FOCUS on mg
FALL 2021
a publication of the MYASTHENIA GRAVIS FOUNDATION OF AMERICA

It's a good day for giving.

Today is an extraordinary day to give to our year-end appeal.

Fighting for better treatments and a cure for myasthenia gravis through research, advocacy, education, and community programs.

Phil Kirschner (Donor, Fundraiser, and MG Patient) & family share their story. After contracting COVID during the summer of 2020, I started experiencing a constellation of symptoms that were not obviously associated with the virus. Nothing was serious or consistent, so I wasn't immediately concerned. But a few months later, in November 2020, new and more serious symptoms got my attention: difficulty swallowing, a weak jaw and facial muscles, progressive loss of speech, and weakening of the tongue. A neurologist visit and an MRI later, I was diagnosed with myasthenia gravis.

More tests revealed a small tumor on my thymus called a thymoma. My best chance for reducing or even eliminating my dependence on medication was removing my thymus, so that's what I did. For now, I'm still taking a daily regimen of steroids and another medication that prevents the breakdown of the neuromuscular chemical that my immune system is attacking. Throughout this process, I have benefited from the resources available through the MGFA.

So, today is a good day to give because generosity like yours made it possible to receive a treatment and support. My world changed over the past year and a half. Making a gift means we can support the researchers studying MG to find a cure, and help fund the programs that improve the life of those living with MG. ***Please join me and make your gift today.***

***DONATE** online at **Myasthenia.org** or mail to MGFA*
290 Turnpike Road
Suite 5-315
Westborough, MA 01581

MGFA: FUNDING ONLY THE MOST PROMISING MG RESEARCH

At MGFA, we support myasthenia research that will improve the lives of patients with myasthenia gravis and related neuromuscular junction disorders. Clinical trials and studies that we select for funding represent some of the most promising and potentially successful research that could have strong outcomes for better treatments and a cure for MG. This is one of MGFA's most critical responsibilities.

OUR GOALS INCLUDE:

- Funding high-impact research with promising treatment pathways.
- Providing post-doctoral fellowships to bring the best and brightest to the field of MG.
- Fostering collaboration and innovation through national and international conferences.
- Advocating for critical research funding.
- Advancing the understanding through the MG Patient Registry and clinical trials.

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Highlights in this Issue

THE CEO'S LETTER

Dear Friends,

As the year comes to a close, there is so much to be thankful for and we wish to celebrate YOU, our MG Community. I'm proud and excited about all that WE have accomplished despite the pandemic's disruptions, and hope that you enjoy reading about our activities and accomplishments over the past year in this issue of Focus on MG. Together we will continue to work toward a world without MG.

MGFA continues to **expand and enhance our programming through patient and community services and education, as well as our physician and research networks**, to meet the growing needs of our MG Community.

- This year we hosted 19 webinars on wellness and research, expanded our regional conferences from two to five, and expanded and repurposed our networks such as MG Friends, Partners in MG Care, and MAYA.
- To **ensure that the patient voice is front and center as our programs evolve**, our team developed the national **Patient Leadership Advisory Council (PLAC)**.
- We redesigned our **MyMG Mobile App** to include new functionality, including a symptom tracker, launching soon.
- **We have increased our research funding and overall research activity.** This year will mark the greatest contribution to research in the organization's history, ***funding over $700,000 in research.***

I continue to be inspired and impressed by the resilience and fortitude of the MG community. In this edition of Focus on MG, you will read patient stories of perseverance and what it means to be #MGStrong. I hope that you enjoy reading these stories. Thank you to the featured patients who have invited us into their lives to share their journey.

At MGFA, we are charged with empowering our community members to make decisions that improve their quality of life. Whether you are reading this magazine, attending a webinar, or talking with other patients in a support group, I hope that you glean hopeful and helpful information, advice, and strength from your affiliation with MGFA.

We look forward to connecting with you in 2022 and beyond.

Sincerely,

Samantha Masterson

Samantha Masterson
President and CEO

Meet New MGFA Team Members

Our organization continues to grow and offer many new programs to improve the lives of those living with MG. We hope you will reach out and say hello to these wonderful new members of the MGFA staff.

TASHA DUNCAN — National Director of Field Development

As the National Director of Field Development for the MGFA, Tasha will be working directly with donors, volunteers and staff, leading strategic fundraising initiatives throughout the country to support MGFA's mission and goals. Tasha brings more than 15 years of non-profit development experience to MGFA as a multi-faceted fundraising professional. Prior to her time at MGFA, Tasha was the Director of Major Gifts at Lutheran Medical Center – SCL Health, and before that she served as the Director of Regional Development, Southwest for the National Brain Tumor Society.

AMY PETERSON — Project Manager

Amy has worked for more than 10 years in the educational nonprofit sector, most recently connecting Harvard Business School alumni in Northern California to pro bono consulting opportunities with nonprofits through the HBSANC Community Partners program. Prior to this, she worked for an education fund whose mission was to empower individuals in the healthcare workforce to advance their careers. Amy offers programmatic project management support to the MGFA team as part of their education, advocacy, and research efforts.

DARYL LEE — National Director of Finance

Daryl comes to MGFA with a diverse business background. Starting his career as an aerospace engineer, Daryl has transitioned to various finance and leadership roles within the fields of technology, health care and non-profit. He is known for using his team building skills and analysis to support his coworkers throughout the company. His most recent positions were at Providence St. Joseph Healthcare and Working Wardrobes for a New Start.

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.

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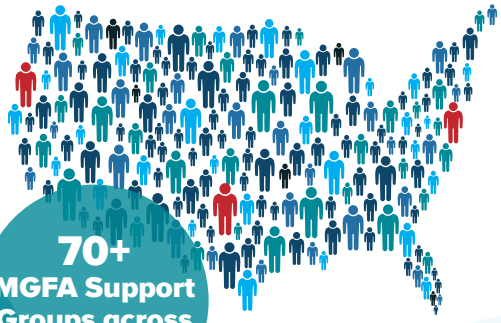
290 Turnpike Road, Suite 5-315, Westborough, MA 01581 | 800.541.5454 | mgfa@myasthenia.org | www.myasthenia.org

THE MYASTHENIA GRAVIS FOUNDATION OF AMERICA

IMPACT BY THE NUMBERS



70+ MGFA Support Groups across the U.S.

We've expanded our reach through the virtual option and connect with patients across the world

21,000+ monthly reach on social media

25 blog posts in 2021 to educate and inspire

61,000+ global email contacts reached through email communication

22 brochures of information for patients in our resource library

73,577 monthly pageviews

MGFA's website

4,300+ patients and caregivers reached through the Wellness Series Webinars to date

20K+ people reached through our PRINT MGFA publications

Remembering Nancy Law

Leader, Mentor, Board Chair, and MG Patient

It is with a heavy heart and deep sadness to let you know that Nancy Law, MGFA Board Chair and an extremely active friend of the entire myasthenia community, passed away on September 23, 2021. Nancy was loved and respected beyond measure by so many. She was so special.

Nancy touched and supported all of us in so many ways. As a person with myasthenia gravis, she served as a mentor, role model, guide, and friend to anyone with MG. She actively reached out and talked with MG patients and caregivers all the time – offering suggestions, listening intently, and simply being a caring confidante. Nancy, who previously served as a long-time MGFA board member as well as our Chief Executive Officer, played a pivotal role in the evolution of what MG education, awareness, and patient advocacy looks like at MGFA.

Nancy helped establish extremely robust patient and community services programming that was near-and-dear to her heart including MG Friends, Partners in MG Care, our volunteer-led MGFA support groups, the MAYA young adult program, and key advocacy campaigns and partnerships.

She had most-recently been the MGFA Board Chair over the past two years and worked tirelessly to grow and evolve the MGFA to ensure its long-term success. We are indebted to Nancy for her dedication, commitment, and love of the MG community and MGFA.

You can offer your own written tribute to Nancy and her family on our MGFA Online Memorial Wall. Simply go to this webpage link below and add your tribute today.

myasthenia.org/MG-Community/In-Loving-memory-of-Nancy-Law

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The process for selecting key research grants is an extremely thorough, objective, and transparent approach that includes our Medical and Scientific Advisory Board, a strong group of medical professionals. MGFA does not accept proposals outside of the scope of the Research Agenda and supports a wide range of science and innovation. These grants can be categorized in the research agenda as follows:

- **Biomarkers:** facilitate early diagnosis, predict clinical outcomes and immunosuppressive therapy response and utilize in clinical trials
- **Disease Mechanisms:** understand basic mechanisms and self-tolerance loss throughout course of disease
- **Targeted Therapies:** develop new therapeutic targets, prevent widespread immunosuppression and off-target side effects, optimize treatment strategies with existing therapies
- **Patient Outcomes:** understand the full impact of disease on daily living and patient treatment priorities, understand collateral effects of disease; related medical conditions, side effects and financial impact
- **Pediatric Treatment:** identify strategies, safety concerns, and long-term outcomes

MGFA focuses on several key research funding areas:

High-Impact Pilot Project Awards: pilot studies leading to new federal, pharmaceutical or private foundation supported investigations.

Transformative Research Awards: focused, innovative investigations that are highly likely to produce fundamental alterations in understanding myasthenia gravis.

Targeted Research and Special Projects Awards: further greater understanding of MG and its impact on quality of life.

Awards to Engage and Support Young Investigators and Clinicians: recognize the importance of good clinical research and encourage young investigators' involvement in clinical studies.

The 2021 Research Grants have been announced and MGFA has committed $110,000 per grant over 2 years:

PILOT GRANTS

The use of Survivin as a Diagnostic Marker for Myasthenia Gravis

Dr. Linda Kusner, The George Washington University

Nine percent of patients with myasthenia gravis (MG) cannot have a clinical diagnosis confirmed by laboratory testing for detectable antibodies, designated seronegative MG (SNMG). Diagnostic confirmation is dependent on electrodiagnositic methods with poor to uncertain sensitivity and specificity, experience of the examiner, and access to specialists. We have found the expression of survivin in circulating lymphocytes to correlate with the diagnosis of acetylcholine receptor antibody-positive (AChR+) MG and not in controls with other neurological disorders. We have also found survivin expressed in circulating lymphocytes from patients with muscle specific kinase antibody-positive (MuSK+) and rigorously defined SNMG patients, demonstrating the potential of survivin positivity as a diagnostic marker for MG. We propose to confirm positive survivin expression in circulating lymphocytes for the context of use as a diagnostic adjunct for MG. Presently, patients with symptoms of MG have difficulty in having a diagnosis confirmed, and thereby are denied effective therapies and often excluded from clinical trials. Establishment of an algorithm that combines the clinical phenotype and survivin positivity has the potential to increase the speed of diagnosis and therapeutic intervention. The analysis of lymphocytes for expression of survivin provides a verification of an autoimmune process due to the function of survivin in promoting proliferation and inhibiting apoptosis.

Indoleamine-2, 3-dioxygenase 2 (IOD2) as a Novel Therapeutic Target for the Treatment of Myasthenia Gravis

Dr. Laura Mandik-Nayak, Lankenau Institute for Medical Research

Myasthenia gravis (MG) is widely recognized as a B cell-mediated disease, with autoantibody production critical to its development and progression. While there has been intense interest in the development of therapies that deplete B cells or prevent B cell activation, these therapies are not effective in all patients and there is a continued need for new

Making Our Combined Voices Heard

Our MG Voice is the MGFA's ongoing MG patient advocacy program that puts the future of our community in your hands. The call to action? We ask you to step up and engage in activity that could make a huge difference in people's lives.

ACTION ALERT

Avoid Continuing Resolutions and Push Congress to Fight for Faster Medical and Health Progress

On September 30, Congress passed (and the President signed into law) a "Continuing Resolution" (CR) averting a government shutdown by flat-funding federal agencies through December 3.

That date should not be interpreted as a reason to wait on completing the FY22 appropriations process, which would mean waiting to apply more resources to the fight against deadly and debilitating health threats.

MGFA joined a sign-on letter to congressional leaders asking them not to wait until December, but to assign urgent priority to setting funding levels for FY22, making the case that CRs stymie desperately-needed faster medical, health, and scientific progress.

Americans want our nation to fight back. According to a national public opinion survey Research!America commissioned just before the pandemic emerged in the U.S., 88% of Americans believe it is important for the President and Congress to assign a high priority to ensuring faster medical progress. The National Institutes of Health, the Centers for Disease Control and Prevention, the Food and Drug Administration, the Agency for Healthcare Research and Quality, the National Science Foundation and the full array of R&D-critical federal agencies fuel progress that restores health, saves lives, and fosters prosperity. CRs hamstring these agencies, stalling momentum and breeding stultifying uncertainty. Further, CRs extend spending that may no longer make sense, needlessly draining dollars from taxpayer pockets. The American people deserve better.

The dangerous impact of CRs is clear: in the science & technology realm, CRs stall progress, even though our nation cannot afford stasis. Whether the measure is the health and wellbeing of Americans and populations across the globe, U.S. economic competitiveness, or our ability to develop solutions to a host of challenges that our nation faces — from health security to water security to energy security to national security — our ability to advance is compromised by a budget that stalls crucial science, technology, and engineering advances and is clearly misaligned with current opportunity and need.

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therapies, particularly those that can affect the underlying factors that initiate and perpetuate production of pathogenic autoantibodies. The studies in this proposal will investigate a new therapeutic strategy that interferes specifically with the activation of autoreactive B cells and their ability to produce autoantibodies by inhibiting the immune modulating enzyme indoleamine-2,3- dioxygenase 2 (IDO2). Recently, using IDO2 genetically deficient mice, we demonstrated that loss of IDO2 reduced autoantibody levels and alleviated inflammation in preclinical models of arthritis and lupus. Our studies showed that IDO2 was required specifically for the activation of autoreactive B and T cells, as IDO2 deficient mice show no defects in normal immune cell development or function. Therefore, unlike current MG therapeutics that can leave individuals immunosuppressed, inhibition of IDO2 has the potential to provide therapeutic benefit without severe side-effects such as increased risk of infection and cancer. In this proposal, we will use a preclinical model of MG, together with a novel IDO2-targeting approach, to explore IDO2 inhibition as a therapeutic strategy to treat MG. In the short term, our studies will provide an initial step in the preclinical evaluation of IDO2 as a therapeutic target in the treatment of MG. If successful, the potential longterm impact of this project would move the concept of IDO2-directed therapy into development as a novel strategy to treat human MG.

GET INVOLVED

Volunteer Today!

Wondering how you can get more involved to help and support the MG Community? We have so many opportunities for you to dive right in! **MGFA offers many fun ways to volunteer and get involved to support us in our quest for A World Without MG.**

Volunteers are the heart and hands of the Myasthenia Gravis Foundation of America. We are currently seeking uniquely qualified volunteers, who are empowered by their experience with MG and can join us in bringing awareness, educational programming and support to local MG communities across the country. We seek volunteers in with a wide array of expertise, ranging from social media, to healthcare to fundraising.

BECOME AN MG FRIEND

If you are a person living with MG, or a caregiver of someone with an MG diagnosis, and can provide practical advice, an understanding ear, and emotional support, consider becoming an MG Friend! Our MG Friends volunteers are of many different age groups and have experienced MG for at least two years – as an actual patient or as a caregiver. Demonstrate empathy and a sincere desire to help others.

Through phone and email communication, an MG Friend provides confidential conversations, active and reflective listening, techniques to overcome day-to-day challenges, local resources as well as information and answers to FAQs. To become an MG Friend, you will be scheduled for a 30-minute interview. You must meet the requirements and satisfactorily complete the MG Friend two-hour online training course. Contact Genna Mvalo at gmvalo@myasthenia.org to learn more. You can also fill out this EASY ONLINE FORM.

SUPPORT GROUP LEADERS AND CO-LEADERS

Are you interested in forming an in-person or virtual Support Group in the MG Community? The MGFA has resources and training to help you get started! Our Leaders and Co-Leaders are trained volunteers who organize and give structure to meetings that take place with those living with MG and their families. Leaders establish and run Support Groups by coordinating meeting spaces, guest speakers and local promotion. Leaders receive facilitator training, to ensure members feel welcomed, the atmosphere is friendly and that everyone has an opportunity to speak.

Don't have a Support Group in your area? Our Support Group Calendar is home to existing and forming groups across the country. Don't see your city or state listed? Consider forming a group. You will receive a Support Group Leader's Manual, training and support from the MGFA in getting your group off the ground and keeping it going. You can contact Dova Levin at dlevin@myasthenia.org or Volunteer Today! You can Volunteer using this EASY ONLINE FORM.

MG PATIENT ADVOCACY: MAKING OUR COMBINED VOICES HEARD

The MG Community faces challenges that impact how we live our lives with myasthenia. In order to overcome those challenges, we must come together and make sure our voices are heard clearly at all levels of government, across the medical and insurance communities, and around the world.

Our MG Voice is the MGFA's ongoing MG patient advocacy program that puts the future of our community in your hands. The call to action? We ask you to step up and engage in activity that could make a huge difference in people's lives. We do so much to help drive action and results that can help our community including writing to Congress to ensure patient rights, submitting proclamations, creating advocacy alerts to influence stakeholders, and driving MG Awareness around the world. Learn more about becoming an MG patient advocate by contacting Genna Mvalo at the MGFA – gmvalo@myasthenia.org. This online VOLUNTEER FORM can help you get started.

JOIN OUR GIVING CIRCLES

Your donations change the world for people affected by MG by driving research to find better treatments and eventually a cure for MG. Your gifts ensure people can easily access the information they need to live with MG and connects them with each other to learn, share and cope. YOU can be an MG Community powerhouse — Consider donating today and help create a world without MG. You can also be part of our MGFA GIVING CIRCLES to obtain special recognition and access to research updates and MG experts as well as valuable incentives. Learn about ALL OUR GIVING OPPORTUNITIES and support MGFA today! You can contact Caroline Gayler at cgayler@myasthenia.org to learn more.

COMMUNITY EVENTS AND DO IT YOURSELF FUNDRAISING

Both Community Events and Do It Yourself Community Initiatives are carried out by people LIKE YOU in local regional areas that raise funds for MGFA independent of our staff-driven walk or golf events. A Community Event is when an MGFA Volunteer Leader decides to take on the logistics and planning of a tangible event to benefit MGFA, such as planning a softball tournament, a dinner party or small walk just to name a few. A Community Initiative is when an MGFA Volunteer Leader initiates any other fundraising opportunity in their community such as asking a local restaurant to donate a percentage of each check to MGFA, asking for donations in lieu of birthday or holiday gifts which make great Facebook fundraisers!

Step up, plan your event, and fundraise today. Learn more about Do It Yourself Events by contacting Tasha Duncan at tduncan@myasthenia.org.

MGFA BIRTHDAY CLUB

Everyone has a birthday. So, for your next one, start your own birthday fundraiser. We make it easy for you. Visit our Birthday Club webpage to get started.

NATIONAL EVENTS, WEBINARS, AND SPEAKING OPPORTUNITIES

Participate in or become a speaker and presenter for one of our many MGFA EVENTS or WEBINARS throughout the year. Speak about your expertise, experiences, and opinions about myasthenia and living the patient experience.

GET YOUR MGFA WEARABLES

MGFA has opened up its very first online store with branded items such as face coverings and a long sleeve shirt. More to come, but be the first one in your neighborhood to purchase an MGFA wearable. Check out the "Buy MGFA Stuff" page on myasthenia.org.

MG AWARENESS MONTH IS IN JUNE

June is MG Awareness month around the world, and in 2021 we Took Action and created awareness and understanding of the challenges and opportunities faced by everyone in the MG Community. This year, we "changed" the theme to MG Action Month – Turning Awareness into Action – and offered specific calls to action for the MG Community and beyond to find creative ways to show that WE ARE MUCH MORE THAN OUR MG. Check out the many ways YOU CAN DRIVE AWARENESS OF MG.

MG Patient Data in the MG Registry Helps Researchers Discover Better Treatments

The Myasthenia Gravis Patient Registry is an active database of persons with myasthenia gravis (MG), developed for the purposes of research, treatment, and patient information. The Registry is managed by the Coordinating Center of the University of Alabama at Birmingham (UAB) with oversight by the MGFA Patient Registry Committee.

As an MG patient, you are asked to submit your MG symptom information and data in a totally confidential and secure online form. The data is aggregated with other patients and used by clinical researchers and academic institutions to actually build trials and research studies to find better treatments and a cure for MG. Without this critical, real-life data, researchers would be building trials "in the dark" with no guidance for what to test or how to structure the study.

By providing your patient data, YOU, will be directly helping these researchers build studies with important outcomes that would benefit the whole MG Community.

THE MG PATIENT REGISTRY IS:

- **For myasthenia gravis research**
- **Participant-driven**
- **Free to enroll**
- **Confidential**
- **Open to Adults 18+ in the U.S.**

There have been a number of active and published studies that directly relied on patient data from the MG Registry. These studies have led to new, important discoveries in MG that could lead to better treatments.

ACTIVE AND PREVIOUSLY PUBLISHED MAJOR STUDIES FROM DIRECT MG REGISTRY PATIENT DATA

ACTIVE: RLS and MG – George Washington University study – *Abstract presented*

ACTIVE: COVID-19 Survey – Ongoing – *Abstract submitted*

ACTIVE: Longitudinal Analysis of MG data – UCB – Ongoing – *Data extracted*

ACTIVE: MRG Validation Study – UCB – *2021 start date*

ACTIVE: COVID-19 Winter Study – *Pending update survey*

ACTIVE: MG Diagnostic Delay Survey – Ongoing – *Data extracted*

ACTIVE: Ocular MG Study – Pending – *2021 summer update survey pending*

PUBLISHED: Gender and Quality of Life in MG Patients from MGFA Registry - Muscle Nerve - February 21, 2018

PUBLISHED: Gender Differences in Prednisone Adverse Effects – Neurol Neuroimmunol Neuroinflamm – *October 15, 2018*

PUBLISHED: Impact of Refractory MG on Health-related Quality of Life – *June 20, 2019*

PUBLISHED: Employment in Refractory MG – Muscle Nerve – *September 3, 2019*

PUBLISHED: Examining Impact of Refractory MG on Healthcare Resource Utilization in U.S. – *July 15, 2019*

PUBLISHED: Cross-sectional Analysis of MG: Disability and Treatment – Muscle Nerve – *September 5, 2019*

PUBLISHED: Longitudinal Analysis of Disease Burden on Refractory/Nonrefractory Generalized MG – Neuromuscular Dis – *September 22, 2020*

What types of questions are in the enrollment survey?

- General contact information.
- Demographic information, for example, education, employment status, income, insurance.
- Year, month, and place of birth of parents and grandparents.
- Information on places where you lived when you were under 25 years old.
- MG medical history; including tests and diagnoses, treatments, other conditions, family's MG history.
- Information on quality of life and lifestyle.

Future, follow-up surveys will contain a subset of the enrollment questions as well as one new section of questions.

JOIN THE REGISTRY TODAY BY VISITING THE FOLLOWING PAGES:

To learn more about the MG Patient Registry, visit: www.mgregistry.org/

To join the MG Patient Registry, visit: mgregistry.soph.uab.edu/MGRegistry/SignUp.aspx

Catch up with the MG Community

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

myasthenia.org

mg™ PATIENT REGISTRY
MYASTHENIA GRAVIS FOUNDATION OF AMERICA

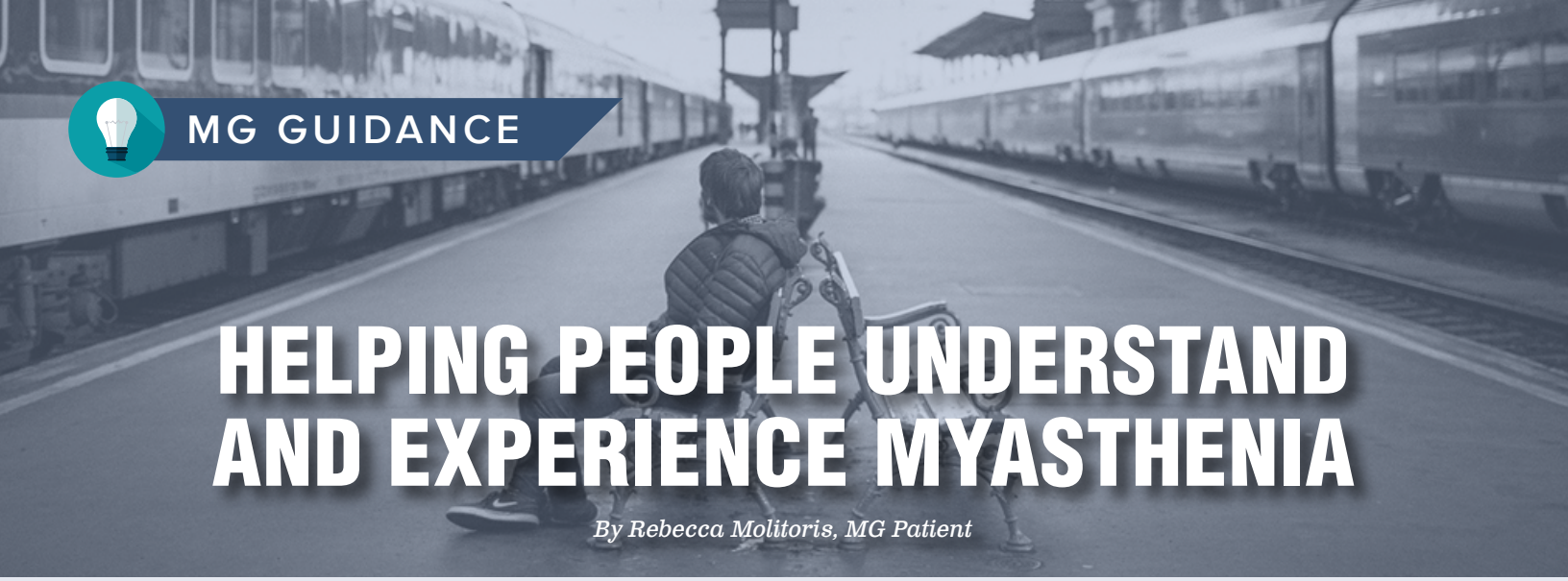
Do You Want to Wake up to a **World without MG?**

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.



MG GUIDANCE

HELPING PEOPLE UNDERSTAND AND EXPERIENCE MYASTHENIA

By Rebecca Molitoris, MG Patient

You may be newly diagnosed, or you may have been living with MG for many years. You're doing what's right for you – following your doctor's plan, getting enough rest, and discovering ways to cope with a long-term illness. But how do you explain myasthenia gravis to your family and friends? What do you say when someone asks, "Are you sure you're ill? You look so good." Or hear them say, "You just need to exercise more to get stronger." Or "If you'd just lose some weight, you'd be able to do more."

We all cringe just a little inside when those around us try and diminish what we know to be true – that we are living with a serious, difficult, tricky, and sometimes invisible disease.

There are many of us in the Northeast Ohio MGFA Support Groups who were struggling with how to educate our circle of family and friends as to what MG feels like for someone living with it every day.

One day I was struck with a thought about how to accomplish this task in a fun and interactive learning environment. I call it the MG Experience.

I first rolled it out at a June Awareness MGFA fundraising Bar-B-Que. I created eight different stations. Each station concentrated on a different aspect of MG. At the ticket window, every participant was given an MG Awareness lanyard with a train ticket attached, and 10 "coins" to spend at each station. Utilizing Granny Bev Nason's poem A Pocket Full of Nickels, each person had to use the coins at the stations along the way and if they ran out, they could earn more by resting. This beginning exercise was to demonstrate how we expend our limited energy on tasks throughout the day and get it back by resting.

Next the participants followed "train tracks" which took them to each station in order:

STATION ONE – ARMS

At this station, each person was given a set of small plastic cups to stack and unstack. First, they did it normally, then with weights attached to their hands. It's definitely harder when using the weights and demonstrates what it feels like to have weak muscles in hands and arms.

STATION TWO – LEGS

Here there were two tasks. The first one had participants stepping up on a small stool. Then after attaching ankle weights, they had to step up and down again. The second task involved walking against a resistance band. Both of these tasks demonstrated what it feels like to have weak leg muscles.

STATION THREE – EYES

Here again there were two tasks. At the first one, participants held up a pair of glasses over their eyes. The glasses simulated what it feels like to have ptosis (droopy eyelids). Next, each person was asked to read a paragraph that simulated double vision. They could also use the glasses AND try and read the doubled copy for the full MG effect.

STATION FOUR – BREATHING

Each participant was given a disposable smoothie straw. Placing it in their mouth, they were asked to hold their nose and breathe through the straw. Next, each person took a cotton ball and taped it to the bottom of straw to hold the ball in place. Then, they tried to breathe through the straw again noticing how difficult it was to get air in. This simulated the feeling of a weakened diaphragm and the difficulty some MG patients have in breathing.

A second activity for breathing involved wearing a weighted vest and noticing how difficult it was to breathe against the weight, again simulating the

weakness of the diaphragm muscle in someone with MG.

STATION FIVE – CHEWING

Perhaps the most popular station. Each participant was given a mini marshmallow and told to chew and swallow as normal. Then each person was given a s'more sized (super large) marshmallow and was told to put the whole thing in their mouth and try and chew. This simulated the difference between a normal person's ability to chew and what it feels like with weakened jaw muscles.

STATION SIX – NEUROMUSCULAR JUNCTION

This station involved a game of catch with a hook and loop mitt and a fuzzy bean bag labeled ACh that represented acetylcholine. One of the mitts was labeled "Nerve" and the other "Muscle". During the first game of catch, the acetylcholine bag was tossed and caught easily between the nerve the muscle. Next, a new set of mitts were given the participant. This time, sections of the mitts were blocked by AChR antibodies, MuSK antibodies, RAPsyn on the muscle side and Choline Acetyltransferase (CHAT) and Voltage Calcium or Potassium Channel blockers (VGCC and VGKC) on the nerve side. The game was played again, only this time it was very hard to catch the ACh bag as many sites within the mitts were blocked. This simulated what is happening within the neuro-muscular junction, also known as the connection between the nerve and muscle for a person with MG.

STATION SEVEN – NAVIGATION

Each participant was asked to navigate a walker through a series of varying surfaces, levels, and turns. How did it feel to try and walk over concrete, gravel, grass, or carpeting? They were asked to notice which surface was hardest and which was the easiest to travel over.

STATION EIGHT – REMEMBER

Each participant was given a small rock and allowed to decorate it in a way that would allow them to remember their MG Experience. They got to take the rock with them to serve as a reminder of the MG patients who always carry the weight of this disease with them.

FUNDRAISING

Our MGFA Coast-to-Coast 2740 Challenge Brought the MG Walks Together in an Unprecedented Way

For the first time ever, MGFA combined our MG Walks across the United States and raised funds to help the MG Community. **It is approximately 2,740 miles across the U.S. from Los Angeles to New York City – a journey that no MG patient should WALK alone.** That's why on Saturday, November 13, 2021, MGFA held its online **COAST-TO-COAST 2740 CHALLENGE** fundraising event to recognize and honor all our MG Walk teams and participants as well as MG patients and key partners that support the whole MG Community.

By raising funds in the months leading up to the event, you helped us work towards finding better treatments and a cure for Myasthenia. We challenged our community to individually raise or donate $274 per person to earn special prizes. During our online event, MG Walk Team Captains and teams told their MG stories and highlighted why they get involved, create teams, and give every year. Our wonderful teams celebrated their success and years of dedication and commitment to the MG Community – and to the MGFA.

Teams gathered together their friends, family, co-workers and community (virtually and safely) to support the MGFA and help us knock out MG. Fundraising never stops, and you can continue to give to the MGFA at myasthenia.org and click or tap on the donate button at the top right corner. You can also go to MGWalk.org for more information and VIEW our event on the MGFA YouTube channel page – just search for Myasthenia Gravis Foundation of America on YouTube.

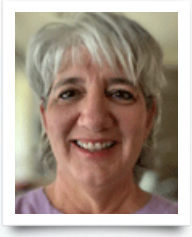
MG Patient Advocates Make Their Voices Heard During Rare Disease Week 2021

By Genna Mvalo

The EveryLife Foundation hosted its annual Rare Disease Week meetings from July 14th to 22nd 2021, and several dedicated and committed MG patient advocates from the MGFA Our MG Voice advocacy program participated this year. These virtual meetings, conducted online for the second year in a row, helped to connect rare disease patients with key members of the United States Congress in order to discuss important issues, policy changes, and medical challenges facing the rare disease community.

There is power in numbers, so MGFA partnered with The EveryLife Foundation to ensure MG-related issues are always "on the table" during these advocacy meetings.

Our MG volunteers wanted to talk about their positive, inspiring experiences, and several volunteers are brand new to this program!



TAMMY MENTER – Baton Rouge, LA

This was my first time attending this conference. I became both a sponge and sieve during the week. As a patient with a 16-year history with Myasthenia Gravis (MG), it was important to learn when and how policy makers learn and become aware of rare diseases. I was able to soak up knowledge that impacted my MG and sort away misconceptions I had developed regarding public health.

My biggest take away from the conference was HOW to become an effective and meaningful advocate. It's complicated, in the sense that all rare diseases don't fit into a one-size-fits-all category. It's tough because the individual determines where their strengths lie and how to use them to their advantage. It's as simple as one well-versed phone call or one flyer which includes critical information that can change the opinion of many. It was surprising to learn the wealth of resources currently available to be a part of or a contributing member for various groups.

Bottom line is the body of knowledge that currently exists for MG is leaps and bounds from 16-years ago. I'm grateful for the opportunity to attending such a comprehensive format for learning more about the future.

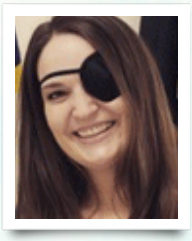
DEBORAH VICK – Chula Vista, CA

This year has been a very unique one as we learn to embrace the use of tech-nology to create accessible Virtual Events. Rare Disease Week fully embraced the use of virtual platforms to create a fun learning, networking and advocacy platform. As I was recovering from a spinal surgery, the ability to access this advocacy platform virtually was very much welcomed and the only way in which I would have been able to advocate.

It was truly amazing to see so many familiar faces in our advocacy community while still meeting new ones. In fact, during some of the networking rooms and trainings', I encountered several other MG Advocates. The added benefit of the virtual advocacy is the ability to include my younger son during several of the advocacy meetings with legislative staff for several House Congressional Members.

I advocate for the MG Community in hopes that sharing our stories, struggles and need for legislative support will help to expedite research

and/or treatments that will enhance our lives. More often than not, legislative staff members have not heard of MG. Those that have are not fully aware of the impact MG can have on the patient and/or their family. We know the strongest impact one can have is to share their story. When we can tie our story into that of a legislative act, it can be extremely powerful. I have advocated for several pieces of legislation. First and foremost, I advocate for the S.T.A.T. Act, the Benefit Act and the Newborn Screening Act.



LAURA CHANDLER – Brookline, NH

As a Myasthenia Gravis patient (or family member/friend/caregiver), we are already Rare Disease Advocates. Many of us have to advocate for ourselves in everyday life. We have to find ways to make MG make sense to our friends, families, coworkers, and doctors. This part sometimes makes me feel very vulnerable; having to share the shortcomings of my body, my career, my life, and sometimes my worst fears. But, using my story to effect change is a way to flip that script and bring empowerment to the patient experience. I encourage every MG-er to practice advocacy in our everyday lives by telling their MG story and being honest and vocal about their needs. For me, this process entailed finding a way to explain MG in everyday terms and becoming comfortable sharing how it has affected my life.

> There is power in numbers... ensuring MG-related issues are always on the table...

Advocacy on Capitol Hill is similar, but it connects our story to our needs in terms of policy. During Rare Disease Week, this entails meeting with your representative or a member of their staff. You'll have time for a 1-2 minute "pitch" or "elevator speech" in which you explain the disease, give your story and how it has affected your life, and make an "ask." Your ask is a request to support policy that effects not only those with Myasthenia Gravis, but the Rare Disease community of over 7000 other Rare Diseases as well.

This was my second time participating in Rare Disease Week. I encourage all fellow MGers to practice being vocal about your story with Myasthenia Gravis in whatever way bests help you to express your experience and your needs. Myasthenia Gravis Foundation of America and Rare Disease Legislative Advocates both provide excellent resources to help on this journey.

CARA BROWN — Grants Pass, OR

This is my first time attending Rare Disease Week! Although it was virtual, Rare Disease Week was very informative and interactive. They had mentors for new advocates to help guide us through the process and prepare us for our meetings with Congress. I had a great time, met wonderful people, and learned what is happening in legislation in regard to Rare Diseases.

I choose to advocate for the MG community because I am a patient and I have become close to my fellow MG Warriors. Together we are stronger. Raising awareness by participating in Rare Disease Week and having the opportunity to meet with Congress in hopes of being apart of new legislation that will benefit everyone in the Rare Disease Community including those with MG. I advocated for the Speeding Therapy Access Today (STAT Act), the Newborn Screening Saves Lives Reauthorization Act, and the Access to Genetic Counselor Services Act.

ELIZABETH SHANNON – Wolfeboro, NH

I recently had the pleasure of attending Rare Disease Legislative Advocacy Week 2021. This is the first time I have participated in the event. Although the meetings were held remotely by, I think it was an incredible experience. I became involved in Rare Disease Advocacy when I was appointed to the State of New Hampshire Rare Disease Advisory Council. I serve in the capacity of patient advocate as a "person living with a rare disease." I was diagnosed with Myasthenia Gravis in 2010 and am doing well with treatments. I feel it is very important to advocate for all rare diseases and being an MG patient, I can share my personal experiences and insights to help others cope with the daily challenges we face. This position also allows me to represent the MG community by helping influence legislation that will improve our care outcomes.

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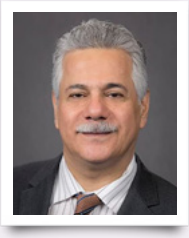
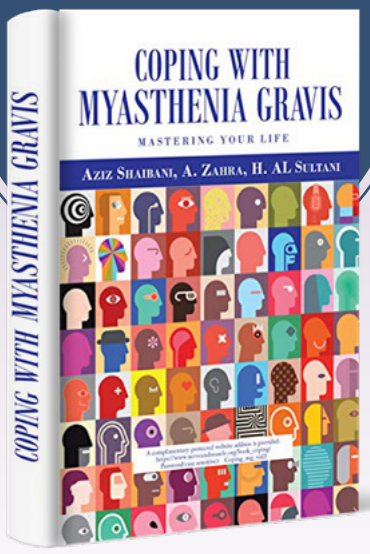
New Book by a Leading Doctor Will Help You Cope with MG



Dr. Aziz Shaibani, a physician who directs the Nerve and Muscle Center of Texas at the Texas Medical Center, has treated hundreds of patients with myasthenia gravis. He's channeled his expertise into a new book, Coping with Myasthenia Gravis, which is designed to provide support and information for patients.

Dr. Shaibani spent five years collecting stories from MG patients. His resulting book provides a rich resource for those coping with MG. They can learn about others' experiences in dealing with the disease, including side effects of medication and strategies for coping with symptoms.

The book is available for purchase on Amazon.



In addition to the stories told in the book, readers can access video recordings of patients talking about managing their MG. A website with these recordings is available with book purchase.

Dr. Shaibani was inspired to write because he saw the need among his MG patients for a resource on how to cope with the disease. Especially lacking was information by patients...for patients. “There really was no book on the market of that kind,” he says.

In the spirit of support for his MG patients, Dr. Shaibani will donate the net proceeds of his book to the Myasthenia Gravis Foundation of America. This donation will further MGFA's vision of a world without MG, supporting patient education, advocacy, and research.

“MGFA is the leading advocacy and educational organization for MG patients,” he says. “It deserves our support and recognition.”

MG Patient Advocates continued from page 11

During Rare Disease Week, I had the honor of meeting with the staff of Representatives from State of New Hampshire, including Congressmen Chris Pappas, Congresswoman Ann Kuster, and Senator’s Maggie Hasson and Jeanne Shaheen. I used the opportunity to advocate for support of the “21st Century Cures Act 2.0”, which is currently in discussion on the Senate Floor.

As many Myasthenia Gravis patients are immunosuppressed, it was especially important for them to be able to continue care without being subjected to the risk of contracting Covid -19. Unfortunately, these extended benefits will end when the Public Health Emergency expires. Long term solutions are necessary, and steps should be taken to ensure the 1135 Blanket Waivers given to Health Care Agencies, by the Centers for Medicare and Medicaid (CMS) , remain in place.

Congressional and Senate support for the “21st Century Cures Act 2.0” as well as the “Telehealth Modernization Act” will allow patients with Myasthenia Gravis, who use Medicare and Medicaid Services to continue to use Telehealth Services. Additionally, many MG patients have specialists and neurologists who are not geographically close to their homes. Therefore, these services work incredibly well for follow up visits. They are also helpful because, at times, a physician may be able to ascertain a patients’ status through a telehealth video call. It would be incredibly helpful for Rare Disease Patients and Caregivers to continue using these services long after the pandemic ends.

You can read this in the MGFA Insider Blog as well: https://myasthenia.org/About-Us/Blog.

iMaGine my MG

Janssen
PHARMACEUTICAL COMPANIES OF
Johnson & Johnson

We are excited to announce that our **Phase 3** study in **Generalized Myasthenia Gravis** will be starting soon.

COVID-19 RESOURCES

LATEST COVID-19 VACCINATION DOSE STATEMENTS

COVID-19 Resources for the MG Community: Check out our online COVID-19 Resource Center at: myasthenia.org/MG-Community/COVID-19-Resource-Center

The CDC has announced authorization of an additional COVID-19 vaccine dose for people with compromised immune systems, including patients with myasthenia gravis (MG) taking immunosuppressive treatment(s). This recommendation is specifically for patients that completed the mRNA vaccines (Moderna and Pfizer). The recommendation does not apply to the Johnson & Johnson vaccine because available data are insufficient at this time.

Recent data suggests that patients with weakened immune systems, such as those on immune suppressing medication(s), may have a reduced protective immune response to the COVID-19 vaccine. An additional vaccine dose can increase the immune response to the vaccine. Although similar data specifically for patients with MG is lacking, given the currently available information, the widespread increase in the more contagious and severe delta variant, and the good safety profile of available SARS-coV2 vaccines, the potential benefit of the additional vaccine outweigh the risks.

Therefore, the MGFA supports the CDC authorization of SARS-coV2 vaccines for patients with compromised immune systems and recommends that patients with MG taking immunosuppressives discuss getting an additional mRNA vaccine dose with their treating provider. SARS-coV2 vaccines may not be available in all areas. The MGFA continues to strongly support the use of recommended precautions to reduce the risk of getting a COVID infection (e.g., masking, social distancing, frequent handwashing, avoiding close interactions with non-immunized individuals, etc).

***Regardless of whether you are vaccinated, if you get a COVID infection, it is very important to immediately notify your treating provider(s), including your MG provider, to determine whether there should be changes to your treatment, such as a monoclonal antibody treatment.*

We continue to recommend that you reference the CDC site. cdc.gov

You can also view and FDA announcement from earlier this year. fda.gov

NEW MGFA "WHAT'S NEW IN MG RESEARCH" WEBINAR – LONG COVID

Presented by MG expert Dr. James "Chip" Howard

We invite you to view the MGFA's latest "What's New in MG Research" webinar titled "Long COVID." This webinar focuses on the longer-term concerns and considerations in dealing with COVID-19 – especially for immunocompromised people such as myasthenia patients. Hear about these issues and learn how to stay healthy during this ongoing pandemic. You can find the playback video at: https://myasthenia.org/Webinars/Whats-New-in-MG-Research

Q&A: COVID-19 AND MG: THE LATEST ON VACCINES AND MORE

With Srikanth Muppidi, MD, *Clinical Associate Professor, Neurology & Neurological Sciences, Stanford Health Care*

Dr. Muppidi spoke as part of a regional conference in early 2021. He outlined key thoughts and medical suggestions concerning the COVID-19 virus and its impact on MG patients. We would always suggest that you speak to your own primary and specialist doctors before making health decisions that will impact your MG, but Dr. Muppidi's responses are informative, and will help you live your life during this pandemic. The following questions are only guidelines, and you must speak with your own doctor or MG specialist to create a COVID-19 vaccination plan that is right for you. MGFA does not provide medical information and is not associated with Dr. Muppidi nor is MGFA directly affiliated with the responses in this Q&A.

Q: Should I stop my immunosuppressant medicine so I'm less likely to get COVID-19?

Stopping your treatment may worsen your MG symptoms. If you get weak and you must be hospitalized, you might increase your risk of getting COVID. We don't recommend stopping your treatment unless advised by your physician.

Q: How would catching COVID-19 affect my MG?

Data from the CARE-MG patient registry, which tracks people with MG who have had COVID-19 or COVID-like symptoms, shows that the virus tends to worsen myasthenia gravis symptoms. Patients report increased fatigue and weakness. myasthenia.org/Professionals/Resources-for-Professionals/CARE-MG

Q: What is the efficacy of the COVID-19 vaccines for MG patients, and what are the risks?

All three vaccines currently authorized for emergency use in the United States are very effective. The vaccines manufactured by Pfizer and Moderna are mRNA vaccines that require two shots, the Pfizer vaccine given three weeks apart, and the Moderna vaccine given four weeks apart. The remarkable thing about these two is that about 12-14 days after the first jab, you have clinically significant immunity. It only gets stronger after the second shot.

The Johnson and Johnson vaccine uses a different technology and only requires one shot. Overall the vaccine is highly effective.

None of the vaccine trials included people who were immunocompromised or immunosuppressed. For that reason, we aren't sure what the vaccine efficacy is for the MG population. Certain therapies do reduce the efficacy of the vaccine, including Rituximab.

In terms of safety, the clinical trial data was very strong, and there have been no reports of serious side effects from those millions around the world who have so far had the vaccine. Pain at the injection site is the most commonly reported side effect, along with some fatigue, aches, and low-grade fever.

Per CDC data, there have been no reported bad outcomes of immunosuppressed people who have received the vaccine. For that reason, I recommend all MG patients get the vaccine, unless there is a specific reason they can't, like a history of allergies to a component of the vaccine.

Q: What if you do plasma exchange therapy? Will that effect vaccine efficacy?

Plasma exchange is a treatment for MG in which we remove a patient's blood, filter out the antibodies that cause myasthenia, and then give it back to you. This is done for both acute patients who are hospitalized, as well as for patients who are not responsive to other therapies.

We don't know yet if COVID-19 antibodies could be removed from the blood through this process, but researchers have reviewed this issue for other vaccines and found that sufficient antibodies were present to prevent disease. Anecdotally, one of our patients who receive outpatient plasma exchange has continued her therapy, and we've found that she still has antibodies against COVID (for many months now).

I recommend that you stick to your regular regimen of treatment while you are getting a COVID vaccine.

Q: Could I get COVID-19 antibodies through IVIG treatment?

In IVIG therapy, a patient receives an infusion of a donated blood product called gamma globulin that helps those with autoimmune disorders get antibodies to fight their illness. Donor blood is pooled from thousands of individuals. Given the level of COVID-19 spread in the United States today, it's unlikely you could get enough COVID-19 antibodies in one bag of plasma to give you

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Covid-19 Resources continued from page 19

antibodies. I suspect that donation centers may also be screening COVID-19 patients out of their donor pools at present to obtain plasma for treatment of actual patients with COVID.

See more on IVIG - https://myasthenia.org/What-is-MG

Q: Will IVIG treatment reduce the efficacy of the vaccine?

We don't know. But the reality is that if you're on IVIG, that means you need it, and you might get weaker by delaying it or canceling. I recommend that my patients stick to their regular treatment plan while getting vaccinated.

Q: Will immunosuppressed patients be included in future vaccine trials?

I am not sure, but we can do population studies, which look at those people who are immunosuppressed and have received the vaccine. What was efficacy like for them? Did side effects differ from the general population? Over time this adds to the pool of knowledge and helps us better understand how MG affects all kinds of vaccines.

MGFA CARE-MG REGISTRY PROVIDING COVID-19 DATA WITH MG PATIENTS

COVID-19 Associated Risks and Effects in Myasthenia Gravis (CARE-MG)

CARE-MG, a physician-reported registry, is a joint effort of the International MG/COVID-19 Working Group and neurologists from across the globe to capture outcomes of people with MG who have developed COVID-19 infections formally launched on 09 April 2020. Robust international participation and collaboration is critical to our collective success in answering fundamental questions: Do MG patients face special risks? Do baseline therapies impact risk? Together, the two groups along with several independent experts have designed and launched this international registry. Click here to learn about the current CARE-MG Research Policy.

We hope to capture outcomes in all types of myasthenia gravis (AChR, MuSK, LRP4, Seronegative) irrespective of current treatment status who have confirmed of suspected COVID-19 infection.

Definitions:

Laboratory Confirmed COVID-19 - Positive viral RNA tests or positive serology for SARS-CoV-2

Suspected COVID-19 but not confirmed - Fever with Dry cough, +/- anorexia, myalgias, dyspnea, anosmia/ageusia, potential exposure, Chest imaging suggestive of COVID

Myasthenia Gravis: As defined by treating physician based on antibody status and if seronegative (based on standard testing such as repetitive testing, single fiber EMG, response to acetylcholine esterase inhibitors)

We ask you to register any appropriate patient, regardless of severity (including asymptomatic patients detected through screening). Please report only after a minimum of 7 days and sufficient time has passed to observe the disease course through resolution of acute illness or death. Reporting a case to this database should take approximately 10 minutes. Necessary permission to collect these data from university institutional review board (IRB) has been obtained.

We are counting on international physician participation and collaboration, and hope to capture the majority of cases of COVID-19 in people with MG. We will rapidly define the impact of COVID-19 on patients with MG and how factors such as age, comorbidities, and treatments are associated with COVID-19 outcomes.

Cases can be reported by physicians two ways:

- To report a case directly through the EDC (REDCap) system, redcap.duke.edu
- To report a case using the paper case report form (CRF), please download the paper form here myasthenia.org/Portals/0/CRF%20CARE-MG_30APR2021.pdf and submit to Dr. Srikanth Muppidi via email to: COVID-19MGstudy@duke.edu

You can download and print out the CARE-MG brochure PDF myasthenia.org/Portals/0/MFGA%20CARE-MG%20Brochure%20Final%202021.pdf

Please reach out to us with any additional questions pertaining to CARE-MG via email to COVID-19MGstudy@duke.edu

Evan Greene Reaches New Peaks in Spite of His MG

Meet Evan Greene. He's an MG patient, active MGFA volunteer, advisor and donor. He also used to be an avid outdoorsman and adventure sportsman. Myasthenia has put many of his favorite activities out of reach, but not all. Here he shares about his incredible recent extreme-endurance adventure in California this past summer.

I love being outdoors and in situations where I must rely on my own skills and abilities. MG has severely affected my arms and my upper body strength, making my previous lifestyle impossible. Fortunately, my legs have not been impacted.

After 18 months of COVID-led quarantine, and the closure of America's national parks, I was desperate to get outside and off the couch. So, one day, on a drive to the mountains with my family, I took notice of Mt. Whitney, and immediately committed to reaching the tallest point in the continental U.S.

There are a limited number of climbing permits issued each year, and after applying to the Mt. Whitney lottery process, I was fortunate enough to be granted a slot. I was assigned the date of June 17, 2021, so that was the target I worked towards.

Wanting to really challenge myself, I decided that rather than spending two to three days on the mountain, and camping at night, I was going to do all 22 miles in a single, non-stop push. I did my research, determined the optimal nutrition plan, and evaluated the elevation gain, length of time and overall logistics of the trek to the summit.

I began my climb at 10:15 p.m. on June 16, and, hiking all through the night, I experienced pure solitude and serenity. I was treated to an incalculable number of stars in the evening sky. I had my breath taken away by sunrise at over 14,000 feet, and after 11 miles and over 6,000 feet of elevation gain, I reached the summit at 7:00 a.m. on June 17.

As I got closer to the peak, I became more and more energized. The perspective from that altitude is spectacular, humbling, and life-affirming all at the same time. Standing on the summit made the previous nine hours well worth it.

After a glorious 45 minutes at the tallest point in the continental U.S., I began my descent, reaching my car once again at 3:00 p.m., almost 16 hours after I started.

While my MG diagnosis forced me to re-evaluate who I thought I was – my sense of self, the activities that defined me and my future goals -- it did not stop me. More than eighteen years after my diagnosis, I feel more determined than ever to appreciate the blessings in my life.

MG is a thief! It has taken so much from me. It has taken things I love away... certain of life's pleasures... my lifestyle. But it cannot take away my spirit and my sense of life.

I'm proof positive that I define me, not MG. MG has slowed me down, bit it can never stop me. I often remind myself to reaffirm the joys in life that can be achieved with the right mindset and commitment.

From MG to MD: a story of hope and persistence

By Kate Stober – Contributing Editor

A second-year UC San Francisco medical student with myasthenia gravis shares his story of diagnosis at a young age and how MG inspired him to pursue a career in thoracic surgery. His name is confidential at his request.

I was born and raised in the San Francisco Bay Area of California. In high school, I already knew that I wanted to pursue some kind of career in research... physics, biology, chemistry... I was always into the sciences. I was fortunate to be accepted into a research-heavy institution in New York for college and was planning to move out for my freshman year.

But right before college, I was diagnosed with MG. I actually had symptoms during high school – the classic double vision. I just sort of ignored it – I thought it was fatigue from school stress.

Then in July, the month before moving to New York, I started having weakness in my facial muscles. Chewing and swallowing became difficult. I went to the neurologist, and, luckily, I was diagnosed right then and there. I know a lot of people in the MG community whose diagnosis is missed multiple times, but I am grateful to my neurologist for diagnosing me quickly.

I started treatment with mestinon and prednisone. (I have seronegative MG.) Mestinon helped a little, but the prednisone was much more powerful. I know a lot of people who have had a similar experience as mine: prednisone-related side effects — I was more stressed out, more anxious. It also really affected my sleep. I asked my neurologist to see what other options were available. I continued on the prednisone, but he was open to decreasing the dose. That didn't help with the side effects, but it did control my disease really well.

In being diagnosed with a completely new disease and having had to deal with the numerous side effects from medicine, the first two months of college in New York were really difficult. I was away from family and friends, and it was a completely new culture and atmosphere. It was a stressful experience, but I knew I just had to trudge on -- continue on with my life and my time in college. I was lucky that my neurologist from California worked with me through the different treatment options. As long as I took my meds, I was doing okay in terms of symptoms. That felt like a big victory at the time.

STARTING IVIG TREATMENT

In the third month of my first year, I started having weakness in my fingers and hands to the point that typing was difficult. I remember I was typing an essay for a class and my fingers just wouldn't move any more. I called my neurologist, and he told me to urgently make my way to the Emergency Department for treatment. This was four nights before my midterm exam on organic chemistry. They gave me an intravenous immune globulin (IVIG) bolus, and I stayed the night at the hospital. I vividly remember having my chemistry textbook open in front of me while getting this treatment. (All this studying was not wasted, however; I passed my exam!)

My symptoms did improve drastically, but the next day I got a massive headache. This pattern repeated itself every four weeks after that. I got the treatment at the hospital, then got this headache. The side effects of the treatment for MG were more severe than the MG itself.

Amazingly — and I take pride in this — I was still able to conquer my school work. It took a lot of planning, a lot of emailing professors, "I have this condition; if you can help me manage through, that'd be great." I was also fortunate to have a good family and friend support system. At first my parents couldn't quite believe the diagnosis, but they slowly accepted it and were really supportive after that. My mom would keep track of my medicines and would call me every morning to make sure I took prednisone at the right time.

The first six months after you're diagnosed takes some adjustment. Then I sort of fell into a routine. I knew my trigger points, what to avoid, how many hours of sleep I needed. My MG got better... I just adjusted to it as a part of my life.

NEXT PHASE OF TREATMENT — A THYMECTOMY

The summer after my freshman year, I had a thymectomy using minimally invasive, endoscopic techniques. Fortunately, I didn't have that many complications because I'm relatively young for this disease. I am forever grateful for the healthcare team and was able to recover well from the surgery.

For people who obtain a thymectomy, the benefits (if any) don't show until a few years down the line. Some patients improve, some don't. This uncertainty did not really bother me; instead it transformed itself into hope for me. I just had to wait and see. In the meantime, I still continued the IVIG. I had eventually learned to manage the disease.

About two years after my surgery, my neurologist made a bold move to stop the IVIG and see what happened. Nothing terrible happened, although I would get some MG-related fatigue now and then. My symptoms were starting to stabilize.

By the end of college, I had stopped prednisone completely, and I've been pretty stable since then. I'm off meds now and, knock on wood, I stay like this. I think the thymectomy worked.

PURSUING A CAREER IN HEALTHCARE

Seeing the impact the medical field has made on me, inspired me to pursue medicine. The entire healthcare team... nurses, neurologist, PTs... collectively work together as a team. I wanted to be a part of that team in improving people's lives.

I also am super amazed by the treatment plans available when it comes to current remedies for autoimmune diseases. Right now, I have one or two small scars in my chest that are barely even noticeable—symbols of my triumph over the disease. I am still amazed at how the surgeons managed to squeeze the entire thymus gland out of those small incisions.

My dream to study medicine eventually came true: Currently, I am a second-year medical student at UCSF, and I cannot emphasize how much my friends' and family's support were essential throughout this journey.

"Don't let this disease limit you in any way! Everything is open to you."

Every day I waver on what I want to do post-med school, but I keep going back to pursuing thoracic surgery. I think I'm probably meant to. Eventually, I want to do a balance of research and patient care, with an emphasis on the latter.

THE POWER OF MG SUPPORT GROUPS AND ACTIVITIES

In New York, I was part of a support group in Manhattan led by Susan Klinger. She was the absolute best, inspiring us all and giving us advice on how to manage the condition. I really wanted to support the group in every way I could. I shared my story and listened to and engaged with others in the support group. Everyone has a lesson learned that they want to share. In a way, the support group gave us a "third space" away from home and work to talk freely about how we've been impacted by this condition.

I attended an MG walk in Brooklyn, too, and I was so inspired by the mindset of all the folks with MG. If all of these people with MG can walk long distances, why can't I do it? That sort of pushed me to engage in fitness and become a fitness trainer, which has become one of my favorite hobbies. If it wasn't for MG, I never would have gone into fitness, so in a way MG has actually improved my cardiovascular health!

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SLEEP RIGHT, SLEEP TIGHT.

By Kinjal Madhav, MD, MBA

Sleep is vital to biological functioning as it has an impact on physical and mental health. The essential quantity of sleep varies by age. It is recommended that a healthy adult aim for 7-9 hours of sleep a night. Although, the total sleep time a person may allocate on day-to-day basis may vary based on familial and work life commitments or be behaviorally induced. As you get older the quantity of sleep you need does not change, but the quality can. Overall, poor sleep can increase your risk of cardiovascular and cerebrovascular disorders- such as a heart attack, irregular heart rhythms, heart failure, high blood pressure and stroke. It is important to understand the effect comorbid medical conditions may have on your sleep as well.

When you sleep, your body cycles through two primary stages of sleep — non-rapid eye movement (NREM) and rapid eye movement (REM) sleep. NREM sleep is further subdivided into stage N1 and N2 (light), and N3 (deep) sleep. These stages are specific in their functions. During NREM sleep your body repairs and regenerates tissues, strengthens the immune system and builds bone and muscle. In other words — the body restores itself. REM sleep is where you dream. Here your body works on consolidating memories and improving mood. This is where the mind restores itself.

As you get older, sleep architecture changes. The amount of deep sleep and dream sleep decreases which makes you a lighter sleeper and increasing the risk of sleep fragmentation. In addition, poor sleep habits, certain medications and underlying sleep disorders can affect the quantity and quality of each sleep stage, influencing your physical and emotional wellbeing.

There is limited research on the direct impact of myasthenia gravis (MG) on sleep. But there is an overlap of some MG symptoms with common symptoms of disturbed sleep — such as daytime fatigue, sleepiness, leg movements during sleep, and pain. The most commonly reported sleep complaints are trouble falling and/or staying sleep, waking up unrefreshed, and daytime sleepiness. Medical conditions that can cause or contribute to these symptoms include- insomnia, sleep apnea, restless legs syndrome, narcolepsy, pain, depression, anxiety and medication effect to name a few.

Due to lack of literature, many times these symptoms are attributed to a neurological process rather than neuromuscular disease. Regardless, evaluating for underlying sleep disorders and treating them will improve overall functioning.

Our sleep-wake cycle is influenced by chemical signals from neurotransmitters in our brain. A shift

in this balance can make us more awake or drowsy. External factors can affect this balance as well- alcohol, caffeine, smoking and medications to name a few. Steroids, such as Prednisone are commonly prescribed in patients with MG. They can affect mood- making you more irritable, depressed or anxious. Steroids can also make you feel wired, making it difficult to fall asleep.

Once asleep, you may experience more wakeful episodes as well. This is why it is recommended to take the dose as further away from bedtime as possible. Benzodiazepines are frequently prescribed as an adjunct to treat anxiety. They can help you fall asleep quicker and longer, but decrease the amount of deep sleep you get. You may also experience daytime sleepiness despite allowing adequate hours of sleep at night. A restful night's sleep would be achieving a balance of both good quality and adequate quantity of sleep, instead of focusing on just one.

Good sleep hygiene allows you to get enough quality total sleep time. Ensure a regular bedtime and wake up time on all days of the week, allocating between 7-9 hours. Envision your bedroom as a space of Zen and relaxation. Declutter and make sure your bed and pillows are comfortable. Have a pre-bedtime relaxation routine — may it be brushing your teeth and taking a warm bath or sinking into a book and listening to soft music. This allows your body to unwind and prepare for sleep.

Your bedroom environment is also important. A cooler temperature is conducive to sleep. Light is one of the regulators of our sleep-wake cycle. Black out shades allow your body's melatonin production to rise and increases your drive to sleep. What you eat can also have an impact on sleep. Avoid consumption of alcohol close to bedtime or a heavy meal within 2-3 hours of bedtime. Despite these measures- if sleep continues to be dysregulated and symptoms are daytime fatigue and sleepiness persist, seeking medical help is suggested.

Rest and sleep is critical for patients with MG. Ensuring good sleep can allow the body to perform its vital function of repair and restoration. Improving mood, lowering pain threshold, reducing daytime fatigue improves daytime functioning and overall quality of life in a patient with MG. I urge you to discuss your sleep habits and sleep related concerns with your doctor. Further evaluation with a detailed history, physical, review of medications and sleep study may be warranted.

From MG to MD continued from page 23

For the future, I'm thinking of starting a local support group as well as a fitness support group for patients with MG. My goal is to use my fitness certification to educate patients with MG on how to exercise while living with this condition.

ADVICE TO OTHER PATIENTS WITH MG

Don't let this disease limit you in any way! Everything is open to you still. If you want to play piano, play piano. If you want to go swim, go swim. It actually will help you in the long run. Of course, we have a new equilibrium, in terms of at what point you call it "done." Don't push yourself to be exhausted but go do what you enjoy the most. Relax. Take ample rests as needed. But most importantly, pursue whatever passion you want.

My second piece of advice would be to work closely with your neurologist. Be as educated as you can about the condition. The more educated you are, the more you're aware of different treatments. Always get a second or even third opinion, and don't be afraid to speak up if treatments are not going well or they are interfering with your daily life! There are a plethora of treatments for MG, fortunately, and something's bound to work for you.

For the newly diagnosed, my last piece of advice is that the first year post-diagnosis is the hardest. Push through the first year and don't let this disease define who you are. The good days are yet to come!

Consider Applying for Active MG Clinical Trials Today

MGFA is dedicated to driving research to better understand, treat and cure myasthenia gravis for good. To achieve this goal, we are committed to creating awareness about clinical trials for those with myasthenia gravis and related neuromuscular joint disorders. There are a number of active MG-focused clinical trials that are currently accepting patients now. Please consider joining one of these active trials so you can help us get to better treatments and a cure for myasthenia.

You can go online to National Health Institute Clinical Trial Research Database to find MG-related trials. Also, utilize the link below: clinicaltrials.gov/ct2/results?term=myasthenia&recr=Open

Following are the names of active trials that you can join. Search for these on the MGFA website myasthenia.org/Research/Clinical-Trials

Active Clinical Trials

- Study of Pyridostigmine with Ondansetron in Subjects with Anti-AchR Positive Myasthenia Gravis. *Active and recruiting.*
- Evaluating the Pharmacodynamic Noninferiority of Efgartigimod PH20 SC Administered Subcutaneously as Compared to Efgartigimod Administered Intravenously in Patients With Generalized Myasthenia Gravis (ADAPTsc). *Active and recruiting.*
- Efgartigimod Expanded Access for Generalized Myasthenia Gravis. *Active and recruiting*.
- The MINT study is a randomized, double-blind, multicenter, placebo-controlled phase 3 Study with open-label period to evaluate the efficacy and safety of inebilizumab in adults with Myasthenia Gravis. *Active and recruiting*.
- A Phase 3, Multicenter, Randomized, Double Blind, Placebo-Controlled Study to Confirm the Safety, Tolerability, and Efficacy of Zilucoplan in Subjects With Generalized Myasthenia Gravis. *Active and recruiting*.
- A Study to Test Efficacy and Safety of Rozanolixizumab in Adult Patients with Generalized Myasthenia Gravis. *Active and recruiting*.
- A Study to Evaluate the Safety and Preliminary Efficacy of Descartes-08 CAR T-cells in patients with Generalized Myasthenia Gravis. *Active and recruiting*.
- An Open-Label, Multicenter Study to Evaluate the Efficacy, Safety, Pharmacokinetics, and Pharmacodynamics of Eculizumab in Pediatric Patients with Refractory Generalized Myasthenia Gravis. *Active and recruiting*.
- A Phase 3, Randomized, Double-Blind, Placebo-Controlled, Multicenter Study to Evaluate the Safety and Efficacy of Ravulizumab in Complement-Inhibitor-Naïve Adult Patients With Generalized Myasthenia Gravis. *Active and recruiting*.
- RVT-1401-2002: A Phase 2a, Multicenter, Randomized, Double-Blind, Placebo-Controlled Study of RVT- 1401 in Myasthenia Gravis Patients. *Active and recruiting*.
- 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. *Active, Not recruiting. For more updated information.*
- Catalyst Pharmaceuticals Clinical Trial for Firdapse in MuSK-MG Patients. *Active and recruiting.*




Living with Generalized Myasthenia Gravis (gMG)?

You may be eligible to participate in one of UCB's investigational studies for adults with gMG. We're committed to transforming the lives of people living with gMG and other rare diseases. Contact UCB at ucbCARES@ucb.com or 844-599-2273 to learn more.

Inspired by **patients.**
Driven by **science.**

Ra Pharma now a part of UCB

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

Sarah M. Jones, MD, Department of Neurology, University of Virginia
Ikjae Lee, MD, Department of Neurology, Columbia University

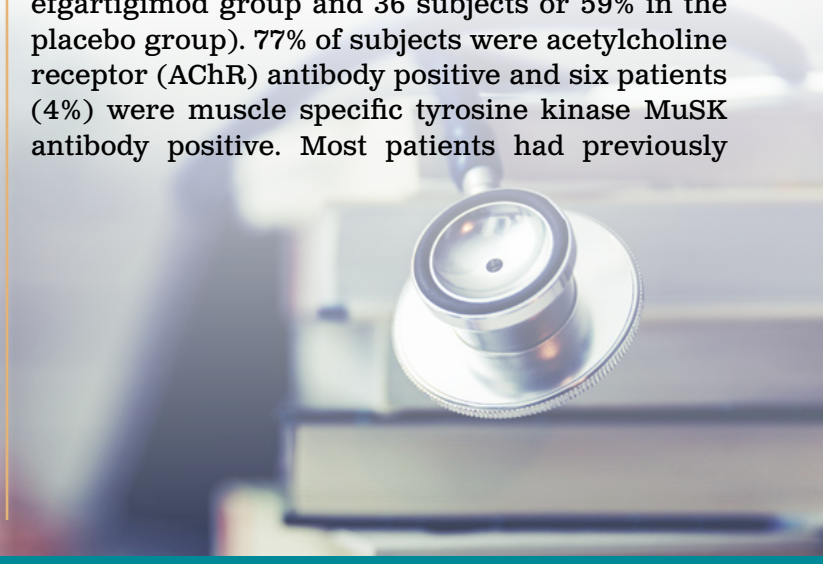
EFGARTIGIMOD: THE FIRST OF THE NOVEL FCRN INHIBITORS THAT IS AWAITING FDA APPROVAL

Neuromuscular diseases are most often antibody mediated, and at least 85% of patients with generalized myasthenia gravis (MG) have IgG antibodies that are thought to be disease-causing. The neonatal Fc receptor (FcRn) helps to extend the half-life of IgG antibodies by preventing cell mediated degradation. FcRn inhibitors selectively interrupt this process, thereby reducing disease-causing IgG and IgG immune complexes. Efgartigimod is an investigational drug that consists of an IgG1 fragment that can bind and block FcRn. This results in reduced IgG antibodies by affecting IgG recycling within cells. Earlier this year, Howard et al. published promising phase 3 study results about an investigational drug that demonstrating positive results in reducing disease severity for patients with myasthenia gravis.

In this study, the investigators evaluated sero positive and seronegative patients with generalized MG. Subjects were randomized to Efgartigimod intravenous infusions or placebo for the duration of the 26-week study. Subjects were eligible for the study if they were older than 18, met standard clinical diagnostic criteria, had MGFA class II to IV disease severity and had an MG-ADL score of at least 5 with greater than 50% of the score due to non-ocular symptoms. Exclusion criteria included pregnancy, recent thymectomy, had infections, or recent treatment with intravenous immunoglobulin (IVIg), plasmapheresis, eculizumab or rituximab. Disease modifying treatment for MG, including acetylcholinesterase inhibitors and corticosteroids were required to be stable before screening and for the duration of the trial.

Treatments were administered weekly for four weeks in a row followed by a 5 week period of monitoring. The primary outcome measure was the Myasthenia Gravis Activities of Daily Living (MG-ADL) score, which is a patient-reported, physician-recorded outcome measure. Several other secondary outcome measures were assessed including the Quantitative Myasthenia gravis (QMG) score and Myasthenia Gravis Composite (MGC) scale. Treatment response was measured by an improvement in MG-ADL score by at least 2 points. Subjects were eligible for re-treatment with additional cycles no earlier than 8 weeks after the start of the prior cycle if (1) their MG-ADL score was at least 5 with greater than 50% attributed to non-ocular symptoms and (2) if they demonstrated improvement in MG-ADL score when compared to baseline but the treatment response was waning with worsening MG-ADL score of greater than or equal to 2 points. A maximum of three treatments were possible during the 26 week study.

After screening, 167 subjects were randomized and treated between Sept 2018 and Nov 2019. Patient characteristics were similar to each other and the general population, with the exception of more subjects in the efgartigimod group having had a prior thymectomy (59 subjects or 70% in the efgartigimod group and 36 subjects or 59% in the placebo group). 77% of subjects were acetylcholine receptor (AChR) antibody positive and six patients (4%) were muscle specific tyrosine kinase MuSK antibody positive. Most patients had previously



been treated with immunosuppressive treatment. After cycle 1, a significantly greater number of AChR antibody seropositive subjects demonstrated improvement of MG-ADL in the efgartigimod group when compared to the placebo group (68% versus 30%, respectively; odds ratio 4.95 with 95% CI 2.21-11.53, p< 0.0001). This corresponded to improvements in QMG scores between the groups, with 63% of patients in the efgartigimod group demonstrating a significant improvement in QMG score compared to only 14% of patients receiving placebo (p<0.0001). Similar differences were observed in the overall study population, which included MuSK and seronegative patients and were also supported by other metrics. Most patients had improvement within 2 weeks of starting treatment.

Adverse events were reported to a similar degree in both groups, which headache and nasopharyngitis being the most commonly reported adverse events. A similar number of patients discontinued treatment during the study.

Limitations of the study included that the trial was not statistically powered to test seronegative patients and patients with ocular myasthenia gravis were excluded from the trial, so the usefulness of efgartigimod in these populations is yet to be determined. Thymectomy higher in the efgartigimod group, but with the mean time since thymectomy was 10.84 years (SD 9.0) this suggests it should not have a significant effect on the results of the study. Durability of treatment response is expected to be measured during the ongoing open-label extension study.

Efgartigimod is the first FcRn inhibitor to demonstrate efficacy and safety through this pivotal trial. We anticipate that this will allow for a new era of treatment strategies for myasthenia gravis.

CAPTURING DISEASE SEVERITY THRU THE TELEPHONE

Telemedicine has been used widely at a higher level than ever before as we strive to provide care for our patients with chronic neurological conditions. Though phone visits can allow for continued conversation in between in-person clinic visits, this visit type poses several challenges to the patient and their provider. Often times, provider based measurements – such as what is captured on a physical exam – may help to modify the diagnosis and treatment plan or reveal an unexpected finding that leads to a different management strategy. The lack of a physical exam for telephone-only telemedicine encounters and the restricted exam available with video telemedicine encounters may affect the accuracy of capturing disease burden and subsequently affect clinical decision making.

In this single-center retrospective observational study, Menon et al. modified the Myasthenia Gravis Impairment Index (MGII) to create a composite score based on patient's verbal responses. This new scale, called the virtual Myasthenia Gravis Impairment Index (vMGII) was measured retrospectively based on telemedicine phone interviews between April and August 2020. The vMGII was compared to two other available patient-reported outcome measures that were administrated via phone interviews instead of self-survey in the clinic: the patient-acceptable symptom state (PASS, now modified to virtual PASS or vPASS) and the single simple question (SSQ, now modified to virtual SSQ or vSSQ) response. The MGFA post-intervention classification was also used to grade disease status.

214 patients who met criteria for clinically definite MG – as defined as appropriate clinical history with single-fiber electromyography showing increased jitter – were included in the study. Every patient had previously been evaluated in the same center with MGII, PASS, and SSQ measurements obtained during prior visit(s). The majority of patients, 84%, were characterized as general myasthenia gravis and 56% were antibody positive. The mean age was just over 61 years, 62% were female and the average duration of MG was 10 years (SD 8.2). The majority of patients – nearly 94% – were taking disease modifying treatment and a little over 50% had prior thymectomy with 42% of these demonstrating thymoma on pathology.

Statistical analysis demonstrated that the vMGII scores had excellent correlation with vPASS and vSSQ, reflected patient's disease status and appeared to perform equally well with the MGII obtained during the most recent in-person clinic visit. It was possible, therefore, to assess change in disease status based on change between the MGII and vMGII scores.

Limitations of this study include that the cohort measured had a lower percentage of patients with seropositivity and a higher percentage of patients with thymoma than expected for the general population, which limits the generalizability of the findings. There is a concern that the method of administering questionnaires may impact patient

continued on page 30

continued from page 29

responses, which may impact not only the vMGII but also the virtual versions of the PASS and SSQ.

When compared to other metrics, the vMGII is easy to administer and may have better psychometric properties, which requires further study on a larger scale among varying patient populations. Use of a metric prior to or during the visit may help to direct the interview and improve delivery of care as telemedicine is expected to continue to be a portion of health care delivery system for years to come.

PREDICTORS OF SEVERE COVID INFECTION IN MG PATIENTS

There are several factors that could make persons with a diagnosis of myasthenia gravis particularly vulnerable in the COVID-19 pandemic and there has been great concern that infection with SARS CoV-2 could lead to a worsened disease state or more complications when compared to age-matched peers.

In their study, Jakubíková et al evaluated retrospective data from patients in two specialized centers for MG in the Czech Republic. Patients with MG diagnosis and had a positive throat/nose smear real-time polymerase chain reaction (RT-PCR) assay for SARS-CoV-2 viral RNA. COVID-19 infection severity was classified on a 7-point scale with a value of 5 or greater indicating infection that was so severe that it required hospitalization, ventilation or resulted in death. Worsening MG symptoms due to infection were also measured based on a change in MGFA scale classification.

The data from 93 MG patients with COVID-19 were reviewed. Interquartile range for demographic variables were reported. The median age was 65 and 80% of the subjects were treated with low-dose corticosteroids (median dose 5mg). The median MG disease severity based on MGFA classification was IIa and this was unchanged after COVID-19 infection. Duration of infection was a median of 14 days and severity of COVID-19 infection was a median of 4, which equaled an influenza-like infection without admission to the hospital based on the author's pre-defined COVID-19 severity scale. Twelve patients, or 13%, required a change of their medication due to COVID-19 infection and 14 patients, or 15%, had an exacerbation of MG. 34 patients, or 37%, were admitted to the hospital. Subgroup analysis using odds ratios with 95% confidence intervals demonstrated that corticosteroid use and rituximab increased the risk for severe COVID-19 pneumonia. Pre-infection forced vital capacity measurements were inversely related to severe COVID-19 pneumonia. Of note, the definition of severe COVID-19 pneumonia was not clarified in the manuscript.

This study is the largest cohort of MG patients with COVID-19 infection that has been published to date, however there are several limitations that limit interpretation of conclusions and generalizability. This study supports that frequency of severe COVID-19 infection requiring hospitalization appears to be related with baseline MG disease control, long term high dose prednisone treatment, rituximab treatment, other medical comorbidities and older age.

A note from the authors:

We strongly recommend our readers protect yourselves and your community and receive your COVID19 vaccine. Please note that there have been reports of MG exacerbation after vaccination and patients are encouraged to speak with their MG provider or primary care provider for specific concerns. In general, immunizations have been demonstrated to be safe and effective for patients with myasthenia gravis. The COVID19 vaccine trials included people with autoimmune conditions, and the results in this population was similar to the general population.

Howard JF Jr, Bril V, Vu T, Karam C, Peric S, Margania T, Murai H, Bilinska M, Shakarishvili R, Smilowski M, Guglietta A, Ulrichts P, Vangeneugden T, Utsugisawa K, Verschuuren J, Mantegazza R; ADAPT Investigator Study Group. Safety, efficacy, and tolerability of efgartigimod in patients with generalised myasthenia gravis (ADAPT): a multicentre, randomised, placebo-controlled, phase 3 trial. Lancet Neurol. 2021 Jul;20(7):526-536. doi: 10.1016/S1474-4422(21)00159-9. Erratum in: Lancet Neurol. 2021 Aug;20(8):e5. PMID: 34146511.

Menon D, Alnajjar S, Barnett C, Vijayan J, Katzberg H, Fathi D, Alcantara M, Bril V. Telephone consultation for myasthenia gravis care during the COVID-19 pandemic: Assessment of a novel virtual myasthenia gravis index. Muscle Nerve. 2021 Jun;63(6):831-836. doi: 10.1002/mus.27243. Epub 2021 Apr 19. PMID: 33792967; PMCID: PMC8251129.

Jakubíková M, Týblová M, Tesař A, Horáková M, Vlažná D, Ryšánková I, Nováková I, Dolečková K, Dušek P, Piťha J, Voháňka S, Bednařík J. Predictive factors for a severe course of COVID-19 infection in myasthenia gravis patients with an overall impact on myasthenic outcome status and survival. Eur J Neurol. 2021 Oct;28(10):3418-3425. doi: 10.1111/ene.14951. Epub 2021 Jun 25. PMID: 34080271; PMCID: PMC8239548.

RITUXIMAB: Why B Cell Reduction Therapy Doesn't Work for All MG Patients

By Kevin O'Connor, PhD

Rituximab (brand name Rituxan) was originally developed to treat B-cell lymphoma. This therapeutic targets the cancerous B cells, eliminating them with remarkable efficiency. It has also been used to treat patients who have autoimmune diseases, including MG, though it is not FDA approved for MG and consequently used "off label."

For a person with MG, the immune system is self-reactive, targeting and damaging the body's own healthy tissue—in the case of MG, receptor sites at the neuromuscular junction. As patients know, this causes muscle weakness and fatigue. Disease-affecting autoantibodies, which target neuromuscular junction receptors in MG, are produced by B cells. Consequently, removing B cells is effective in reducing autoantibodies and lessening MG symptoms, thus allowing patients to lead more active lives.

As effective as the treatment is, nature finds a way to challenge us; rituximab works well in some patients, but not all. Specifically, patients with the MuSK form of MG have suffered relapses after completing a course of rituximab and getting their symptoms under control. Colleagues at Yale and I conducted research, published last year in JCI Insight, to find out why.

WITH A BETTER UNDERSTANDING... PHYSICIANS CAN ADJUST COURSES OF TREATMENT

In our study, we looked at patients with MuSK MG who had suffered a relapse after treatment with rituximab. When we studied their blood, we found B cells that persisted despite the treatment. We were able to determine that these cells were not newly produced B cells, but clones of the patient's B cells that had been present before treatment. Essentially, the treatment puts out the flames, but the embers remain burning, and when you remove the treatment, the fire can light up again.

We don't yet know why these B cell clones persist in the body, but with a better understanding of why some patients with MG relapse, physicians can adjust courses of treatment accordingly or can apply new treatment options that may better reduce symptom burden.

**This article shares study results and is not meant to be medical advice. Talk to your physician if you have questions about how this study's findings may affect your individual course of treatment.*

Dr. Kevin C. O'Connor is an Associate Professor of Neurology and Immunobiology at Yale University School of Medicine and the Vice Chair of the MGFA Scientific Advisory Board.

Looking to connect with others

in the generalized myasthenia gravis (gMG) community?

Making Connections

Education and support for
generalized myasthenia gravis

Register for a free webinar or in-person event at the link below*

Register at **AlexiongMGEvents.com**

Based on the event you'd like to attend, you could receive information about one or more of the following:

- Disease education from a physician
- Stories from people living with gMG
- Tips for managing symptoms

*These events are open to gMG patients and caregivers in the United States.

ALEXION

Start Your Own Do-it-yourself Community Fundraiser Today

If you've been to an MGFA walk or golf tournament, you know how fun these events are. Meeting other people with MG, sharing your story, getting your friends and family involved – the joy and positivity last far beyond the event itself. These events are an important way to foster awareness of MG, as well as raise funds to support our advocacy, research, and patient support activities.

Did you know that you can host your own MGFA event or fundraiser in your community? It's true! Here are two simple ways you can activate your community to support MGFA's mission.

1. **Host an event**... a walk, softball tournament, golf outing, yoga class, or anything you set your mind to! There are different ways to raise funds through these events, from registration fees to sponsors. You can keep it very small, or go as big as your time and energy allow.
2. **Host a fundraising initiative**, such as a birthday fundraiser or asking a local restaurant to donate a portion of checks one evening to MGFA.

While you're the organizer and handle logistics and outreach for your event, we have a lot of resources to support your initiative. Here's what you can expect from MGFA:

Staff support: Our National Director of Field Development Tasha Duncan is just an email or call away. Review your event with Tasha, obtain key resources, and learn about additional ideas to make sure your event is a success! Contact Tasha at tduncan@myasthenia.

Website: MGFA works with a fundraising platform called CLASSY that will allow you to design a fundraising page suited for any type of event you choose to host. We will work with you to create your page and then give you the resources to help you manage it.

Materials: Request materials for your event such as a disposable banner, pamphlets on MGFA, and more.

Social Media: We'll amplify your posts and photos if you share your information with us or tag the Myasthenia Gravis Foundation of America.

Press Kit: We want to make it easy for you to share your event with your local community and media, so we'll provide you with a templated press kit and a how to guide on marketing your event.

Community Events Calendar: We'll share events in our national event calendar on the MGFA website.

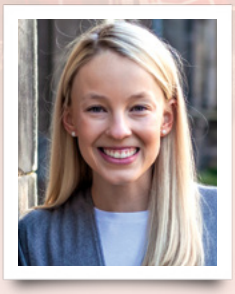
Are you ready to host your event? Contact Tasha Duncan at tduncan@myasthenia to begin planning your event and check out the community event resource page at: myasthenia.org/Get-Involved/Community-Events-Do-It-Yourself-Fundraising.

WE CAN'T WAIT TO WORK WITH YOU!

PS – Need inspiration? Check out Andrea, Drea, Paula, and Jeff's stories on the myasthenia.org/About-Us/Blog.

Join Our Giving Circles to Make an Impact

By Caroline Gayler



If you are a donor to any organization, no matter the size of your gift, it can be challenging to directly understand the impact your gift is making. And I can assure you, no matter the size, your gift matters. We are ready to change that challenge at the Myasthenia Gravis Foundation of America (MGFA) and make sure you, as a donor, understand exactly how your gift continues to make an impact.

I am thrilled to be part of the MGFA team as the new Director of Development. I have worked for a variety of health-related non-profit organizations in the past, including my most recent role in Development at March of Dimes HQ in the Washington D.C. area. As the new Director of Development at MGFA, my focus is to ensure the sustainability of the organization by connecting donors with impact.

What exactly does that look like and what does it mean?

Growth and change are driven by our donors. It's the only way we are able to fund new research, launch new programs, and support all the rock star individuals in this field and on our team who make things happen. So, my role as Director of Development is solely to make sure that each donor knows exactly how their support made that growth and change happen – and to help donors who want to continue investing in our mission do so in a way that is meaningful to them.

One of the many ways we are demonstrating impact to our donors is through our newly-launched Giving Circles. By joining a giving circle, you as a donor will have the opportunity to hear more directly from our team. As a result, you can be more up-to-date on inside information from the organization. More importantly, it gives our team a way to appropriately recognize and share our gratitude with these individuals who make change happen here at MGFA.

Joining a Giving Circle allows you to take a more active and engaged role in the organization. We offer benefits that are unique to each circle to demonstrate our recognition of how critical donors are to our operations. More benefits become available based on the level of investment you, as a donor, decide you'd like to make. This is just one of the many ways we hope to share our gratitude with you for supporting us in continuing this critical work.

I am incredibly grateful to be part of this team and serve as a resource for each of you. Thank you for letting me be part of your journey to helping achieve a world without MG. For more information on joining a Giving Circle, visit myasthenia.org/Get-Involved/Donor-Giving-Circles or email me directly at cgayler@myasthenia.org.

**P.S. If your annual individual giving exceeds $1,000, you'll automatically become part of a Giving Circle and will receive information directly from me. You can join a Giving Circle anytime!*

MGFA GIVING CIRCLES

MGFA Support Groups

Are you looking to connect with others who share common life experiences? Support Groups can offer you support, resources, educational programming as well as social and recreational activities.

SHARE YOUR STORY. Support Groups are an opportunity to share your experiences openly and freely in a safe setting. Sharing your journey will not only offer you a sense of empowerment, but will help others in finding reassurance and learning new strategies to living with MG.

LEARN FROM LOCAL PROFESSIONALS. Support Groups offer educational programming and invite guest speakers directly from your community to present on a variety of topics. There are opportunities to learn about exercising techniques, insurance information, wellness, diet and more.

OFFER SUPPORT TO YOUR FAMILY & FRIENDS. Support Groups are led by the community and naturally become family-oriented. We typically turn to our family and friends first, but they may need support too! Support Group meetings are an opportunity for your family, caregiver and / or friends to learn more about MG.

ONLINE SUPPORT GROUPS are open to anyone regardless of where you live. In the face of the COVID-19 pandemic, we have been conducting virtual Support Groups using the Zoom video conferencing platform. These online groups are open to anyone in the MG Community no matter where you live. Many groups have educational guest speakers so anyone can learn from their expertise.

If you are interested in starting a support group, please reach out to Dova Levin at dlevin@myasthenia.org.

As we continue to experience the uncertainty and volatility of the Coronavirus/COVID-19 pandemic, MGFA has asked all Support Group Leaders to not host in-person support group meetings until further notice. However, MGFA has provided Support Group Leaders with the ability to conduct online videoconference meetings. Please check our virtual Support Group schedule links below to find a meeting.

Online Support Groups are available to anyone regardless of where you live. You can live in any region across the country or around the world and access this valuable information.

We want to reiterate that our top priority is the safety and wellbeing of all members of the extended MGFA family. Should you have any questions, please do not hesitate to contact the MGFA at 1-800-541-5454 or email mgfa@myasthenia.org.

We invite our spanish speaking community members to join our spanish-language support groups.

Please check our MGFA Support Group pages to obtain the latest dates for the coming year. Contact: Leah Gaitan-Diaz lamgchampions@gmail.com

COMMUNITY ALERT

WE'RE NOT ALONE: Creating a Spanish-Language Support Group

By Leah Gaitan-Diaz

For the Spanish Translation of this blog titled No Estamos Solos: La Creación de un Grupo de Apoyo en Español, please see below.

I was diagnosed with Myasthenia Gravis with MuSK antibodies in 2015. It was a confusing and overwhelming time. I didn't know much about the disease, and neither did the neurologist who diagnosed me. He assured me I'd be fine, but I had my first crisis about a month later, and I realized I had a lot to learn about MG. I was struggling with my cocktail of medications. I needed more information and support.

I found a support group in Los Angeles, about two hours from where my husband and I lived. We'd drive back and forth just to attend. The community and support was so important to me in those early days. When we later moved to L.A., I started another support group in our area, near USC's campus, so there would be another option for people closer to that area.

There aren't a lot of people out there who have this disease. We don't look sick, so people don't take us seriously, especially doctors. We need to advocate for ourselves, speak up, and share our concerns. That's why support groups are so valuable.

I try to run my group with a lot of interaction. I want people in the group to hear each other's stories, trials and errors, and what works for them. I want people to get these "ah-ha" moments as they hear how we're all handling our disease. Even though we're symptoms, medications and treatments are different, we're all the same. Living with a rare, invisible, chronic disease.

L.A. is a very large city, and I saw people of different ages and backgrounds in the group. I started noticing some of our attendees struggling to follow the conversation in English. One couple, for instance — the husband had MG, and his wife/caregiver. She couldn't understand all the technical terms. Then there was another gentleman who also has MG, and he wanted his mom to attend a meeting and understand what he was going through.

I realized there is a need, even when those in some groups deemed it unnecessary. So with the continue support of Senior Director of Programs, Dova Levin, I started hosting the only Spanish MG Support Group in the Nation with the MGFA. When COVID hit, I transitioned the USC and Spanish MG support group to a weekly Zoom meeting. I realized it was a lot easier to host a Spanish-language meeting on Zoom because we could invite people from anywhere to attend - they didn't have to be local to the L.A. area.

I now host a Spanish-Language support group every other month on Zoom. It's not only for patients but for family members, friends, nurses, doctors... anyone who feels like Spanish is their go-to language. Myasthenia Gravis can already be isolating and complex to understand. People shouldn't feel confused or pushed aside because of a language barrier.

I want others with Myasthenia Gravis to understand that they're not alone. At the group meetings, we share our experiences and talk about how we reduce stress and handle crises, what doctors we have found to be knowledgeable and responsive, what medications and treatments work for us. We feel like we have a shared experience, which makes it all less frightening, but we also talk about how we are different. MG presents differently in different people - that's one of the challenges of the disease.

There are times when I really hate having this disease. I can't lift my arms to wash my hair or do any activities without having to take breaks or even a nap. We are all human. We're such few of us that we need to stick together and support each other. Not judge each other. Everybody is going through different challenges and travels in their life.

Running a support group is a commitment I am proud to make. Even if I start the call and there's just one other person, I'm happy knowing I can make a difference for them that day. That one person needed to reach out and talk to somebody, and I feel good knowing they have someone to listen to.

Spanish-Language Zoom sessions are every other month. Visit the Support Group page and scroll down to Special Meetings to RSVP for the next session and email me at lamgchampions@gmail.com.

NO ESTAMOS SOLOS: LA CREACIÓN DE UN GRUPO DE APOYO EN ESPAÑOL

En el año 2015 me diagnosticaron con Miastenia Gravis (MG) con anticuerpos MuSK. Fue un momento muy confuso y abrumador. No sabía mucho sobre esta enfermedad, ni tampoco sabía mucho el neurólogo que me diagnosticó. Él me aseguró que estaría bien, sin embargo tuve mi primera crisis aproximadamente un mes después y entonces me di cuenta lo mucho que me faltaba por aprender sobre la MG. Estaba luchando con mi cóctel de medicamentos. Necesitaba más información y apoyo.

Encontré un grupo de apoyo en Los Ángeles, a dos horas de donde vivíamos mi esposo y yo. Para asistir teníamos que conducir dos horas de ida y otras dos horas de vuelta. Pero la comunidad y el apoyo fueron muy importantes para mí en esos primeros días. Más tarde cuando nos mudamos a Los Angeles, comencé un grupo de apoyo, cerca de la Universidad del Sur de California (USC), para ofrecerles una opción a las personas de esa área.

No hay mucha gente que tenga esta enfermedad. No parecemos estar enfermos, por lo que la gente no nos toma en serio, especialmente los médicos. Necesitamos defendernos a nosotros mismos, hablar y compartir nuestras preocupaciones. Por eso los grupos de apoyo son tan valiosos.

Yo procuro dirigir a mi grupo ofreciéndoles mucha interacción. Quiero que las personas del grupo escuchen las historias, las pruebas y los errores de los demás, y lo que sí les funciona. Quiero que la gente tenga estos momentos de "¡ajá!" al escuchar cómo todos estamos manejando nuestra enfermedad. Aunque nuestros síntomas, medicamentos y los tratamientos son diferentes, todos somos iguales. Vivimos con una enfermedad crónica rara, invisible.

Los Angeles es una ciudad muy grande y llegan personas de diferentes edades y orígenes al grupo. Comencé a notar que a algunos de nuestros partícipes les era difícil entender la conversación en inglés. En el caso de una pareja, por ejemplo, el esposo tenía MG y su esposa es la cuidadora. Ella no entendía todos los términos técnicos. Luego estaba otro caballero que también tiene MG, y quería que su mamá asistiera a una reunión para que ella pudiera entender lo que estaba pasando.

Así me di cuenta que existe una necesidad de crear fuentes de información en español para las personas con MG, un asunto de comunicación urgente a pesar de que los miembros de algunos grupos no lo consideraban necesario. Entonces, con el apoyo continuo de la Directora de Programas, Dova Levin, inicié el único Grupo de Apoyo en español para MG con MGFA del país. Cuando llegó el COVID, fue necesario cambiar de grupo de apoyo en persona en Los Angeles en español, a una reunión semanal a la distancia por Zoom. Me di cuenta que era mucho más fácil organizar una reunión en español por Zoom porque podíamos invitar a las personas de cualquier lugar para que asistieran; no era necesario que vivieran en Los Ángeles.

Ahora organizó un grupo de apoyo en español cada dos meses por Zoom. No es sólo para pacientes, sino también para sus familiares, amigos, enfermeras, médicos ... cualquiera que sienta que el español es su idioma preferido. De por sí, la Miastenia Gravis puede resultar aislante y compleja. Por eso es aun más importante que las personas no se sientan confundidas o apartadas debido a la barrera del idioma.

Quiero que las personas con Miastenia Gravis comprendan que no están solas. En las reuniones de grupo, compartimos nuestras experiencias y hablamos sobre cómo reducimos el estrés y manejamos las crisis; quiénes son los médicos que hemos descubierto que sí están bien informados y que sí nos escuchan y responden, y qué medicamentos y tratamientos nos funcionan. Tenemos una experiencia compartida, lo que hace que todo sea menos aterrador, pero también hablamos de cómo somos diferentes. MG se presenta de manera diferente en diferentes personas y ese es uno de los desafíos de la enfermedad.

Hay momentos en los que realmente odio tener esta enfermedad. No puedo levantar los brazos para lavarme el pelo o realizar ninguna actividad sin tener que hacer descansos o incluso tomar una siesta. Todos somos humanos. Somos tan pocos que tenemos que mantenernos unidos y apoyarnos unos a otros. No juzgamos. Todo el mundo está pasando por diferentes desafíos y experiencias en su vida.

Dirigir un grupo de apoyo es un compromiso del que estoy orgullosa. Incluso si inicio la llamada y sólo hay otra persona, me alegra saber que pude marcar la diferencia para ellos ese día. Esa persona necesitaba acercarse y hablar con alguien, y me siento bien sabiendo que tienen a alguien que los escuche.

Las sesiones de Zoom en español son cada dos meses. Visite myasthenia.org/MG-Community/Find-MG-Support-Groups/Schedule-for-Virtual-Meetings-via-Zoom-by-State para confirmar su asistencia para la próxima sesión o envíeme un correo electrónico a lamgchampions@gmail.com.

You May Be Able To Help Researchers Understand More About MG

See if you are eligible to join this two-year-long **MyRealWorld™ MG** study.

MyRealWorld™ MG is a global research project focused on understanding myasthenia gravis. The study relies on anonymous data recorded in the **MyRealWorld™ MG** app by adult patients diagnosed with MG. The more information the study collects, the more researchers may be able to understand MG and how it shapes the lives of people who live with it every day.

Why you may want to participate:

- **You may be able to help increase understanding** by joining this international study of myasthenia gravis.
- **You may be able to help researchers and the medical community** better understand the lives of people living with MG.
- **You may learn more about MG** through educational content provided via the app.
- **Your participation may support the larger MG community** by increasing knowledge about the patient experience.

Once you download the **MyRealWorld™ MG** app, you'll be asked to set up a medical profile where you can record information about your MG experience and management. You'll also receive regular surveys about additional diagnoses, symptoms and your daily-life activities. Over a two-year period, the **MyRealWorld™ MG** app aims to capture more real-world evidence data of MG's effects than ever before.

HOW TO JOIN THE STUDY.

Download on the App Store

GET IT ON Google Play

This app is available in Spanish.

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MGFA Lucky Ken-Ducky Derby Fundraiser

One of the most fun and anticipated MGFA fundraisers each year is the Lucky Ducky Derby. These fun, informal yet intense fundraising campaigns pit fun-loving MG Community members against each other as they root on their own rubber ducks while they "race" down a water-filled canal. The duck jokes run rampant each year, and there are always team and individual winners — all in support of the MGFA. We thank our MG volunteer Jessica Simmerman for planning these events over the past two years.

In 2021, while in the grip of the COVID-19 pandemic, the Lucky Ducky Derby returned by popular demand with a "twist." We played on the timing of the world famous Kentucky Derby horserace, and named our spring event the MGFA Lucky "Ken-Ducky" Derby – get it? The Ken-Ducky Derby, where our Feathered Friends went 'Waddling for the Roses' as they raced towards the finish line.

Duckville was chompin' at the bit for another specDuckular event. So these ducks saddled up and the MG Community raised money for the MGFA! And since it was the Lucky Ken-Ducky Derby, that means big hats and mint juleps were in – Jessica and the team wore the finest hats and outfits for the day.

The winning ducks earned:
WIN: $1000 Amazon Gift Card
PLACE: $350 Amazon Gift Card
SHOW: $150 Amazon Gift Card

We thank Jessica, Samantha Gardner, and all our MG Community members who raised funds and participated in the derby. Three cheers for our top teams and individual fundraisers:

TOP TEAMS:
The Weiss Quackers
SA River Walk Muddy Ducks
Pierre's Canards

TOP INDIVIDUALS:
Elroy Tschirhart
Sue Kenyon
Pierre Clement

You can relive this exciting, fun, and successful event on our YouTube page.

MGFA WEBINARS SERIES

As the pandemic brought most in-person events to a halt, it was our goal to support you however possible. Last year, we introduced the MGFA Wellness Webinar Series and the What's New in MG Research? Webinar Series. These webinars connect, educate, and empower MG patients, care partners, and medical professionals. You can also learn about the latest research results, key clinical trial phases, and current outcomes from top research trials taking place right now.

You can watch recordings of all the webinars on our website:

Wellness Webinars myasthenia.org/MG-Community/Wellness-Strategies/Wellness-Series

What's New in MG Research? https://myasthenia.org/Research/Whats-New-in-MG-Research

To hear about the latest offerings, make sure you've signed up for the MGFA email list or contact us at mgfa@myasthenia.org.

MYASTHENIA GRAVIS FOUNDATION OF AMERICA

290 Turnpike Road, Suite 5-315
Westborough, MA 01581
(800) 541-5454
mgfa@myasthenia.org

www.myasthenia.org

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.

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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.

CONSIDER GIVING IN YOUR WILL OR TRUST

MGFA ELLSWORTH SOCIETY

MGFA is there for you when you need resources, information, and the support of others who know what you are going through. Help us ensure our work continues far into the future. When you make a gift to MGFA through your will or trust, you will make a difference for the MG community.You can make a bequest in our will, name MGFA as a beneficiary, or consider other estate gift options. Contact Craig Strenger, Vice President, Development for MGFA, at cstrenger@myasthenia.org today so we can answer any questions you have or help you set up your gift.