing videos!



There are lots of fun things for families to do in Ft. Worth. What other city has a daily long horn cattle drive? Our conference planning team of staff and volunteers are busy putting the curriculum together, and we have some top clinicians who have already let us

know they want to be there to speak. We expect this to be our biggest and best conference yet. Everything is bigger in Texas, right?

We know that not everyone can travel to the National Conference, and staff are working with community volunteers to put together regional meetings. This fall, we have had conferences in the Pacific Northwest, Houston and New England. Next year, we are already looking to expand to other areas. Please let us know if you think your community would like to organize a patient education meeting in your area in 2020.

Our support group network is more than 90 groups strong nationwide!

We also wish to take the time out **to thank each of you that participated in our MG Community Strategy Survey** to help shape the future of MGFA. **With nearly 850 responses**, we heard your feedback about our programs and services, and what we can do in the future to better serve the MG community. To see some of the early takeaways of the survey and learn more about our plans for the future, please see the article on the front cover.

There are so many good things happening for our MG Community right now. I want to thank all of you. I don't think MG Net could have happened without all of the efforts from people living with MG to raise awareness. And it is because of the support of our donors that MGFA was able to make the financial commitment to the project, demonstrating the dedication of the MG community recognized in this award. It is amazing to see how our MG community is growing—bigger and stronger every day.

OUR TIME IS NOW!

With gratitude,

Nancy Law

Nancy Law, CEO

*I don't think
MG Net could have
happened without
all of the efforts
from people living
with MG to raise
awareness.*

If you or someone you know is experiencing sudden or gradually increasing symptoms of muscle weakness, it could be a sign of MG or another serious condition. Talk to your doctor if you are short of breath, have difficulty smiling, talking or swallowing, or cannot walk any distance without having to rest.

This publication is intended to provide the reader with general information to be used solely for educational purposes. As such, it does not address individual patient needs and should not be used as a basis for decision making concerning diagnosis, care, or treatment of any condition. Instead, such decisions should be based upon the advice of a physician or health care professional who is directly familiar with the patient.

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MGFA part of 7.8M Initiative to Establish Rare Disease Network for MG!

MGFA is proud to represent the MG community as a member of MG Net, and has committed \$250,000 of funding (\$50,000 for each year) to support the project. This commitment from MGFA, as well as that of Illinois-based Conquer MG, was instrumental in demonstrating the support of the MG community for the project—an essential component of the criteria for funding established by the NIH.

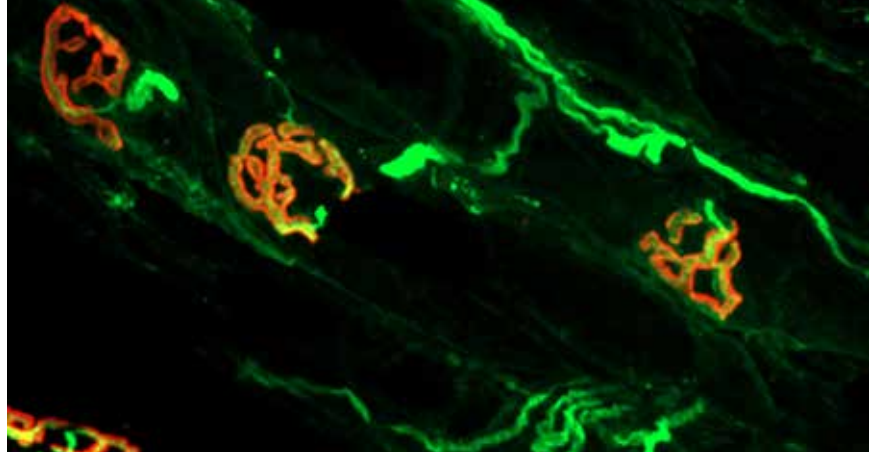
The grant will fund research into the underlying pathophysiology of the disease, provide fellowships in MG for young investigators, and fund pilot grants. This funding will also ensure that the serum bank created by the MGFA's transformative grant will continue.

Official press release below:

GW RESEARCHERS RECEIVE \$7.8 MILLION TO ESTABLISH RARE DISEASE NETWORK FOR MYASTHENIA GRAVIS

This is the first large, organized effort to search for improvements in myasthenia gravis, in not only research and treatment, but in education

WASHINGTON (Oct. 3, 2019) — The National Institutes of Health (NIH) awarded a research team at the George Washington University (GW) \$7.8 million to establish a rare disease network for myasthenia gravis. The network, which will be part of 25 established NIH Rare Diseases Clinical Research Networks, will include basic and clinical investigators, patient advocacy groups, and biotechnology and pharmaceutical companies working together to enhance therapeutic development for this rare disease.



Henry Kaminski, MD, chair of the Department of Neurology and Meta Amalia Neumann Professor of Neurology at the GW School of Medicine and Health Sciences (SMHS), is a world-renowned expert in myasthenia gravis and has spent decades studying the disease. He is joined by Linda Kusner, PhD, associate research professor of pharmacology and physiology at GW SMHS, and Alison Hall, PhD, associate dean for research workforce development at GW SMHS, in leading this grant.

“Myasthenia gravis is a chronic autoimmune disease that affects how well the nerves and muscles communicate with each other. Often patients experience extreme weakness, struggle with their vision, and are even hospitalized because of difficulty breathing,” said Kaminski. “This grant will give the researcher community the needed infrastructure to study this rare disease in order to develop new therapies.”

The grant will fund research into the underlying pathophysiology of the disease. There is a lack of understanding of the different subtypes of myasthenia gravis, no known biomarkers, and a scarcity of research labs studying the disease. Upwards of 30% of patients are treatment resistant and all suffer from undesirable to dangerous adverse effects as a result of treatment. To remedy this, the grant will focus on studying the differences between ocular myasthenia and general myasthenia – they produce different antibodies that begin attacking nerve and muscle communication, which often change over time – and individualized medicine approaches for the 10% of myasthenia gravis patients who develop tumors triggered by the disease. The research team will also identify and collect biospecimens for future study and follow myasthenia gravis patients in order to identify biomarkers.

Having defined disease variability and clinical outcome measures will enhance clinical trial readiness. Through the grant, the research team will pilot their own clinical trial to determine whether a current cancer drug that works to eliminate cells producing harmful antibodies might also be effective for myasthenia gravis patients.

In order to increase the number of labs researching myasthenia gravis and aid further discovery in the field, the grant will also support a career enhancement program. This will include new training and educational opportunities for scientists, physicians, and the lay public. These opportunities will not only increase the pool of young investigators focusing their careers on rare diseases, specifically myasthenia gravis, but improve awareness of the unique needs of myasthenia gravis patients.

“The grant is not a just a single project, but the establishment of a resource that will drive research for many years,” said Kaminski. “Other rare disease networks funded in the last 10 years have advanced treatments for these disorders that otherwise would have been impossible.”

The GW research team will be supported by commitments from the Myasthenia Gravis Foundation of America and Conquer Myasthenia Gravis. They will also consider collaborations with the Muscular Dystrophy Association and other organizations.

Media: To learn more or to interview a member of the research team, please contact Lisa Anderson at lisama2@gwu.edu or 202-994-3121.

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About the GW School of Medicine and Health Sciences

Founded in 1824, the GW School of Medicine and Health Sciences (SMHS) was the first medical school in the nation’s capital and is the 11th oldest in the country. Working together in our nation’s capital, with integrity and resolve, the GW SMHS is committed to improving the health and well-being of our local, national and global communities. smhs.gwu.edu



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extensive executive level business experience having served as Chief Financial Officer for major corporations Mondelēz and Dell. Thanks to Brian's relationships, MGFA is the beneficiary of consulting support from Bain & Company and a non-profit organization called Inspire, which provides world-class assistance in planning to nonprofits. Inspire is a national organization with four host firms – Bain & Company, The Parthenon Group, L.E.K. Consulting, and Deloitte Consulting LLP – experts in business strategy who are offering their services pro bono. It is a tremendous gift for MGFA to have this leadership and expertise enabling us to have the deepest and most thorough planning process in our history—one that will set the direction for the organization for 2021-2023 and beyond. Joining Brian in leading the Strategic Planning Task Force are Board Chair Emeritus, Sam Schulhof, current Board members, Phil Cogan, Mike Ursic, and Dr. Katherine Ruzhansky, and Georgia Support Group Leader, Alexis Rodriguez.

As one of the first steps, we conducted an online survey designed to gather detailed feedback from members of the broad MG community on how they feel about MGFA and what they want from MGFA in the future. The survey was open for the month of September and we received almost 850 responses! We heard from family members, clinicians and others, but the vast majority of respondents (85%) were MG patients, with almost half having connected with MGFA in just the past 3 years.

Here are some early takeaways from this process:



Most of our stakeholders initially connected with MGFA via online search, our website and social media pages ... while legacy stakeholders learned about MGFA from their healthcare providers



Over 75% of our stakeholders use the MGFA website and read our newsletters regularly ... and these offerings are highly rated by the respondents



When asked to rate various MGFA programs/capabilities – most respondents were positive or very positive on all offerings



More than half of respondents rated key MGFA offerings as good or excellent ... newsletters, social media content, conferences and peer support programs



When asked to prioritize our future efforts – the top three areas were website, MGFA support programs, and educational materials for healthcare professionals ... with social media, MGFA conferences and newsletters as the next three areas





Perhaps the most important message:

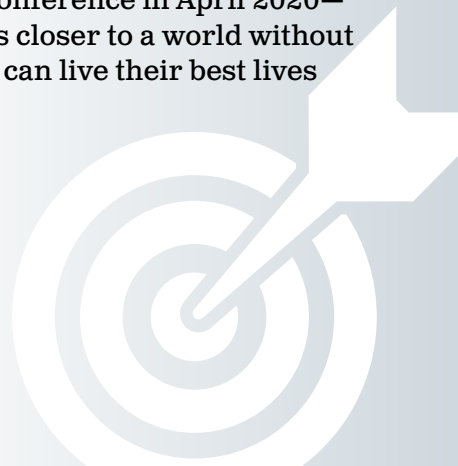
Our stakeholders would overwhelmingly like us to prioritize future investment into research ... both in improving treatment and disease management, as well as the finding the underlying causes and mechanisms of MG that could lead to a cure.

We also asked all respondents to share any other thoughts or inputs for MGFA, and we received a broad range of feedback ... both good and bad, but all very constructive. Some of the comments pointed us to short-term opportunities to improve MGFA, which we are working to address in the near future.

In addition to this input, team members are reaching out to have deeper conversations with a few dozen key MGFA stakeholders ... including regional community and support group leaders, clinicians and scientists, industry partners, donors, fundraisers and others.

Board Chair Edward Walsh expresses appreciation to all who are participating. “Thanks to Brian, the team from Inspire, the planning team, the MGFA Board and staff, and ALL who are participating in the survey and interviews. Working together, we will create the right plan to make MGFA the organization that the MG community needs and deserves.”

There is more to come in the next few months. We are at an exciting time for the MG community, with growing understanding of our disease from scientific research, and unprecedented interest from industry in developing new and better treatments—while growing programs and connections for those who live with the disease every day. We expect to be able to share a draft of the 2021-2023 Strategic Plan at our National Conference in April 2020—a plan that we hope will bring us closer to a world without MG, while ensuring that people can live their best lives with MG. More to come! ✨



Do You Want to
Wake up to a
World without MG?
YES?

Then help by
joining the **MG**
Patient Registry

The MGFA Patient Registry is helping to expand our knowledge of MG and move us closer to improved treatments and a cure. By making a patient community more accessible and understandable, a patient registry and its bounty of information can encourage pharmaceutical developers to pursue drug discovery in a disease.

To learn more about the registry please visit www.myasthenia.org home page banner and click on the banner when it turns to MG Patient Registry. Or, call the MGFA office at (800) 541-5454 and request the *MG Patient Registry* brochure.



In an inaugural campaign, the Myasthenia Gravis Foundation of America (MGFA) asked our communities to help light their states teal on our digital map by completing any one of the following tasks:



Lighting Up Teal: corporate buildings, sports stadiums, bridges or street lights



Proclamation Nation: establishing city, town, and state proclamations



Press Coverage: receiving any press around June Awareness; newspaper, magazine articles or TV station interviews – MG Walk promotion included here too!



DIY Fundraising: complete a Do-It-Yourself fundraiser during the month of June



Showing Support: send us your support group meeting photo with everyone dressed in teal

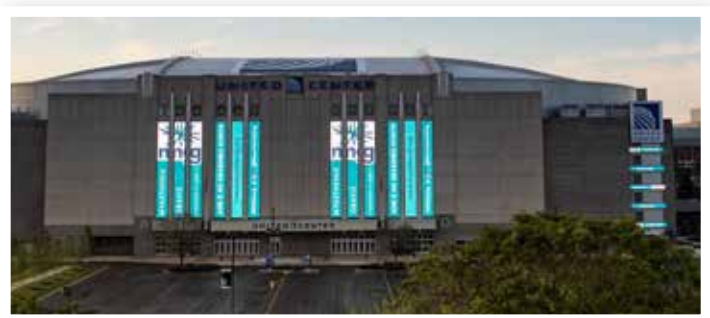


Celia Meyer and friends raising funds and awareness for MG!

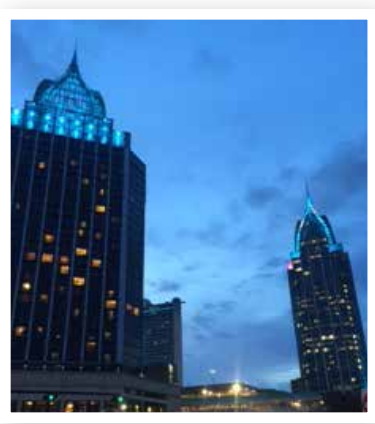
#MGStrong

From illuminating sports stadiums, business buildings and street lights, to garnering city, town and state proclamations, and being a part of more than 15 newspaper and online publications, the messages of #MGStrong and myasthenia gravis awareness spread worldwide and were fast and furious in 2019.

For the second consecutive year, **the United Center in Chicago**, where the Bulls and Blackhawks play, displayed #MGStrong signage all along the outside of the arena and LED display boards, and also lit up the arena teal.



Barbara Wilson lit multiple buildings teal in **Mobile, Alabama**;





Donnalee Whitaker helped light up the Legislative Hall in **Dover, Delaware;**

and **Sharon Byrge** continued her annual tradition of lighting up several streets in **Knoxville, Tennessee.**



Special thanks to Superwoman **MG warrior Paula McGinnis** who completed these awareness efforts in five different states - **Illinois, Kentucky, Hawaii, Wyoming, and Tennessee.**

The Messenger
Wednesday, June 26, 2019
HEALTH
Myasthenia Gravis awareness promoted throughout June
June is Myasthenia Gravis Awareness Month and Illinois is one of the states to hold associated events, well, ally s, a me der by the sas sr, k, e, ut s, d
held associated events, well, ally s, a me der by the sas sr, k, e, ut s, d
PAULA MCGINNIS
Ms. McGinnis said, "Since I am from Metropolis, known as the home of Superman, it was interesting to know the founding of the MGFA. The first chair of the foundation in 1955 was George Reeves."
The Myasthenia Gravis Foundation of America, www.myasthenia.org, is the only national organization dedicated to research, about MG, and it gives me the opportunity to let other MG patients know that they are not alone in the world with the rare neuromuscular disease," Ms. McGinnis said. "If you have MG, never underestimate the inspiration you can be to others as you live with MG with dignity and courage. Your life may be different from what it was before MG, but you are not alone

MG proclamations in Georgia, Massachusetts, Nevada and Texas.



Immunovant team wears teal for MG awareness in June!



WE THANK ALL OF YOU for a very successful inaugural campaign of "Make June #MGStrong and Light the Map Teal".

We look forward to building a wonderful 2020 June Awareness campaign with you next year! Stay tuned via our website and social media to learn more about the 2020 campaign as well as ways that you can raise awareness year-round. ✨



University of California, San Francisco, Launches First Consortium on Pediatric MG

For families with children that have myasthenia gravis, we have some exciting news to share. Thanks to a generous gift from an anonymous donor to the University of California, San Francisco, the first clinical Pediatric Myasthenia Gravis Consortium is now a reality. MGFA was honored to provide a grant to underwrite the costs for the September inaugural meeting of this exciting new project, and to participate on the advisory committee for the Consortium.

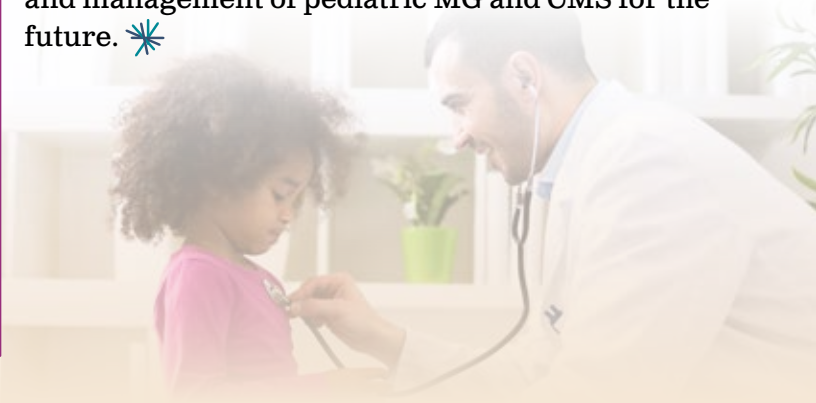


Leading the Pediatric MG Consortium is Dr. Jonathan Strober of UCSF Benioff Children’s Hospital. Other initial members of the Consortium include: Dr. John Brandsema, Children’s Hospital of Philadelphia; Dr. Diana Castro, UT Southwestern; Dr. Emma Ciafaloni, University of Rochester; Dr. Nancy Kuntz, Ann & Robert H. Lurie Children’s Hospital of Chicago; and Dr. Ricardo Maselli, University of California, Davis. The Advisory Committee is comprised of patients and their families, along with Nancy Law and Dova Levin from the MGFA, staff of the Muscular Dystrophy Association, and representatives from industry – Alexion and Momenta.

A critical goal of this project is to develop a pediatric patient database. Unlike the MGFA Patient Registry, where patients self-report through a survey about their health and symptoms, this will be a clinical registry with data direct from patients’ medical records. This pool of data will help clinicians better understand and treat pediatric MG and Congenital Myasthenic Syndrome (CMS).

At this initial meeting, the Consortium made decisions around what data to collect, how to collect data without increasing burden on the healthcare provider, and how to standardize the gathering of data. The Consortium also looked at methods of data collection, database options and possible plans for publication.

All the members of the committee are looking forward to the collection of this highly valuable data in order to enhance research, understanding and management of pediatric MG and CMS for the future. ✨



**SMILE
FOR
MGFA**

Did you know you could donate to the Myasthenia Gravis Foundation of America while shopping on **amazon**? It’s simple to set-up on an existing account or by creating a new one. You can shop as you normally do, there’s no change in cost or convenience to you. Tens of thousands of products are covered.

Go to smile.amazon.com/about to learn more and make **MGFA your charity!**



Programs to Help You Stay Connected and Supported Year-Round!



MG FRIENDS ARE HERE TO SUPPORT YOU!



MGFA's peer-to-peer phone support program, MG Friends, helps ensure that everyone in the community gets the information they need, and know that they are not alone in living with myasthenia gravis.

Since the program launched in 2017, our highly trained and professional MG Friends have provided phone support to nearly 300 patients and their families!

While Support Groups are critical to service delivery, there are many people who are not able to access this service or who feel more comfortable talking one-on-one rather than sharing in a group setting. MG Friends provides the opportunity for a person with questions and concerns to connect to someone else with MG—no matter where they live in the United States. Are you or someone you know looking for support via phone?

Here's what you need to know:

WHEN can an MG Friend help you?

Tele-support services are open to people with MG, caregivers and family members. An MG Friend can help people who meet one, or all, of the following criteria:

- Are in their first year of diagnosis.
- Are experiencing fear, confusion, a sense of isolation, and concerns about the future.
- Are worried about treatment side effects.
- Are coming out of remission.

WHAT does an MG Friend provide?

Through phone and email communication, our MG Friends provide:

- Confidential conversations.
- MG experience; someone who will listen actively and unhurriedly.
- Techniques to overcome daily challenges of MG
- Local resources that may be helpful (free or low-cost transportation, food banks, friendly visits, support groups, MG Walks).
- Information and answers.
- Neurologist names and contact information from the MGFA physician programs.
- Comfort, empathy and emotional support.

WHO are MG Friends?

MG Friends are men and women of varying ages and experiences. MG Friends have at least two years of experience living with MG (either as a person diagnosed with the disease or a family member). In order to be an MG Friend, you must possess the following qualities:

- Demonstrate empathy and a sincere desire to help others.
- Present good listening skills.
- Satisfactorily complete the MG Friends training program. ✨



Connect with an MG Friend Today! Visit the “Resources & Community” section of our website at myasthenia.org or contact us at **1-800-541-5454** or mgfa@myasthenia.org.



“Energy and Passion Personified”

By Tommy Santora | MGFA Board of Directors | MGFA Communications Committee Chair

KATHERINE RUZHANSKY, MD

Associate Professor of Neurology, Director of the EMG Lab, at the Medical University of South Carolina | MGFA Board of Directors | MGFA Medical & Scientific Advisory Board

When you listen to Dr. Katherine Ruzhansky talk about myasthenia gravis, her passion and energy are unwavering. From discussing the future of new clinical trials and research, to her work around consensus standards of quality care, to the importance of awareness, advocacy, and education for MG, her dedication is truly amazing.



MGFA Board of Directors and the Medical Scientific Advisory Board, in addition to being an active part of the MGFA Strategic Planning Committee and Education Committee. She is currently working on the second edition of the MG Healthcare Provider Manual, a massive undertaking!

Dr. Ruzhansky attended her first MGFA National Conference in 2015, after meeting

“This is not just a disease; it’s personified in every MG patient I meet, and the energy that I get from their resilience makes me always want to strive to do more for the MGFA community,” Ruzhansky said.

Mount Pleasant Support Group Leader Janet Myder and former member of the Nurses’ Advisory Board, Ruthann Devine. “Being involved helps drive research and awareness. MGFA has evolved, and has supported a lot of great scholars and projects. I want to volunteer and contribute as much as I can,” said Ruzhansky.



“I am always motivated by my patients, fellow members of the board, and colleagues in my profession.”



By day, Ruzhansky is an Associate Professor of Neurology and Director of the EMG Lab at the Medical University of South Carolina (MUSC). Along with her colleagues, she manages care for upwards of 250 MG patients. When she is not seeing patients or teaching, she attends the Low Country MG Support Group and participates in local MGFA fundraisers such as the MG Walk and golf tournament. Dr. Ruzhansky also serves on the

Dr. Ruzhansky was born in Russia and moved to New York at the age of nine. Inspired by her grandmother, a pediatric neurologist, she decided to become a neurologist herself. “My grandmother took care of children with seizures and cerebral palsy. She was truly a special doctor and person!” Ruzhansky shared.



“This is not just a disease; it’s personified in every MG patient I meet, and the energy that I get from their resilience makes me always want to strive to do more for the MGFA community”

Prior to relocating to Charleston, South Carolina, she trained in neurology and clinical neurophysiology at Yale-New Haven Hospital and Columbia University Medical Center. Her clinical focus has been the diagnosis and treatment of neuromuscular disorders. Since living in Charleston, she has met many wonderful people and patients who are actively bringing awareness to MG. “Treating patients with MG is both challenging and rewarding, but it is a treatable disease. With new clinical trials and emerging therapies, we are seeing more patients improve and control their symptoms.”

Ruzhansky said in the last two years she has been impressed by the volume of research, clinical trials and the expanded presence of pharmaceutical companies studying MG. In 2017, the FDA approved Soliris® (eculizumab). This was the first FDA-approved treatment in more than 60 years for patients with generalized myasthenia gravis. If you visit the Clinical Trials website of the National Institutes of Health,

a search for myasthenia gravis yields 80 results of recruiting, enrolling, active, or completed clinical trials. “There are more focused therapies and treatments evolving, and that’s very exciting. We still have the challenges of costly therapies and drugs, insurance issues, access to a limited number of neurologists or MG experts in the field, but I feel that these issues are coming to the forefront because of increased awareness and the collective voice of the patients and MG community.”

In her spare time, Ruzhansky likes to travel and enjoys the beach and marine activities. When



Ruzhansky is not raising awareness for MG, her dog Nora steps into help. With more than 1,300 followers on Instagram, “Lady_Nora_Sweetheart” can be found wearing an MG Walk shirt to promote the next fundraiser in South Carolina. “She’s an Instagram superstar, and for some odd reason, go figure, likes to wear teal.” ✨

Catch up with the MG Community

Learn more and share your story... on our website, Instagram, Facebook, Twitter and YouTube

myasthenia.org    





2019 Volunteer Spotlight: Making Us Stronger!

We truly value those who share their time, expertise and dedication in serving the MG community. We would like to take this opportunity to highlight and celebrate a few volunteers that have done amazing work in this past year. Many volunteers have come to find that volunteering is not only a rewarding experience, but that it also raises MG awareness! Putting MGFA volunteers in the spotlight is our way of showing gratitude to everyone that gets involved to help us stay #MGStrong!

“I am a voice for others who are not able to advocate for themselves!”



When I talk to people about myasthenia gravis, they tell me “I have not seen any commercials on TV.” Or they might ask “why don’t you have a TV advocate, like Michael J. Fox?” My response is “I am the commercial”. As a leader in the New England area, it is my goal to work with the state and local government officials, pharmaceutical companies, medical personnel and other MGRers to bring myasthenia gravis awareness to the forefront, in hope of finding a cure.

Awareness starts at home. I challenge each and every MGRer to become their own commercial by sharing their MG story in their community via local media. Let’s start planning to light a building teal in your town or city during MG June Awareness Month”

— **GLENDA THOMAS**
New England Support Group Leader, MG Walk Lead and Advocate

“You cannot lead others until you learn how to serve.”

Being involved in my local MG support group, advocating for myself and fellow MG patients, raising awareness, and fighting to find a cure for MG — that is what it means to be a leader in my MG community!

I am heavily involved in my local MG support group and help run the group with leaders Denise Allen and Ted Monica. I also help organize fundraisers in our area for the MGFA. In addition, I am helping plan our local walk. Awareness and fundraising are crucial to MG and finding a cure!

— **CASSIE HURST**
MG Walk Lead, DIY Fundraiser, Tallahassee Support Group Co-Leader and Advocate



“By working together, I truly believe a cure can be found.”



The number one reason I volunteer is to pay forward all that I have received when I needed it most. While no one wants to be diagnosed with a rare disease, I consider those I have met on this journey my closest friends. There is a special bond we all share and I can't imagine life without these people in it. It is these people, the patients, the medical personnel and the caregivers that have become a part of everyday life - without a doubt, this means more to me than anything. Through my volunteer work, I feel as if I have a huge family that understands what life with MG is like.

Life with MG is actually easier when you are involved in the MGFA. It is empowering to know that you are helping others. I urge each and every one of you to get involved in some way. Find an MG Walk, attend a local support group, become an MG Friend, go to a National Conference and please take the time to join the MG Patient Registry.

– **ROGER MORSE** *Maine Interim Support Group Leader and MG Patient Registry Advocate*

“I’ve started a support group to help others know they aren’t alone.”

My symptoms varied in severity, from double vision, slurred speech, to trouble chewing and swallowing. I lost over 40 pounds in less than 3 months. MG left me unable to move and breathing at only 40% capacity, yet, doctors were unable to give me a correct diagnosis.

I came to accept I had myasthenia gravis when I tested positive for MuSk antibodies. I accepted that I would need more aggressive treatments to treat my MG.

Despite my difficult journey towards an MG diagnosis, I have been able to reduce the need for the cocktail of pills, IVIG treatments every two weeks, and have much less hospital stays.

Today, I live as much as possible to end the stress and negativity in my life that kept me from getting well. “Being available when somebody needs it the most” is what volunteering means to me.

– **LEAH DE LA TORRE** *Los Angeles Support Group Leader, MG Walk Lead* ✨



Join the Team!

Become a volunteer today by visiting the “Get Involved” page of our website at myasthenia.org!



MG Community Gets Creative with Fundraising and Friend-raising!



Raising money for the Myasthenia Gravis Foundation of America is easier than ever! With Do It Yourself (DIY) Fundraising, you can design a fundraising event or activity that builds on your passions and interests. You name it! Love the idea of an endurance event? Getting ready to celebrate a special occasion like a milestone birthday, anniversary or Bar/Bat Mitzvah? Do you just need a little motivation to host a themed party? No matter your interest, DIY Fundraising is your way to bring us closer to a world without MG.

This year, more volunteers than ever stepped up to organize events to benefit MGFA. From \$1,000 to more than \$40,000, from cardboard boat races to golf tournaments, volunteers all over the nation raised vital funds and awareness. See highlights of some of the great events that happened this year!

If you want to plan something in your community, contact Betty Ross, Director of Development, bross@myasthenia.org. She can show you how to create your own event website to support your fundraising efforts.

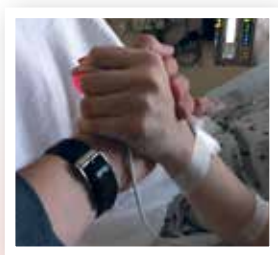
GRIP IT AND SIP IT FOR MG GOLF TOURNAMENT

DAVE AND LAUREN JARMAN

very active MGFA fundraisers and donors, wanted to do even more to help support MGFA. In honor of Lauren, who has been battling MG since 2011, they wanted to support MGFA's work toward finding better treatments and a cure for MG through fundraising. While the Jarmans had a very successful letter-writing campaign, they decided a local event might do even more to help people with MG. With this goal in mind, they hosted the first inaugural "Grip It & Sip It for MG Golf Tournament" in Charleston, South Carolina, at Patriots Point Links Golf Course. The event, sponsored by the South Carolina Stingrays, a minor league ice hockey team, sold out in its first year! **"Grip It & Sip It" netted over \$40,000 for MGFA** including ticket sales, donations and a live auction.



Dave shared that there are many people to thank for the success of the event, including the South Carolina Stingrays, Lewis Barbecue and Revelry Brewing, who all pitched in without hesitation. The Jarmans also wish to thank argenx, Ceterus, R&K Insurance, Infucare RX, MerchantPro, as well as volunteers Joe Devin and Jason Fitzsimmons, all of whom made the event a great success. Dave shared, "It was so amazing to see so many people supporting such a great cause." Dave says,





“Lauren inspires me every day, and I hope more people hear her voice for this terrible disease.” The Jarmans look forward to continuing their work, saying that they “can’t wait for next year’s event!”

2019 HELEN & LEONARD MEMORIAL GOLF CLASSIC RAISES 45K FOR MGFA!

On August 12, 2019, Mother Nature smiled on the 27th Annual Golf Classic. The game went on as planned and rain-free at the Crestmont Country Club near mid-town Manhattan. **The tournament portion netted over \$45,000 (\$5,000 from the silent auction alone) – the most ever raised at the event.**

The annual tournament has become a must-do tradition that honors the legacy of **HELEN AND LEONARD A. GOLDEN**. Jason Gershwin, grandson of the Goldenes and chair of the planning committee, shares that the tournament is dedicated to his grandparents and their incredible passion for finding the cause and cure of MG. The tournament is the largest-grossing golf event for MGFA in the country.



The Gershwin Family (l-r) — Sam, Andrea, Zach, Marisa, Owen, Laynie and Jason

Jason said this year’s tournament featured luxury giveaway items, cigars, scotch and liquor tastings, delicious food, and spectacular hole-in-one prizes such as a luxury automobile and live music. The fundraising event not only features luxury auction items, but also laughs and fun for all those that attend. The silent auction and raffle featured

experience excursions, sports memorabilia, collectibles, golf accessories, equipment and more.

On the heels of such a great event, the Gershwins already have planning underway for 2020!

BBQ COOK-OFF A SIZZLIN’ SUCCESS!



Special thanks to **LOUIS WYLER AND BERGELECTRIC**, Austin, for designating MGFA as the beneficiary of a BBQ cook-off in late April. **The event raised \$1,000 with all expenses underwritten by Bergelectric.**

“I was unsure how successful fundraising would be since it was our first year promoting donations to support MGFA. In past events, we only focused on cooking for the competition and friends. Since my dad has MG, I wanted to help raise money and increase awareness for a cause that’s important to me,” Louis said. They smoked 18 pork shoulders for pulled pork tacos, 15 pounds of venison sausage and fried almost 200 beignets. They also served up some fierce competition in the remaining categories- chicken, ribs, brisket, chili, and salsa. “Based on the tortilla count alone, we served about 700 tacos!”

Louis also reported that their chili won 1st Place and that their ribs won 3rd Place, going up against more than 95 competitors in each category.

Thanks to Louis and all his supporters for a sizzlin’ success!

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BATTLE OF THE BOATS SAILS STRONG, RAISING 2K FOR MGFA



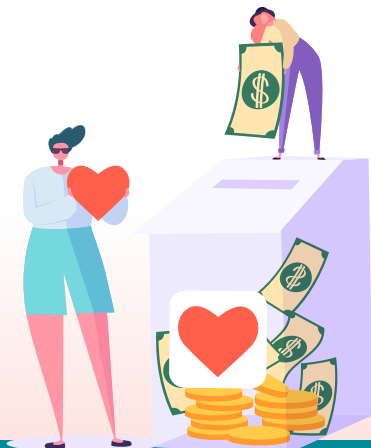
Only 14 years old, **ELSIE AGURKIS** received a diagnosis of MG in 2018. Following the diagnosis, her mother Ann, and dad Johnny, dedicated themselves to increasing awareness for a

rare disease that few in their in their community knew about. From that dedication, a unique and fun community event was born- a cardboard boat competition! The event took place on May 19th at Flax Pond in South Yarmouth, Massachusetts. Teams had the opportunity to build boats in advance or on site. Participant registration fees and **donations generated \$2,000 in its inaugural year.** “It was an amazing day! We were thrilled with the turnout; everyone had a blast,” Ann said. The Agurkis family hopes to make this an annual fundraiser.



BUCKY TAYLOR HOLDS FIFTH ANNUAL MG GOLF TOURNAMENT

After diagnosed with MG in 2013, **DON (BUCKY) TAYLOR** decided after being diagnosed to hold a golf tournament to benefit MGFA. The annual event, which began in 2014, **has raised over \$10,000 since its inception.** Bucky’s daughter, Tori Hebert, shares that her dad’s passion for golf sparked the idea. For many who attend, Bucky’s tournament is often the only opportunity that they choose to play golf at. A family affair with broad support, the event was held on June 23rd at Far Vu Golf Course in Oshkosh, Wisconsin. Bucky proudly described the day as “lots of fun and filled with great prizes.” Prizes included a Green Bay Packers raffle with an autographed football, an autographed helmet, and an autographed plaque. It’s not hard to see why the event is so popular; the tournament includes a 50/50 raffle, basket raffles, a team poker game and a great opportunity for socializing. The golfers enjoyed a beautiful day out on the course while non-golfers enjoyed the clubhouse and patio. Roxy Supper Club provided lunch for all attendees. Bucky and his family are looking forward to their sixth annual golf outing in 2020! ✨



OUR HEARTFELT GRATITUDE TO ALL FOR BRINGING US CLOSER TO A WORLD WITHOUT MG!



The “Snow Angels”: A Granddaughter’s Quest to Raise MG Awareness

By Kendyl Grant

It all started during October 2017, when my grandfather took a fall. I was a sophomore in college at The University of Tampa at the time. Despite the geographical distance from Pennsylvania (my grandparents are “snowbirds” that winter in Florida), I was always incredibly close with them. My parents divorced when I was young and I could always count on my grandparents for advice and support during tough times. They are my very own “snow angels”.

After my grandfather’s fall in October 2017, we noticed some symptoms the following month, when we all gathered for Thanksgiving dinner. While my grandfather thought the symptoms might be due to the fall, we still had questions about whether it could be something more. The following June, my grandfather had surgery and was given a diagnosis of myasthenia gravis shortly after. My grandfather has always been a strong and independent person; the MG diagnosis was incredibly frustrating and limiting for him. We all saw how the loss of independence affected him and the daily struggles he encountered. My grandmother and I then decided that resources outside of his strong family support might be helpful. Thankfully, MGFA had an MG Support Group near my university, the University of Tampa. My grandfather is proud (and a bit stubborn), so we knew that this would take some convincing!



Kendyl Grant presenting at her university’s research symposium

My grandma knew that he would be more likely to attend the meeting if I tagged along to offer some familiarity and comfort – the power of grandkids! We knew that driving was a challenge for my grandfather, due to the neck droop from his MG. After some discussion, we decided that attending the MG Support Group meeting together would be a great way to help support him and encourage him to be part of the group. When we arrived at the meeting, the MG Support Group leader, Jessica Simmerman, was amazing! The group really helped my grandfather understand that he was not alone in his struggles with MG. It was eye opening to hear all of the different MG journeys from other group members, who came from all ages, genders and backgrounds. This really helped me truly understand that each case of MG is unique, like a “snowflake”.

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St. Petersburg MG Support Group



Are You A Young Adult with MG? Be Part of the Buzz on MAYA!



Our **Myasthenia Advocacy for Young Adults (MAYA)** program is guided by the desire to educate young adults on how to live a successful and positive MG lifestyle. In an effort to create a community for young people with MG to share their experiences and knowledge, the program develops discussion topics and engagement opportunities geared towards young adults. MAYA provides exceptional resources and networking experiences, where all individuals feel welcomed and supported.

We'd like to take a moment to thank and highlight our community leaders, who represent the program nationwide: **Co-Chair: MIKE URSIC** **Co-Chair: NIKI GROSSHEIM** **Secretary: BRITTNEY FOLEY**

Regional Coordinator, Northeast: BRITTNEY FOLEY

Regional Coordinator, Mid-Atlantic: MIKE URSIC

Regional Coordinator, South: LAUREN JARMAN

Regional Coordinator, Midwest: NIKI GROSSHEIM

Regional Coordinator, West: VICTOR MENDEVIL

To join the Myasthenia Advocacy for Young Adults group and to receive updates, please follow us on Facebook at <https://www.facebook.com/groups/MGFAMAYA/> or contact us at 1-800-541-5454 or mgfa@myasthenia.org. ✨



PARTNERS IN MG CARE: Is Your Health Professional Connected?

Through physician outreach, MGFA is striving to make our Partners in MG Care program as comprehensive as possible. To make that a reality, we need your help! As a patient with MG, a caregiver for someone with MG, or a community leader, you are knowledgeable about MG care in your area. Our request is small; if you have, or know, a great MG health professional in your area, encourage them to be part of the Partners in MG Care program!

WHO'S A GOOD FIT FOR PARTNERS IN MG CARE?

- Experience with, and interest in, treating MG patients
- Ability to refer patients to MGFA for support and resources
- Involvement in the MG community
- Willingness to promote and support MGFA's work

HOW DO THEY GET CONNECTED?

Interested health professionals can contact MGFA:

Toll-Free: 1-800-541-5454

Email: mgfa@myasthenia.org

Want to step up outreach efforts in your community? Contact MGFA for more information on how you can get started!





Educators Unite for MG Support in Texas!



Retired educator, Robert Rumph, with the help of now part-time teacher, Melayne Daniel, created a local support group to connect with others who have MG in San Angelo, Texas.

The dynamic duo initially bonded by sharing their experiences with MG. Robert, who was hospitalized for 21 days in May 2018, lost the ability to chew and started having difficulty speaking. Melayne, although never hospitalized, experienced weakness in her hands and legs and had difficulty breathing, speaking and closing her eyes. Their journeys laid a unique foundation for their Support Group, which offers its members understanding, compassion and MG education.

“Our meetings have been informal and I don't necessarily feel like a leader,” says Rumph, “but we share where we are and I know there are others that understand my condition and are there for me if I go back to a crisis.”

Robert and Melayne play vital roles in service delivery for patients in San Angelo, Texas. “I would say San Angelo is a small population covering a large area. It is tough to travel long distances and we wanted to provide support to anyone who has an MG story to share,” expressed Rumph.



San Angelo MG Support Group



Robert Rumph, Dr. Wael Richeh, Melayne Daniel

Luckily, for those who have MG in San Angelo, they are not only offered support, but also receive education. The group invites guest speakers, such as local neurologist Dr. Richeh (pictured above). They also utilize the MGFA website and YouTube channel to present videos and presentations. Distribution of materials to members, such as emergency alert cards and the cautionary drugs list are a priority for San Angelo leaders. “The dynamic of our group is relatively upbeat, with members ranging from ages 50 to 80 years old,” expressed Melayne. “Not everyone has access to a computer, so we feel we can help by distributing resources.”

“I tell Robert, ‘I am so sorry the way we met’ ... but I am so thankful that we have each other and would love to find more people in the community so we can be a support to each other.”

– MELAYNE DANIEL

For more information on the San Angelo Support Group, please contact Robert Rumph or Melayne Daniel by visiting facebook.com/sanangelomg or email sanangelomg@gmail.com.

To locate a Support Group near you, visit our “Resources & Community” section of our website at myasthenia.org or contact us at 1-800-541-5454 or mgfa@myasthenia.org. ✨



What's Hot Off the Press in Neuromuscular Junction Disorders?

Sarah M. Jones, MD¹, Department of Neurology, University of Virginia
Ikjae Lee, MD², Department of Neurology, University of Alabama at Birmingham

THYMECTOMY STILL OBSERVED TO BE BENEFICIAL AT FIVE YEARS AFTER THE SURGERY

The thymectomy trial in myasthenia gravis (MG) patients with acetylcholine receptor (AChR) antibodies and without thymoma (MGTX) clearly demonstrated the benefit of this surgery. At the end of the three-year study period, patients in the thymectomy plus prednisone group had less severe disease and required less steroids when compared to the prednisone alone group.¹ The results of this study were previously featured in the fall 2016 edition of Focus on MG. Dr. Gil Wolfe and MGTX study investigators recently reported the results of a two-year extension of the MGTX trial, a cumulative five years, in order to determine the long-term effects of thymectomy.²

For the extension study, 111 subjects who completed the three-year MGTX trial were given the option to enroll. A total of 68 participants enrolled; 35 patients in the thymectomy plus prednisone group and 33 patients in the prednisone alone group. Of the total participants, 26 patients in the thymectomy plus prednisone group and 24 patients in the prednisone alone group completed the 60-month visit. At 60 months, or five years, patients in the thymectomy plus prednisone group had significantly lower (better) time-weighted average Quantitative Myasthenia Gravis (QMG)

scores from month 0 to 60 than the prednisone alone group indicating lower disease burden. Time-weighted average prednisone requirement was also significantly lower in the thymectomy plus prednisone group than the prednisone alone group (24 mg vs. 48 mg every other day). The extension study continued to demonstrate other benefits of thymectomy through months 0 to 60, including reduced requirements for immunosuppressive agents and hospitalizations.

In summary, the MGTX extension study provides further evidence that the benefit of thymectomy in MG patients with AChR antibodies extends up to five years post-surgery. The importance of early surgery is also evident from the study as thymectomy allows the patient to take less

prednisone and immunosuppressants, leading to reduced exposure to potentially toxic side effects. Still, caution is required when thymectomy surgery is being considered in older (over 65 years of age) MG populations or those without AChR antibodies.

In summary, the MGTX extension study provides further evidence that the benefit of thymectomy in MG patients with AChR antibodies extends up to five years post-surgery.

IVIG MAY NOT BE NEEDED PRIOR TO SURGERY IN WELL-CONTROLLED MG

Intravenous immune globulin (IVIG) is widely used to treat myasthenia gravis. Since IVIG can be used as a treatment for myasthenic crisis, Gamez and colleagues sought to evaluate whether prophylactic use of IVIG prior to scheduled surgery leads to decreased post-operative myasthenic crisis.³ In the study, 47 individuals with well-controlled myasthenia gravis (no significant MG symptoms) were randomized to receive IVIG or placebo (intravenous saline) prior to scheduled surgery. The intravenous infusions were given over five days, with the final dose administered at least 7 days prior to surgery. Baseline characteristics between the IVIG and placebo groups were similar. The mean duration of surgery was about two hours. Among the 47 participants, 16 underwent thymectomy. Other surgeries included both high-risk surgical procedures (cardiothoracic and abdominal surgery) as well as low-risk procedures (gynecological, urological, orthopedic and endoscopic procedures).

The authors concluded that preoperative IVIG use may not be justified in patients with well-controlled MG since myasthenic crisis is rare in this population.

The primary endpoint of myasthenic crisis after the surgery was observed in a single patient who belonged to the placebo group. None in the IVIG group had myasthenic crisis after the surgery. There were also no significant differences in length of stay in the recovery room, length of stay in the hospital, or changes in myasthenia gravis severity between the IVIG and placebo groups. The authors concluded that preoperative IVIG use may not be justified in patients with well-controlled MG since myasthenic crisis is rare in this population. The study did not include MG patients with ongoing MG symptoms such as severe weakness, trouble swallowing, or trouble breathing, which limits the generalizability of the study.

RISK FACTORS THAT MAY LEAD TO MYASTHENIC CRISIS

Acute exacerbations of myasthenia gravis can be life threatening and are a source of significant anxiety for patients and their care teams. Gummi and colleagues evaluated factors that may put patients at risk of an exacerbation.⁴ Patient information was gathered from electronic medical records and a retrospective chart review of 127 patients between 2011 and 2016 was done to characterize exacerbations. The investigators also sought to identify the specific risk of infections or certain medications that may worsen MG by measuring the impact on emergency room visits and inpatient hospitalizations. Since prior studies highlighted the importance of vaccines in MG patients, vaccine preventable infections such as influenza and pneumococcal pneumonia were one of the focuses in this study.

The authors used nine categories to characterize exacerbations: (1) unknown, (2) exacerbations due to medications, (3) exacerbations due to a preventable infections, (4) exacerbations due to a non-preventable infections, (5) medical noncompliance, (6) inadequate treatment, (7) procedure related, (8) social stress, and (9) diagnostic error where MG diagnosis was delayed. Some individuals had more than one reason for an exacerbation. 77 of the 127 patients experienced one or more exacerbation(s). There was no difference in race, sex, antibody status or thymectomy status in individuals who had exacerbations versus those who did not.

Of the known causes identified, the three categories most often linked to exacerbations were preventable infections, non-preventable infections, and medicines that contraindicated in MG. Preventable infections were identified as those that could be prevented with vaccination, such as influenza and pneumococcal infections. This category was a significant predictor of an exacerbation with emergency room visits and subsequent hospitalization. The average duration of hospitalization was about one week. Older patients were particularly at an increased risk of preventable infections. There were no adverse events or exacerbations associated with vaccines.

Medications that are relatively contraindicated in MG also significantly contributed to the development of myasthenic crises. According

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Medications that are relatively contraindicated in MG also significantly contributed to the development of myasthenic crises.

to the authors, the most common medication associated with an exacerbation within the first few days of use was azithromycin, followed by fluoroquinolones and beta-blockers. Prednisone was also associated with an increased risk of exacerbation, but since this is used to treat myasthenia gravis, it is possible that the patients starting prednisone were already more symptomatic.

Results of the study should be interpreted cautiously due to retrospective chart review methods that can be affected by confounding factors and accuracy of the charting. In addition, the number of patients in the study was small and limited to single medical center. Nonetheless, the study results remind us that using vaccines to prevent infections and avoiding medications known to worsen MG are important in reducing the risk of MG exacerbation.

INFLUENZA VACCINE IS SAFE AND EFFECTIVE IN INDIVIDUALS WITH MG

As mentioned above, influenza is a risk factor of myasthenia gravis exacerbation and crisis. Infections with influenza can be prevented by receiving a vaccine. Strijbos and colleagues studied influenza vaccination in myasthenia gravis patients in a prospective, double blinded, randomized study to show that influenza vaccination is effective and safe.⁵ In this study,



a total of 47 adults with MG and 47 adult healthy controls were evaluated. The individuals in the MG group had positive AChR antibodies, were stable with an MGFA Clinical Classification of 3 or less (mild disease), and had a maximum daily dose of 30mg of prednisolone. The group of healthy controls had no autoimmune disease or immunosuppressive medication. Individuals in the MG group were randomized to receive intramuscular injection of the seasonal influenza vaccine or placebo (normal saline) at the start of the flu season in October 2016. Evaluations were performed at baseline and every 4 weeks for up to 12 weeks. At the 4 week point, the subjects were unblinded and individuals in the placebo group were vaccinated with the influenza vaccine. Inquiries of side effects and bloodwork were performed on both the healthy control group and the MG group. The MG group also underwent clinical outcome measures and interviews about MG symptom exacerbations. The primary endpoint was change in titer of antibodies to the influenza vaccine strains. Secondary endpoints included the effect of immunosuppressive medicine on the humoral response, influence of thymectomy on the humoral response, change in clinical outcome measure scores, and change in antibodies against AChR.

A seroprotective antibody titer for all three influenza strains was achieved in both the AChR MG group and in the healthy control group without a significant statistical difference. Immunosuppressive medicines and thymectomy did not seem to influence this response. The non-responder rate was similar between the MG groups and healthy controls. There was no significant difference in the clinical outcome

Side effects of the influenza vaccine were reported more frequently when the receiving group were aware that they were receiving a vaccine.

measures or AChR antibody levels in the MG group. Side effects of the influenza vaccine were reported more frequently when the receiving group were aware that they were receiving a vaccine.

This study shows that individuals with mild to moderate MG are likely to have a comparable protection and side effects from influenza vaccine to the general population, without significant risk of an MG exacerbation. This study did not include MG patients with unstable or severe disease or patients on high doses of oral corticosteroids (prednisone, prednisolone), which limit the generalizability of the study results to those populations. ✨

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Snow Angels continued from page 23

While I was at the Support Group meeting, I started taking notes on my computer. I was so inspired and moved by everyone's story, that I knew I had to do more to raise awareness about MG. I attended two additional Support Group meetings with my grandparents and learned more about MG each time. In spring 2019, I had the opportunity to raise awareness about MG among my fellow students when I took an epidemiology class. As part of my public health coursework, I decided to do a nine-page epidemiology brief on myasthenia gravis. Following my brief, I took part in the university's research symposium and presented a poster. My grandparents always knew that I was working on schoolwork during the Support Group meetings, but they had no idea how passionate I had become about raising MG awareness.

Despite the daily challenges of MG, my grandfather has maintained his strong determination to learn everything he can about MG and to help others in their MG journey. The Support Group has made a huge impact on me as well; it proved to me that I had made the right decision to shift my college study focus from my pre-med track to public health. The opportunity to share this experience with my grandparents and bring it to new heights has given me great insight about my ability to educate others, a strength I did not know that I had before. I look forward to sharing more experiences and being part of Support Group meetings this spring, when my grandparents return to Florida.





Reduce your taxable income and help MGFA today!

Supporting the vital work of MGFA comes in many shapes and sizes – from fundraising for the MG Walk, to responding generously to a donation appeal, to being part of the Ellsworth Society by naming MGFA in your will. We hope you have discovered a way to support MGFA with the gift that is right for you.

Did you know that if you are 70½ years old or older, there is a simple, yet meaningful way to reduce your taxable income by making a charitable gift directly to MGFA from your individual retirement account (IRA)? A qualified charitable deduction, or “QCD”, is often called “charitable IRA rollover”. You can give up to \$100,000 from your IRA directly to a qualified charity like MGFA without counting it as taxable income. For tax-free eligibility, the qualified charitable distribution (QCD) must be sent directly from the IRA payable to the receiving qualified 501(c)(3) non-profit organization. As you think about year-end giving, making a gift through an IRA might be just right for you!

ELIGIBILITY AND DONATION LIMIT

IRA holders must be at least 70½ years of age before the distribution. In addition, beneficiaries of inherited IRAs who meet the age requirement can also take advantage of QCDs.

For those who qualify, the maximum IRA charitable distribution is limited to \$100,000 per tax year. Any distribution in excess of this limit will not qualify for the tax exclusion benefit and will be treated as ordinary income. The provision applies for Traditional, Roth, and inherited IRAs.

BENEFITS OF A QUALIFIED CHARITABLE DISTRIBUTION OR “QCD”

If a taxpayer makes the donation as prescribed by the IRS, then the distribution will be excluded from gross income and counts toward:

- The taxpayer’s \$100,000 exclusion limitation for the year the distribution occurs and
- The taxpayer’s required minimum distribution (RMD) for the current year

With the 2018 increase in the standard deduction to \$26,600 for married filing jointly age 65 or older, and \$13,600 for single filers age 65 or older, more Americans will be using the standard deduction rather than itemizing deductions on their tax returns. QCDs are excluded from taxable income, but do not allow for an itemized deduction. If more

individuals age 70 ½ or older use the standard deduction, the QCD is a great way to keep taxable income lower when satisfying an RMD and still getting the full benefit of the standard deduction. By using the standard deduction, a taxpayer will receive no benefit for their charitable contribution unless processed as a QCD from an IRA. In addition, by not including a charitable donation from an IRA as ordinary income, an individual’s adjusted gross income does not increase, which could affect the ability to:

- Qualify for Roth IRA contributions
- Avoid other potential tax ramifications, such as:
 1. The 3.8% health care surcharge. (Even though distributions from IRAs are exempt from the 3.8% health care surcharge, taxable distributions from IRAs could push income over the threshold amount, causing other investment income to be subject to the surtax.)
 2. Paying more for Medicare Premiums.
 3. Taxation on Social Security Benefits.



QUALIFIED CHARITABLE DISTRIBUTION (QCD) TAX REPORTING

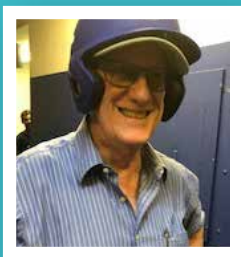
Typically, the custodian of an IRA will report a QCD as a normal distribution on the 1099R tax form, while QCDs from inherited IRAs are reported as death distributions. This gives the IRS no notification that an IRA holder intended to make a tax-free distribution from the IRA to a charity. It is the responsibility of the IRA holder or his or her tax preparer to properly report the QCD on a 1040 tax return. It is also strongly suggested that the IRA holder obtains a receipt from the charitable organization.

For more information about the QCD or other planned giving opportunities to support MGFA, visit mgfalegacy.org.

A planned gift enables you to preserve your assets during your lifetime and leave a valuable legacy. Your gift helps ensure that MGFA remains a place where people who are dealing with MG can turn for help and information.

Before making any planned gift to include a QCD, we recommend you seek the advice of a competent tax advisor, tax attorney or financial advisor for guidance.

Phil Harris, MGFA Volunteer, is a contributor to this article. Diagnosed with MG in 2015, Phil brings 23 years of professional investment experience. Watch for his regular column in Focus on MG to learn more about including MGFA in your charitable plans. ✨



PHIL COGAN, pictured at a baseball fundraiser, is an active volunteer and member of our Board of Directors. He finds making tax-free charitable gifts from his IRA account a meaningful way to

support a charity close to his heart. “I support MGFA in many ways but once I was required to take withdrawals from my IRA, it opened a new door for giving. Whatever impact I can have today in bringing us closer to a cure is one of my highest priorities.”

JOIN The Ellsworth Society



When you make a planned gift to MGFA, you'll be invited to join **The Ellsworth**

Society, named in honor of Jane Dewey Ellsworth, our founder. Ms. Ellsworth

launched the Foundation in 1952 when her daughter Patricia was diagnosed with MG. Today, thanks to her vision, MGFA now touches the lives of hundreds of thousands of patients, families, friends, and medical professionals around the globe.

Your membership involves no dues, obligations, or solicitations, but it does allow us to recognize you for the plans you have made, and it may inspire generosity in others. Benefits include a commemorative Ellsworth Society pin, as well as opportunities for future acknowledgement at events. However, the most important benefit you will receive from joining The Ellsworth Society is the lasting impact you will have on creating a world without MG.

Once you complete your estate plans including MGFA, please fill out the member profile on our website mgfalegacy.org.

For further questions, please contact Betty Ross, Director of Development at bross@myasthenia.org.

Register for the 2020 MG Walks TODAY!

2020 MG Walks

- FEB 8 Coconut Creek, FL
- FEB 22 St. Petersburg, FL
- FEB 29 Tallahassee, FL
- MAR 14 Atlanta, GA
- MAR 14 New Orleans, LA

NATIONAL WALK

- APR 4 Ft. Worth, TX
- MAY 9 Green Bay, WI
- MAY 17 Charlotte, NC
- MAY 30 San Francisco, CA

VIRTUAL: Anywhere, Anytime!

MORE WALK DATES COMING SOON!

Please go to mgwalk.org for more information on a walk near you!

**MORE THAN \$875K
RAISED IN 2019!**



COME TOGETHER TO SUPPORT THE MG COMMUNITY!

The 2019 MG Walk season is coming to an end and we are so grateful for all the participants, volunteers and sponsors that have helped make this year a huge success! We couldn't have done it without you and we can't wait to see you again next year! Although we didn't quite make our 1 MILLION DOLLAR GOAL, we made many new connections and learned more about myasthenia from our MG Medical Ambassadors. Patients, families and sponsors came together as an MG Strong community.

WE NEED YOU IN 2020! Help make it our biggest year yet! If you haven't already done so, now is a great time to get your friends and family excited about the 2020 Walks! **NEW THIS YEAR! Early bird registration prizes!** Stay tuned via email and mgwalk.org for more information! New to MG Walk? It's quick and easy to start a team and join the MG community in this fight! To check out upcoming MG Walks or to register, visit MGWalk.org.

WANT TO GROW YOUR TEAM FOR 2020? We can help! The MGFA team will help you with goal setting, team recruitment and community engagement. Every dollar raised by an MG Walk participant is one more dollar to fight MG! Contact us at 1-855-MG-WALKS (1-855-649-2557) or info@MGWalk.org.

VOLUNTEER! If you are interested in volunteering for an MG Walk, please go to www.mgwalk.org and click on "Volunteer" to learn more!



**CELEBRATING 9 YEARS
OF RAISING AWARENESS
AND FUNDS FOR THE
MG COMMUNITY!**



HELP US GROW THE MG WALK MEDICAL AMBASSADOR PROGRAM!



MG Walk Medical Ambassadors are medical professionals who provide leadership in their local communities in the fight against MG. At every MG Walk, we strive to recognize these passionate, dedicated professionals who help MG patients every day. Alongside these professionals, MGFA aims to reach more people affected by MG, aiding them in their MG journey with critical resources and support. Medical Ambassadors can be doctors, nurses, researchers, lab technicians or medical staff members.

Can we count on your help? Spread the word about our MG Walk Medical Ambassador Program in your community!

MG Walkers are the biggest recruiters for the Medical Ambassador program! For example, our 2018 Seattle MG Walk Hero, Corey Russell, actively spreads awareness by asking any medical professional he meets if they know about MG, even though he does not have MG himself. You can do this too! Corey recommends having a few MGFA flyers in your back pocket during every doctor appointment. Simply ask if they have heard about MG and offer information!

We would be thrilled to follow up with any medical professional who can promote a local MG Walk, become a sponsor or lead a walk team! Please reach out to us at info@MGWalk.org or 855-649-2557 with any possible leads!



2019 Medical Ambassador
Dr. Leo Wang at Neurology
Clinic at UW Medical Center



continued on page 31



STAY CONNECTED   

1-855-MGWalks (649-2557) | Info@MGWalk.org | MGWalk.org



4 Easy Ways to Fundraise for Your MG Walk

- 1. INVEST IN YOURSELF!** Show friends and family how important the MG Walk is to you by kicking off the campaign with a donation to yourself.
- 2. GET SOCIAL!** Are you on Facebook? Instagram? Twitter? Share your fundraising link — and your reasons for supporting the MG Walk. It's a great way to get support and spread awareness!
- 3. SEND, SEND, SEND!** Did you know the #1 way to raise funds for the MG Walk is by sending e-mails to friends and family? We suggest sending a minimum of three (3) e-mails during your fundraising campaign: in the beginning, mid-goal and the week of your walk. It's that simple — just send and watch the donations roll in!
- 4. SHARE YOUR STORY!** Your friends and family want to support you, so tell them in your own words what the MG Walk means to you. You can share your story via email, on your MG Walk page or on social media.

DONATE



“When I signed up to volunteer at the Baltimore MG Walk, I saw a way to give back and support a good cause. I was diagnosed with MG when I was 3 years old, and while my MG is in remission, I am always interested in learning how treatments have changed since the early 80s. But volunteering gave me so much more when I met others with MG for the first time! I’m excited to stay in touch with my new MG Strong friends and to joining future MGFA events.”

Tara — Diagnosed in 1982

“My tip would be to start earlier. I spoke to family and friends in person as well as reaching out on social media, but I started a month before the walk. As soon as it becomes available next year, I will be reaching out. I want to build a bigger team next year!”

— **Kim**, Captain, Wisconsin MG Walk



STAY CONNECTED   

1-855-MGWalks (649-2557) | Info@MGWalk.org | MGWalk.org



2020 NATIONAL CONFERENCE

PROMISE

Caring ★ Connecting ★ Commitment

Ft. Worth, Texas | APRIL 5-7, 2020 | Omni Fort Worth

SAVE THE DATES!

NAT'L MG WALK: APRIL 4 | NAT'L CONFERENCE: APRIL 5-7

Put this on your calendar and plan to attend the National MG Walk and Conference. Add a little R&R if you wish. Check out the beautiful Fort Worth Water Gardens, just a few minutes' walk from the Omni. Visit the Fort Worth Civic Opera Association, the oldest continuously performing opera company in Texas. Check out the historic Stockyards Hotel, where Bonnie and Clyde hid out in 1933. Visit the Kimbell Art Museum, which has a world-class collection of works by Matisse, Picasso and Cezanne. Or kick-up your heels at the "World's Largest Honky-Tonk", Billy Bob's Texas.

Stay tuned for more details!



Fort Worth

- ★ The city is known for its cattle drives, earning it the nickname "Cowtown"
- ★ Home to the Kimbell Art Museum
- ★ Experienced an oil boom in 1917
- ★ Prints approximately 60% of the paper money in the U.S.

www.myasthenia.org   





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Myasthenia gravis is an autoimmune neuromuscular disorder. Symptoms may include double vision, drooping eyelids, slurred speech, difficulty chewing and swallowing, weakness in arms and/or legs.

MGFA is committed to finding a cure for myasthenia gravis and closely related disorders, improving treatment options, and providing information and support to people with myasthenia gravis through research, education, community programs, and advocacy.

Focus on MG is published by the Myasthenia Gravis Foundation of America, Inc. If this issue was mailed to you, you are on our subscriber list. If you would like to add, remove or update a subscription, or request that you receive future issues by e-mail, please contact the MGFA home office.

If you would like to receive Foundation Focus by email only, please email mgfa@myasthenia.org.

**THANK
YOU**

**...to all of our
wonderful donors!**

*your generosity
brings us closer
to a world
without MG.*



The goal of the MG Walk Campaign is to expand into new markets where we can bring together patients, create a community of active/engaged MG families and raise vital

awareness & funding for myasthenia gravis! It is crucial that we go where we know we can garner the support needed to ensure success. If you are interested in seeing the MG Walk come to your area and you are excited to play an active part in its planning, promotion and production, we want to hear from you! Please contact the MG Walk Office at 1-855-MG-WALKS or Info@MGWalk.org or fill out our interest form found online at www.MGWalk.org. Thanks so much!