

CHANGING THE WORLD FOR EVERYONE LIVING WITH MG: PEOPLE MAKING A DIFFERENCE

The Snow/Goldstein Family

In 2009, Jasmine Snow was on top of the world. A recent college graduate, she had landed a plum job working for *Seventeen* magazine. She and future husband Paul Goldstein were enjoying a whirlwind life in New York City, where Paul's restaurant and nightclub (TAO/LAVO) was being recognized in NYC media as one of "THE" places in Manhattan to go for great food and atmosphere.



Jasmine, Paul and Isla

It never occurred to Jasmine or her family that she could get sick—she hardly ever caught a cold.

So, at first she ignored the weird sensations she was having—changes in her speech, difficulty chewing, something funny with her eyes. The symptoms would come and go, but over time seemed to be getting worse. Finally, it was the change in her smile - notable in "before" and "after"

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2019 MG Walks

- ST. PETERSBURG, FL: February 23
- COCONUT CREEK, FL: February 24
- TALLAHASSEE, FL: March 10
- ATLANTA, GA: March 30
- NEW ORLEANS, LA: April 6
- GREEN BAY, WI: May 11

PLEASE GO TO MGWALK.ORG FOR MORE INFORMATION ON A WALK NEAR YOU!



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PARTNERS IN MG CARE:

IS YOUR HEALTH PROFESSIONAL CONNECTED?

MGFA wants to make sure that MG patients are getting as much support as possible. The *Partners in MG Care* program will not only serve as a resource for people affected by MG, but also seeks to enhance knowledge-sharing, professional education and networking opportunities for healthcare providers. Through a multi-faceted approach, *Partners in MG Care* will provide support to health professionals while increasing access to quality MG care for patients. You might be asking, how do we do this?

Through physician outreach, community connections and education, MGFA is striving to

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CEO'S LETTER



PEOPLE MAKING A DIFFERENCE

Dear MG Community Friends and Colleagues,



Reading the articles for this issue of Focus on MG, I was reminded of this quote from anthropologist, Margaret Mead:

“Never doubt that a small group of thoughtful, committed citizens can

change the world; indeed, it's the only thing that ever has.”

Dr. Mead could have been talking about MGFA. In this issue, we focus on a few of the remarkable, passionate people who are contributing to our mission, each in his or her own way. As I read these stories, I am moved by how powerful the MG community is becoming. MGFA is growing as a collective of thoughtful, **committed** individuals. **Committed** to changing the world for everyone who lives with myasthenia gravis. **Committed** to creating a world without MG.

I think that you, too, will be inspired as you read about people who have found their own pathways to make a difference. Families like the Snow/Goldsteins, the Gershwins, and the intrepid mother-daughter trio of “Mira, Dhira and Tira” — all driven and inspired by a member of their family with MG. They’ve taken this passion and transformed it to lead innovative, successful fundraisers to help the entire MG community. You will also meet Roberto,

a professional photographer inspired by his visual issues to create The MG Project, and Susie Johnson, who has made MGFA an important part of her and husband Bill’s philanthropic commitments. You will learn how community and support group leaders, along with our team of MG Friends, ensure that no one has to face MG alone. How social media maven Sarah Noori brings people together and spreads MG awareness on Instagram. How exercise advocates, like Dr. Hafer-Macko, Dr. Naumes and Garry Morehouse help people find pathways to healthier living with MG. You will see how people took something they love and turned it into a DIY fundraiser—like artist Kait Masters who turned an online art auction into a way to support MGFA.



The stories do not stop here. Last week, I attended the largest Scientific Session ever held by MGFA, with more than 200 clinicians and scientists attending and 36 abstracts submitted. It was gratifying to see so many of these experts interested in MG, and to hear about new research. I was struck by the thought that the cure for MG could come from someone in this very room! It gave me chills.

Representatives from five pharmaceutical companies (Alexion, Argenx, Catalyst, Momenta and Ra) were also present at this meeting. All of these companies are dedicated to developing new ways to treat MG. New research brings us closer to more choices and options in the medications that we take to manage MG. It is not an exaggeration to say that a decade from now the treatment of MG will look very different from what we know today.

“I am moved by how powerful the MG community is becoming. MGFA is growing as a collective of thoughtful, committed individuals.”

I also was able to attend our Virginia Walk. It was so much fun; I wish I could go to EVERY MG Walk! The Walk is a rallying point for our MG Community – a place to join with others who want to change the world for people with MG. It is the best feeling to be surrounded by others who are dedicated to doing something to beat this disease. If you have never been to an MG Walk, I urge you to find the nearest one and sign up—or talk to us about how you can start an event of your own in your community.



Finally, I am delighted to introduce you to two new MG staff members: National Program Director, Jessica Hughson-Andrade, and Director of Fundraising, Samantha “Sam” Gardner. The best non-profit organizations engage knowledgeable and talented staff to work hand in hand with our volunteers and event participants—and these additions to our staff team will make MGFA a stronger organization. Jessica brings valuable experience as she fills the vacancy left by Kathy Brown’s retirement, and Sam is our very first fulltime fundraiser—bringing expertise that will help us to grow our Walk and other key programs in the new position. Jessica and Sam join Nakeshia, Betty, Larry, James and Susan in ensuring our key priorities move forward.

MGFA is your organization. We are working together to be the hub of the MG community, and together we WILL change the world—to one without myasthenia gravis!

Hoping to see many of you in Atlanta at our MG National Conference,

Nancy Law

MGFA Chief Executive

NOW!
2019 NATIONAL CONFERENCE
Connect. Learn. Empower.
MAR 30-APR 2, 2019 | ATLANTA, GA
JW Marriott Atlanta Buckhead

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

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

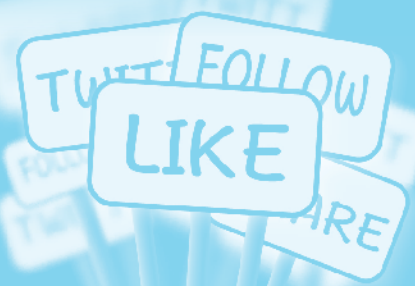
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Catch up with the MG Community, learn more and share your story...on our website, Instagram, Facebook and Twitter.

myasthenia.org   





photographs – that prompted Jasmine to seek help. Not knowing exactly where to go, she started with her dentist, and even took those before and after photos with her. It was the dentist who suggested seeing a neurologist.

The classic presentation of bulbar symptoms led the neurologist to be concerned, and to run a battery of tests. Diagnosis: myasthenia gravis. High dose prednisone was prescribed, and thymectomy recommended. Jasmine’s mother, Mary Beth Snow, recalls the shock and fear that she and her husband, Russell, felt.

“Jasmine had always been healthy and active. It was hard to believe that she had been diagnosed with a serious chronic illness—let alone one that hardly anyone had even heard of.”



A diagnosis of MG affects the entire family, and even though Jasmine was an independent adult, Mary Beth’s “mama bear” instincts kicked in. She took on the role of fierce advocate—doing all she could to learn about MG, helping her daughter get the best care possible.

“The first year after diagnosis was pretty overwhelming,” Jasmine remembers. “The support of my family meant so much. Attending the MGFA’s New York City Support Group was really helpful, too, in giving us a chance to connect

with others with MG.” Through these connections, Jasmine found a neurologist who specialized in MG. She learned a lot about this disease, which is different for everyone, and became a savvy self-advocate in decisions about her MG Care. The recommended thymectomy was performed as a laparoscopic procedure, the right treatments prescribed, and she started to feel better.

“Don’t think of fundraising as a daunting task. You can’t be afraid to ask,” says Jasmine. “The worst thing that will happen is that they will say no.”

It was at the NYC Support Group meeting that Jasmine first heard about the MG Walk, which was just getting organized. One of the group members was talking about his plans to leverage his community connections—with a goal to raise \$50,000. Competitive by nature, Jasmine left the group with ideas percolating. “I kept thinking—we know people too! We can raise money.”

She asked Paul if he thought that the restaurant might be willing to help. She also talked to mom, Mary Beth, who had been involved in charitable fundraising for years, about how to get started. Mary Beth suggested forming an MG Walk team and creating a benefit event of their own, with the

“Make it fun,” Mary Beth advises. “Make your event something people want to be a part of. Be creative—think out of the box.”



The Snow/Goldstein Family



funds raised going to MGFA. Paul talked to his TAO partners, and they were all in. Jasmine formed an MG Walk team, aptly named “Jas and the Riverside Rockstars.” Mary Beth, Russell, and the family, plus lots of friends, signed up. It was game on!

In addition to reaching out to ask for pledges for the walk, the family set out to create an event that would be both fun and inspiring—and profitable. They invited everyone they knew, and reached out to those who might donate items, provide sponsorship, or provide support in any way. There was a silent auction, raffles, and lots of gourmet food and drink. This very first endeavor raised nearly \$87,000!

That was 2011. Over the next years the Snow/Goldstein family, and their family and friends continued to support the MG cause. Just this year, in 2018, the family raised another \$82,000—

bringing their grand total to more than \$556,000, making them the top MG Walk fundraisers of all time!

For an event that has raised more than \$5 million since it’s first year, this family’s contributions to the MG Walk total more than 11% of that total. Amazing!

What’s their secret? Both Jasmine and Paul grew up in families where they believed in helping others. Jasmine’s parents were always involved in charitable work. As young adults, Paul and his brother Mark were founding members of The Section 16H Group—named for their section of the Meadowlands parking lot. In 1998, twelve people stood around a barbeque in 16H and “ate Dave Bernstein’s famous lamb chops, drank beer, played cards and threw around a football.” It was there that they decided that they would start inviting people and make it grow. In 2007, the Section 16H tailgate became a charity event for the first time. The “Tailgate With A Cause” (thetailgate.org) institution was born! Since its inception, Section 16H Group has grown to more than 1,500 people. Each year the members choose charities to donate to—always those that are

“Create an experience that people want to be a part of, benefiting a meaningful cause,” Paul advises.

close to the hearts of the members of the Section 16H group. MGFA has been the beneficiary of \$61,500 from this generous group of participants and donors since 2013, including \$27,150 in 2018.

The team welcomed a new and particularly adorable Riverside Rockstar in 2017, when Jasmine gave birth to beautiful little Isla Blake Goldstein. Pregnancy can be challenging for women with MG—and due to the possibility of neonatal myasthenic syndrome, babies of mothers with MG have to be watched carefully immediately after birth and for the first few days of life. Jasmine and Paul were very proactive, ensuring that they had all the right medical support in place. Happily, Isla arrived healthy and well (the “Rockstar” of the NICU) and continues to thrive and keep her family busy.

We in the MG Community have all benefitted from the efforts of this remarkable family, as the funds raised have allowed MGFA to fund critical research, expand service programs like our growing network of community support groups, and raise awareness of MG nationwide. Thanks to Jas, Paul, Mary Beth and Russell and all of the Riverside Rockstars (not to forget Isla, of course) their donors, and members of Section 16H! ✨



Join the fun and use MGFA’s new Twibbon to promote awareness of MG.



Go to <https://twibbon.com/support/mgfa-june-awareness> to use the new Twibbon on your social media sites.



PARTNERS IN MG CARE:

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



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

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



WHAT'S IN IT FOR THEM?

- Be part of a robust, nationwide database of MG healthcare providers
- Framed certificate from MGFA proclaiming them as a Partner in Care
- Public acknowledgement on the MGFA website
- Referrals of MG patients to their practice
- Literature, information about educational opportunities, research updates and advocacy alerts about MG

HOW DO THEY GET CONNECTED?



Interested health professionals can contact MGFA:
 Toll-Free: 1-800-541-5454
 Email: mgfa@myasthenia.org

Want to step up outreach efforts in your community?
 Contact MGFA at mgfa@myasthenia.org for a bundle of brochures and spread the word! ✨



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.



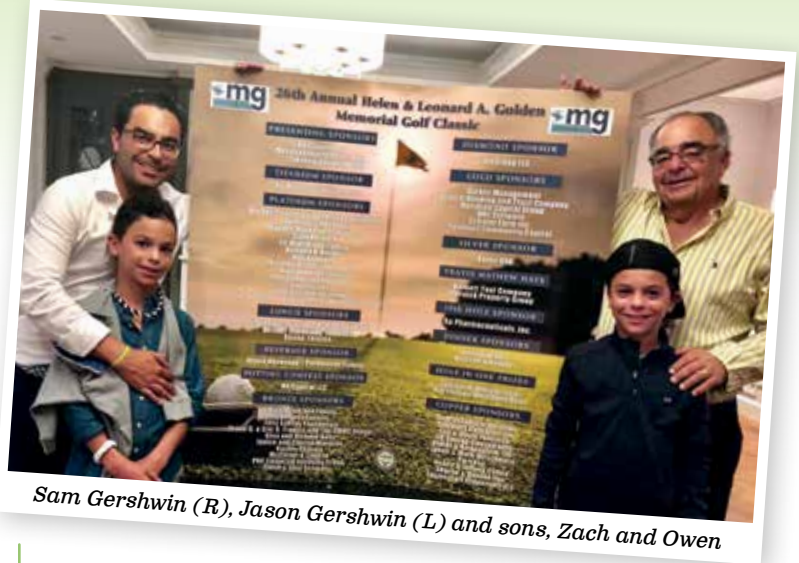


The Gershwin Family

While Mother Nature took a soggy swing across New Jersey, the sun was shining for MGFA! The Helen & Leonard A. Golden Memorial Golf Classic, held on August 13, 2018 in West Orange at the Crestmont Country Club, was a great success, despite the rain. The tournament, with presenting sponsors R4 Capital LLC, Meridian Investments and Sterling National Bank, swung into its twenty-sixth year, raising more than \$62,000 for MGFA.

“We are so pleased that our tournament has been recognized as the largest grossing golf event in the country that raises money for MG.”

Thanks to months of planning by the Gershwin family and a dedicated committee chaired by Jason Gershwin, the event surpassed maximum attendance with more than 130 golfers. Despite the rain, over 100 guests attended the cocktail party and dinner. Jason proudly shared, “Our event continues to honor the legacy of my grandparents and their incredible efforts on behalf of finding the cause of and cure for myasthenia gravis (MG).” This event is truly a family affair with Jason taking on the role of committee leader from his father, Sam Gershwin, still an active committee member. Jason’s young sons, Zach and Owen, are already helping out on the day of the event.



Sam Gershwin (R), Jason Gershwin (L) and sons, Zach and Owen

Jason credits the success of the tournament to “delivering an exceptional experience which features highly coveted giveaway items, delicious food, spectacular hole-in-one prizes, incredible silent auction and raffle items, live music, and a ton of laughs and fun.” Michael Lifshitz, a member of the MGFA Board of Directors and Chair of the MGFA Fundraising Committee said, “The committee delivered a flawless event, as evidenced by the reactions I was privileged to hear at my own table and around the room. It’s obvious they have developed a huge fan base of participants committed to supporting this annual fundraiser. Not even a rained-out game could keep their guests away from the dinner party.”

“We are so pleased that our tournament has been recognized as the largest grossing golf event in the country that raises money for MG”, Jason said. Plans are already underway for next year’s tournament, planned for August 12, 2019 at Crestmont Country Club. Our deepest appreciation to the Gershwin family for their commitment to raising vital funds on behalf of those living with MG. ✨



Demographics and Treatment Analysis

The Myasthenia Gravis (MG) Patient Registry, developed with the support of MGFA, started in 2013 as a voluntary, confidential and patient-driven project with the goal of improving research, treatment and patient information around MG.

The patient registry focus on two patient assessment tools; the Myasthenia Gravis Quality of Life scale (MG-QOL15) and the MG Activities of Daily Living profile (MG-ADL). Through a series of questions focused on how MG affects activities of daily life, the MG Patient Registry is helps healthcare providers understand the true impact of the disease.

We are pleased to report that more than 2,600 people are currently participating in the MG Patient Registry – thank you! As of October 2018, the majority of patients that participated in the survey were female (62%). The average age of participants at enrollment was 57 years old, and self-identified as Caucasian (80%). Of those responses, the average age for the onset of MG symptoms was 40 years old. In a 2017 study, Registry participants reported 23% AChR Ab+ and 6% MuSK Ab+. However, it's interesting to note that the majority of respondents were unaware of their clinical markers.

In terms of medication and treatment, participants reported the following current treatments:

- 71% pyridostigmine
- 42% corticosteroids
- 24% mycophenolate mofetil
- 19% azathioprine
- 19% intravenous immunoglobulin (IvIg)
- 4% plasma exchange

Previous therapies reported included corticosteroids (36%), Ivig (28%) and plasma exchange (26%).

Other immunosuppressive therapies, such as cyclosporine, methotrexate and rituximab, were reported less frequently. The use of these therapies was reported between 5-10% each by participants. This could be attributed to potential safety concerns, which may result in physicians and patients pursuing these treatments less frequently. About 40% of MG Registry participants reported undergoing thymectomy.

Participants in the survey reported moderate to severe impairment in their activities of daily living, information that often goes uncaptured in medical records. Despite symptomatic and immunosuppressive treatment options, the quality of life for many people with MG may go unaddressed. Through increased participation and analysis of the MG Patient Registry, we hope this tool can serve as a catalyst for research, treatment, advocacy and awareness around MG.

We hope that you will participate in the MG Patient Registry to make it as comprehensive as possible in reflecting your experience with MG. To get started, visit the MGFA website at: mgregistry.soph.uab.edu/MGRegistry

More than 2,600 people are currently participating in the MG Patient Registry

Disease Burden in Patients with Myasthenia Gravis – Analysis of the Myasthenia Gravis Patient Registry

Gary Cutter,¹ Haichang Xin,¹ Henry J Kaminski,² Ted M Burns,³ Ramin Farzaneh Far,⁴ Petra W Duda⁴

¹University of Alabama, Birmingham, AL; ²George Washington University, Washington, DC; ³University of Virginia, Charlottesville, VA; ⁴Ra Pharmaceuticals, Cambridge, MA

INTRODUCTION

The Myasthenia Gravis (MG) Patient Registry developed with support of the MG Foundation of America was started in 2013 as a voluntary, confidential and patient-driven project with the goal of improving research, treatment and patient information for patients with MG.

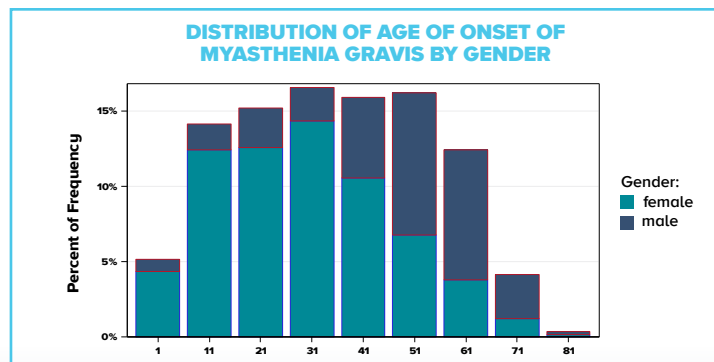
DEMOGRAPHICS	
Age mean±sd (median, range)	54.6±14.8 (57.0, 18-93)
Sex (% female)	66.2%
Race (% White, African, Hispanic)	80.4, 6.2, 0.2

Assessments include two validated scales of health-related quality of life: The Myasthenia Gravis Quality of Life scale (MG-QOL15) is a 15 item disease specific quality of life scale that was derived from a 60 item MG-specific healthrelated quality of life (HRQOL) scale^[1-3], and the MG Activities of Daily Living profile (MG-ADL) is a simple eightquestion survey of MG symptoms^[4,5].

Cross-sectional analyses of the MGFA Registry were done based on all patient records that included information on MG-ADL or MG-QOL by June 2017.

DISEASE CHARACTERISTICS	
Disease duration mean±sd (median, range)	9.9±10.1 (6.0, 2-58)
Age at first MG symptoms mean±sd (median, range)	40.3±18.9 (40.0, 1-81)
AChR Ab+ (% positive)*	23%
MuSK Ab+ (% positive)*	6%
MG ADL mean±sd (median, range), n=1140	6.2±4.0 (6, 0-21)
MG QOL mean±sd (median, range), n=1138	22.2±15.0 (21, 0-60)

*only those who indicated 'positive' are indicated in the table. The majority responded 'unknown' or gave no response for both antibodies: >70% for anti-AChR Ab, and >90% for anti-MuSK Ab



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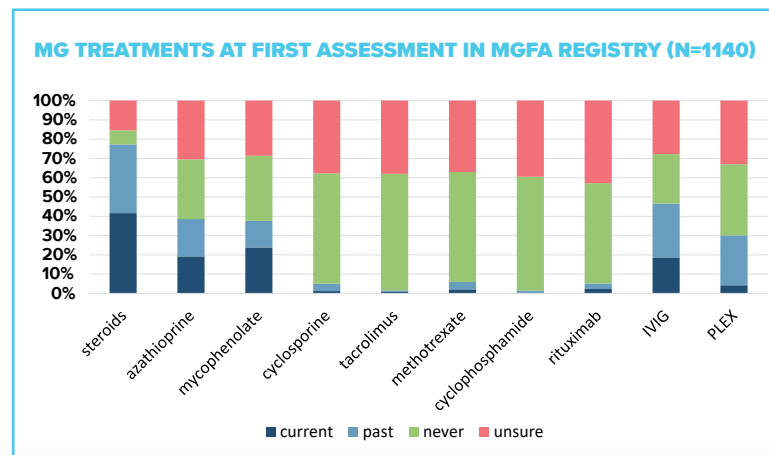
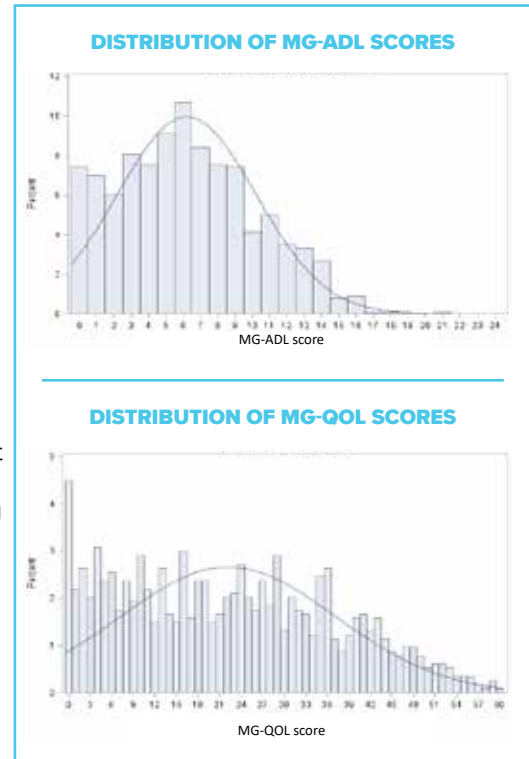
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QOL AND MG SPECIFIC TREATMENT

The majority of patients reported moderate to severe impairment in their activities of daily living as measured by the MG-ADL (N=1140) and MG QOL (N=1138) scales.

Most patients reported receiving pyridostigmine and corticosteroids. Immunosuppressive therapeutics were reported less frequently than expected, especially given the considerable disease burden in this population.

One reasons may be recall bias by patients. However, it cannot be excluded that potential safety concerns may lead patients and physicians to avoid immunosuppressive agents, even when their use is recommended by practice guidelines established by several organizations.



CONCLUSIONS

Contrary to common belief, MG remains a disease with significant negative impact on health-related quality of life of many patients, even in those receiving recommended symptomatic and immunosuppressive therapies.

#MGStrong Flexes Muscles in Most Successful MG Awareness Month to Date!

By Tommy Santora, MGFA Communications Committee Chair; Board Member; New Orleans Support Group Leader



From illuminating stadiums, to mayoral proclamations, to a first-ever satellite media tour, the messages of #MGStrong and myasthenia gravis awareness spread nationwide. Thanks to the hard work and innovation of the MGFA community,

this may have been our most successful June awareness month ever!

But don't forget — MG Awareness does not end in June. Our efforts take place year-round, and there are many ways YOU can continue to make a difference and educate people about MG. Whatever you decide to do for MG Awareness, remember that you're not alone in this journey. There is a lot of good news to spread about the MGFA; increased outreach and support nationwide as well as new advances in research for the MG community. As you battle every day, continue to realize that there is significant work going on behind the scenes to find a cure for MG. Do your best to let people know about it!

Here's a recap of our MG June Awareness success stories. If we've missed any news, please let us know via email with the subject line "June Awareness" to mgfa@myasthenia.org

STADIUMS, BUILDINGS AND ROADWAYS GO TEAL FOR MG AWARENESS

On June 25, the United Center in Chicago, which hosts the Chicago Bulls, Chicago Blackhawks and year-round major events, displayed #MGStrong on and around the stadium and went teal for MG Awareness Month. Thanks to the hard work of MGFA Board volunteers, MGFA staff, and New Jersey-based communications firm, TellMed, the MGFA logo, website and #MGStrong message were prominently displayed. As a result, MGFA reached nearly 30,000 people via social media, bringing awareness to new heights in 2018.



United Center, Chicago, IL



Mercedes Benz Superdome, New Orleans, LA

On June 27, the New Orleans MG Support Group worked with the Mercedes Benz Superdome to light it teal. Social media efforts around the New Orleans Superdome lighting reached more than 20,000 people. But the community's efforts did not stop there. Nearby at New Orleans bar Treo, fundraising efforts for MGFA were underway. Treo owner, Pauline Patterson, raised \$800 in honor of her sister, who has MG.



#MGStrong



Mobile. AL go teal for MG

Alabama, Ohio and Tennessee also wanted to keep the momentum going for June awareness month! In Ohio, Beckie Callaghan's hard work ensured that the Terminal Tower in Cleveland went teal for its second year in a row on June 4. The Cleveland group took

efforts a step further; educating the community about MG by distributing brochures and stickers. In Tennessee, thanks to Sharon Byrge, the picturesque and well-traveled Henley Street Bridge in Knoxville went teal on June 27. In Alabama, Barbara Wilson worked with several buildings, making downtown Mobile go teal for MG.



Sharon Byrge, Henley Street Bridge in Knoxville, TN

CEO NANCY LAW REPRESENTS MGFA IN FIRST-EVER SATELLITE MEDIA TOUR

Thanks to an unprecedented opportunity offered by Alexion, CEO Nancy Law represented MGFA in a "Satellite Media Tour" on June 13. A public relations firm provided by Alexion coordinated radio and television interviews for the day, representing stations all over the U.S. In a four-hour media "marathon", Dr. Tahseen Mozaffar and Nancy Law participated in nearly 25 interviews!



CEO Nancy Law and Dr. Tahseen Mozaffar

PROCLAMATIONS FOR MG AWARENESS MONTH

Thank you to our community members who have gone above and beyond to garner significant city and state proclamations of MG June Awareness Month! Proclamations of June as MG Awareness Month included the following cities:

- Jersey City, New Jersey (Janice Leslie Hochstat-Greenberg)
- New York, New York (Sue Klinger)
- Union City, New Jersey (Janice Greenberg)
- Houston, Texas (Kristine Kocan)
- Nevada, Las Vegas (Tam Mee)
- Tennessee (Sharon Byrge)
- Cleveland, Ohio (Beckie Callaghan)
- Ohio (Rebecca Molitoris)
- Farmington, Delaware (Donnalee Whitaker)
- Haverhill, Massachusetts (Drea Carbone)



Mayor Steven Fulop and Janice Greenberg, New Jersey MG Support Group Leader, with official Jersey City Proclamation

TRI-STATE MG WALK RAISES NEARLY 200K!



MGFA's Tri-State Walk raised \$204,000 this year for MGFA. The walk, which took place on June 9 in Queens, New York, served

as a prime opportunity to raise awareness for MG. Seven individuals raised more than \$10,000 each, including: Paul Goldstein, Sue Klinger, Greer O'Keefe, Dhira Bluestone, Jasmine Snow, and Leni Fuhrman. Five teams also raised more than \$10,000, including: Jas and the Riverside Rockstars, NY Trailblazers, Band-aids for Bliss, MTD_Lite, and Team Gary.

A huge, heartfelt thank you to Jasmine Snow and her family for raising more than \$80,000! MG Walks have raised nearly \$900,000 to-date in 2018 alone. Don't miss out on the momentum! Find a walk near you at: mgwalk.org

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MG REGISTRY ADDS NEARLY 100 PATIENTS IN TWO MONTHS



Thanks to the continued efforts of Roger Morse and Celia Meyer, social

media outreach added 99 patients to the MG registry in May and June. The Myasthenia Gravis Patient Registry is an active database of persons with MG, developed for the purposes of research, treatment, and patient information. The MG Patient Registry supports MGFA's vision of "A World Without MG", while improving the care and quality of life for persons affected by MG. The database offers a confidential means for patients to provide information that can be used by the medical and research communities to assess various therapies and disease costs. The Registry also provides a system for investigators to gauge potential clinical trial recruitment and foster patient communications about potential research investigations. Register today at: mgregistry.org



HOUSTON SUPPORT GROUP TEAMS UP WITH ASTROS FOR MG AWARENESS

Thank you to the Myasthenia Gravis Support Group of Greater Houston! Members Meena Outlaw, Liz Della Torre, Jenny

Yesenia, and Rachel Stewart Higgins, organized an MG Awareness Night at the Houston Astros baseball game on June 23. The group dominated Section 134 down the right field line, donning teal #HoustonWeHaveMG T-shirts. The group also made sure that the scoreboard lighting went teal during the game. The MG Houston community rallied around June awareness month, reaching out to local leaders, businesses, government agencies and community organizations to raise MG awareness. A big thank you to Rachel, who initiated a social media campaign on Facebook with one different fact a day about MG!



MG MEDICAL PROFESSIONALS AND PATIENTS FEATURED AROUND THE GLOBE

Dr. Gil Wolfe, Department Chair for Neurology at the University at Buffalo School of Medicine and Biomedical Sciences, Kim Eldridge, an MG patient from Louisville, Kentucky, and Dawn Warner, an MG patient from Stone Mountain, Georgia, were interviewed in the article "The Road to Surgery" featured in the June/July 2018 edition of *Brain & Life* magazine. The three discussed how MG patients should prepare before various surgeries to help alleviate MG symptoms.

MG patient Linda McMullen was interviewed on June 15 by the *Comox Valley Record* on her battle with the disease. In her interview, Linda brought awareness about MG for the 30,000 Canadians living with the disease. She also promoted the upcoming MG Walk in Comox Valley, which took place on July 14, to heighten awareness even further.

MG patient Greg Hughes was featured in *The Courier*, an Australian daily newspaper, on June 15. Through his story, Greg and his family are hoping to raise awareness about MG in Australia. They believe that a lack of awareness, both within their family and the medical community, delayed Greg's diagnosis.

MG patient Deborah Vick was featured in a *Moonshine Ink* news article, "When There is a Will, There is a Way". Deborah spoke about the importance of her service dog in managing with life with MG, Ehlers Danlos Syndrome and other secondary health complications.

New Jersey MG patient and local MG Walk Hero, Kelly DeVincentis, was



Kelly DeVincentis

interviewed by New Jersey's radio station 101.5 FM on her battle with MG. "I get that I have MG, I know what I have to do to manage it, but I don't accept it," DeVincentis said. "I don't accept this lifestyle for myself or for others who are being diagnosed with this."

Co-Facilitators of the Connecticut MG Support Group, Ed Czackes and Terri Adams, appeared on WTNH's "Good Morning Connecticut" to talk about the MG Walk, which took place on June 10. Over five years ago, Czackes started to develop the symptoms of MG. Adams talked about her daughter, Ronnie, who is living with MG. After their own personal experiences, both were moved to participate in their local MG Walk.

The *Metropolis Planet* newspaper helped raise awareness by promoting the Southern Illinois MG Walk on October 13. Thanks to MG patient Paula McGinnis, who not only educated the community through distributing information but also interviewed with a local radio station.



South Carolina MG Walk

The South Carolina MG Walk, held on May 19, was featured in the *Moultrie News*. At this year's walk, three residents were honored: MG Walk Heroes and support group leaders, Janet Myder and Julian Carnes, as well as 2018 National Hero of the MG Walk Campaign, Lauren Jarman.

Alexandria Bland, communications coordinator with the Department of Neurology and

Neurosurgery at Baylor, posted, "MG: What You Should Know," to the Baylor College of Medicine website blog page.

Jacy Thomas, a freshman at Purdue Polytechnic High School, was interviewed by Fox TV Indianapolis about her life with MG. Despite the challenges of her condition, Thomas is heavily involved in extracurricular activities; she is part of the Robotics Team, the Language and Culture Club, the Black Student Union, Girls Who Code and also manages the cheer team.



Jacy Thomas

Janet Myder, co-chair of the Low Country SC MG Support Group, wrote a letter to the editor of *Charleston's Post and Courier* newspaper about proposals to eliminate the use of plastic straws. While she realizes the impact that plastic straws have on the environment, especially for marine life, she stressed the importance of straws for those with conditions like MG. "As an individual who has MG, a little known and often misdiagnosed neuromuscular disease that causes varying degrees of muscle weakness including difficulty swallowing liquids and food, I am concerned about [the] indiscriminate dismissal of straws. Without a straw, I am at risk of choking on liquids that I drink from a glass or a bottle. Many other individuals with similar conditions or injuries also are at risk." The letter was published in the June 25 edition. ✨

UP YOUR MG IQ WITH MGFA WEBINARS!

Did you know that MGFA provides educational webinars year-round? From the latest advances in MG treatment options, emergency management of MG for first responders and living your best life with MG, we offer a wide range of topics for people with MG, their families and caregivers.

Our webinars are live, so you can interact with experts in the field in real-time! There is time for questions, as well as opportunities to learn about other members of the MG community. Please stay tuned on our website at: myasthenia.org/LivingwithMG/MGFAWebinarSeries.aspx





DIY — Fundraising Your Way!

Supporting MGFA is now easier than ever! With Do-It-Yourself Fundraising, anyone can design a fundraising event or activity that builds on their passions and interests. You name it! Love the idea of an endurance event? Getting ready to celebrate a special occasion like a milestone birthday, anniversary or Bar/Bat Mitzvah? Do you just need a little motivation to host a themed party? No matter your interest, DIY Fundraising can be your unique way to bring us closer to a world without MG. And best of all, you can create awareness about MG while supporting MGFA.

To learn more and to create your own fundraising website visit: give.classy.org/MGFA

VOLUNTEERS GET INNOVATIVE IN RAISING MONEY FOR MGFA!

KAIT STOCKWELL MASTERS, 27, was diagnosed with MG at 11. In September 2018, Kait continued her annual Facebook art auction benefitting MGFA. Kait's friends in the art community donated items ranging from jewelry to paintings to pottery and other artisan crafts. Through an active online bidding process, Kait raised over \$1,600. "Even though I wasn't sure

I could pull the auction off this year we were able to surpass our goal and raise the highest amount of the three years we have been doing this!"

DON (BUCKY) TAYLOR has had MG for 10 years and attends the Northeast Wisconsin MG Support

Group. Four years ago, he had a vision of creating a golf outing to raise money and awareness for MGFA, which he soon made a reality. Thanks to Bucky's commitment, twelve teams participated in the 4th Annual Myasthenia Gravis Golf Outing held June 24, 2018 at Far Vu Golf Course in Oshkosh, WI. The event raised \$1,700 for MGFA. "The day was lots of fun; a 50/50 raffle, a wine chair raffle, a football autographed by the Green Bay Packers raffle, a team poker game, socializing at the clubhouse and, of course, 18 holes of golf with prizes on every hole!", Bucky shares. He says they are looking forward to the 5th annual golf outing in 2019!

LIZ KINNISTEN AND FAMILY held their First Annual Golf Tournament in Sarasota, Florida on September 28, 2018. The event was held in memory of Patti Abramson, a close friend with MG and who passed away from cancer. The event is expected to net about \$10,000, which they hope will become an annual, memorial event supporting MGFA.

On September 29, 2018, **THE BALL COMPANY** in Virginia Beach offered "Mulligans For Sale" at a company golf tournament with proceeds benefitting MGFA. The volunteer who nominated MGFA as the charity beneficiary, Kimberly Wright, has an aunt with MG. Kim raised \$700 in 45 minutes (wow!) and is now eager to get involved in local MG programming with her family.

Thank you to all of our volunteer fundraisers! If you have sponsored a fundraising event for MGFA or if you have questions about planning something new, please contact Betty Ross, Director of Development at bross@myasthenia.org. ✨

Baseball Event Hits a Home Run, Raising 13K for MGFA!

Take me out to the ball game...Take me out to the crowd! There were peanuts, popcorn and Cracker Jacks® all night long on July 17 at The Baseball Center, located on the Upper West Side of New York City. Thanks to Mira Gregory and twin daughters, Tira and Dhira Bluestone, who raised nearly \$13,000 for their MG Walk Team, MTD_LITE, by creating this unique charity event!

Thirteen teams gathered from all over New York City to hit balls in a batting cage at up to 100 mph. Each team had a minimum goal of \$500. During the event, they also organized a silent auction, which helped to raise even more money for MG. Team MTD_LITE named Phil Cogan, a member of MGFA's Board, as the "official ringer with a swing that would put Babe Ruth to shame!" At the opening program, Phil shared his personal story about living with MG and his hope for a cure.

A huge thank you to Gregg Wolpert and The Stahl Organization for sponsoring this fundraiser; Beth Wolpert; Mike Belmont, program coordinator; Jason Stock, managing director; the rest of the team at The Baseball Center. Special thanks to Mira, Tira and Dhira for making the event a big success. This MVP family is committed to continuing efforts in finding a cure for MG, saying that "the real trophy goes to the MG survivors!" ✨



Mira Gregory, Gregg Wolpert, Tira Bluestone, Phil Cogan



Tira Bluestone



THE STATE HAS A PLAN FOR YOUR LEGACY. DO YOU?

Fewer than half of Americans have a will. Without a will, the state will decide how to distribute your hard-earned money. Don't lose control of your legacy. Visit an attorney and prepare a will and when you do, remember the MGFA. Make part of your legacy "A world without Myasthenia Gravis"



THE MG PROJECT

By Roberto Araujo

On Monday, November 13, 2017, my alarm went off at the usual time, 6:45am. I reached for my phone to turn the alarm off and noticed that my eyes were not focusing properly. I assumed my eyes were still recovering from sleep. But there was something different. My eyes weren't blurry. I was seeing double. Two crystal clear images of my phone in my hand. One on top of the other.

I rubbed my eyes, turned the alarm off and closed my eyes once again, thinking a little more rest would somehow “restore” my sight. Like rebooting a computer.

Concerned about it, I got up and went to the bathroom found that the double vision didn't go away.

A couple of days earlier, I had received a new batch of contacts. I have been wearing daily contacts for 3 years now. I attributed what was happening to my eyes to the new batch of contacts. Something must be wrong with the new lenses.

I continued with my day but my vision didn't get better. That same day I made an appointment to have my eyes checked out at LensCrafters. My eyes

were healthy, my sight and prescription hadn't changed. So it had nothing to do with the contact lenses. As a follow-up, they recommended that I go to Fromer Eye Specialists to see Dr. Kaplan.

Thursday, November 16. My birthday. I got together with some friends to celebrate. I got to see some dear friends I hadn't seen in a while. As I started to snap pictures with them to capture the moment, I noticed that my left eyelid was noticeably drooping.

I spent that weekend in DC with my husband who got us tickets for the premiere of Mean Girls. We tried to focus on celebrating my birthday and not stress about my health concerns.

My appointment at Fromer finally came. Dr. Kaplan examined me and after a long and meticulous exam he told me I had to go to the ER immediately. He made a few calls and sent me to Columbia Presbyterian Hospital. Once in the ER, more tests. At that point, my right eyelid was droopy and my left was back to normal. The doctor asked me to do 10 push-ups. I barely made it. That's when I noticed the strength in my arms was decreasing.

Photo Credit: Roberto Araujo



One night, I was making tea for my husband and myself. I went to pick up the kettle and my wrist completely gave up. I didn't have enough strength to pick it up. And just like that, tasks like chopping onions or carrying grocery bags became more and more difficult.

I think the hardest part about dealing with the first symptoms is not only not knowing what's happening, but the fact that no one can really understand what's happening to you.

For me, the disease wasn't debilitating enough to keep me from going to work or taking a ballet class or even doing a photoshoot. I tend to be a positive and high energy person. So at times, I felt like people didn't really believe I was actually going through something real, since I wasn't really sulking around, feeling sorry for myself.

After four separate visits for blood work, two MRIs, a CT scan and an EMG test, I had an answer. Neuro-ophthalmologist, Dr. Odell, diagnosed me with Myasthenia Gravis. Even though there was a certain sense of relief with the diagnosis, I still needed to find treatment.

Dr. Odell referred me to Dr. Cioroiu. Once again, more tests were ordered.

Here's the first time I saw a light at the end of the tunnel. When I went to get my EMG test, Dr. Pitts told me that MG was his favorite disease to treat, because they could really help me. He was the first doctor that really gave me hope.

After all the results were back and Dr. Cioroiu ruled out any other possibility, we finally began treatment. The first few days of the treatment were interesting, to say the least. I was waking up completely cross-eyed. My body was noticing a difference and it was adjusting to the medication.

After about a month, I started noticing a big difference. My eyes looked normal. The double vision was gone. My strength was slowly coming back.

I created this project to share my experience with others. To create awareness. To help people understand those of us who are going through it.

This condition ends up being more than just a vision problem. Being cross-eyed or droopy-eyed made me self-conscious about my appearance. I had someone at my place of work make fun of me because I "looked like I was falling asleep". I had to hold my husband's arm while crossing the street because my depth perception was impaired. Where did the sidewalk end and where were the cars coming from? Sometimes he would forget and walk without me.

As a photographer, MG inspired me to create this project to spread awareness and understanding about MG which I hope will lead to more compassion for people with the disease who are fighting to continue to lead normal lives.



Roberto Araujo is a Mexican photographer, based in NYC. His work has been featured in Playbill.com, ANIMIZE Magazine, and Beautiful Magazine. His work has commanded two solo exhibits in NYC and included as part of The Body Collection for The Exposure Award Exhibit at The Louvre. His work can be viewed at his website www.RobertoAraujoPhotography.com or on his Instagram @robertoaraujophotography. ✨



SUPERHERO SUPPORT GROUPS

Support groups are instrumental in how MGFA and other organizations deliver services to the community. These groups bring people together with common life experiences. Many groups offer education, emotional support, resources and social activities to keep people engaged and empowered!

To learn more about a Support Group near you, visit MGFA's Support Group Calendar for a listing of local meetings: myasthenia.org/CommunitySupport/SupportGroupCalendar.aspx

While not affiliated with MGFA, there are other MG organizations that offer Support Groups and assistance programs in different areas of the country. Please see information for these groups below:

Conquer MG: myastheniagravis.org

The Myasthenia Gravis Association of New England: mgane.org

Myasthenia Gravis Association of Western Pennsylvania: mgawpa.org

***If you do not see your MG organizations and Support Group on our site and would like to be listed, feel free to send us an email mgfa@myasthenia.org*



New York MG Support Group



Tampa MG Support Group



Knoxville Support Group

“TOMORROW IS A DIFFERENT DAY, AND MAYBE EVEN A BRIGHTER DAY...”

“In 2013, an eye specialist looked into my eye with his machine, backed away immediately and said... I don't need to finish the exam, you have myasthenia gravis,” Sharon Byrge, MGFA Support Group Leader recalls. “I replied, ‘I have WHAT? could you please write that down, because I will never know how to spell it.’”

Today, Sharon can spell myasthenia gravis with her eyes closed!

In April 2018, Sharon formed the Knoxville MG Support Group. She has proven to be a fearless leader and advocate for those living with MG. Sharon set three goals for her support meetings: 1) be informed; 2) stay interesting; and 3) have fun!

Sharon brings in a wide variety of guest speakers to her group; ranging from legal topics, to medical issues to nutrition. Knoxville group members leave each meeting with important information, but also take an interactive role in the group. There is often discussion around knowing your numbers, what a crisis is, breathing challenges and other symptoms.



Knoxville Support Group

The Knoxville Support Group also likes to have fun while spreading awareness about MG. This June, they worked with local government agencies to secure a proclamation from the state, city and county for MG Awareness month! They also were able to get the Henley Street Bridge to light up teal for MG awareness!

“When I know one of my fellow MG friends are having a rough day, I like to call, speak with them and then send an uplifting card.” When Sharon has a tough day, she has a mantra that she likes to share. “Tomorrow is a different day, and maybe even a brighter day,” which Sharon has also made as the motto for the Knoxville support group. ✨

“My goal is to help other patients, caregivers and family members have a better understanding of MG. As long as I am able to help others get awareness out about MG, I will do all that I can to get the job done, no matter what it takes. I would like to thank MGFA for allowing me to be a part of their team.” — Sharon Byrge, MGFA Support Group Leader, Knoxville, TN



Over 150 connections...and counting!

This past June, MGFA celebrated the first anniversary of its patient service program, MG Friends. Our highly trained and professional volunteers have provided services to 150 newly diagnosed MG patients to date. Each participant not only receives the most recent information about MG, but also has an experienced friend to help them in their journey with MG.

A BIG THANK YOU TO OUR VOLUNTEERS WHO ARE MAKING AN IMPACT!

Calvin Arnason	Sara Rutledge	Janet Genovese	Melissa Wolhust
Jessica McMullan	Paula Wright	Sarah Noori	Bridget Noujaim
Mary Ingram-Schatz	Nadine Sagaille	Jim LoVecchio	Mary Beth Snow
Michele Argo	Andy Waymouth	Julie Roberts	Kait Masters

A huge thank you to our program organizers and National MG Friends Workgroup for a job well done!

Suzanne Ruff, <i>Patient & Community Services Chair</i>	Toni Brown
	Niki Grossheim
Rebecca Molitoris	Melissa Wolhust
Kathie Bibeau	Julie Roberts





Focus on Fitness

By Garry Morehouse

Myasthenia gravis presents many challenges, not least of which is reduced fitness due to limited capacity for continued muscle use. This is especially true at the onset, where patients often experience long delays in obtaining a proper diagnosis of MG. Many experience weakness and fatigue for prolonged periods of time before achieving some degree of remission (with or without medication). But for most patients with MG, eventually there is an opportunity to recover strength. Every MG patient has their own path, often fraught with challenges along the way. For those who are being helped by treatment, or are experiencing remission, there are ways that you can stay active.

What better source for this information than our MGFA community? We asked some of our physically active volunteers and patients how they cope with the special challenges of MG.



Here's what we wanted to know:

- **What do you do to maintain your sense of wellness while coping with MG?**
- **How did you get started with your activity/routine?**
- **Do you have a particular strategy for maintaining your routine?**
- **How do you get past fatigue?**
- **What's your advice to those who aren't naturally inclined to exercise?**
- **What other advice would you give to fellow MG patients?**



Garry Morehouse

HERE'S WHAT WE LEARNED FROM GARRY:

Garry Morehouse: In addition to MG, I have not fully recovered from a hip replacement. My morning routine consists of: 20 seated chair squats, 10 band resistance exercises on each leg, a 40 second plank exercise, 20 leg raises from a mat and a short breathing exercise. I also walk with poles for about a mile a day.

MGFA: How did you get to this routine?

Garry Morehouse: When diagnosed, I started doing two minutes a day on a treadmill. I worked up to twelve minutes. This was the length of time to play a game of pickleball. My goal was to get back in the game. I now play pickleball almost every day. I have gone from two minutes a day on a treadmill to two hours a day playing pickleball.

MGFA: How do you get past fatigue?

Garry Morehouse: At times I need to push myself out of the house but it is worth it. I no longer get fatigued easily. When I do, a 20 minute rest with a breathing exercise recharges me. Also in general I get lots of rest (10 hours a night) as sleep is my friend.

*“If perseverance is the investment,
success is the reward”*

MGFA: What might you recommend for MG patients that are looking for activities outside of sports?

Garry Morehouse: For those not inclined for sports there are lots of low impact exercises such as walking, rowing machines, recumbent cycling. I saw a video using a band resistance exercise for those in a wheelchair.

MGFA: Do you have a particular strategy for maintaining your activity/ routine?

Garry Morehouse: Setting a goal and measuring progress is important. My goal was to play pickleball again. Having a buddy to exercise with works for many. A motto that I like is “if perseverance is the investment, success is the reward.” Finally, a positive attitude is key to effectively coping with MG.

HERE'S WHAT WE LEARNED FROM JULIA:

MGFA: What do you do to maintain your sense of wellness while coping with MG?

Julia Naumes: Balance. I do my best to balance my work life, personal life, activity, and downtime so that I am able to engage in all the things that are important to me without overdoing it. I work part-time with a dedicated weekday off for doctors' appointments, grocery shopping, cooking, and rest time.

MGFA: How did you get started with your activity/routine?

Julia Naumes: I was very active before being diagnosed with MG and kind of never stopped being active, I just modified how I did the activities, and what activities I did.

Pre-diagnosis I lifted weights and ran frequently. I could not do those activities the first year or so after diagnosis, but instead I did lower impact exercises, like stationary bike, gentle yoga, elliptical, swimming, etc.

MGFA: Do you have a particular strategy for maintaining your routine?

Julia Naumes: I do some sort of exercise every day, whether it be going for a 10 minute walk, resistance training, or playing sports. I guess I just do my best to engage in something that maintains my strength and mobility every day, but I do modify it a lot depending upon how my symptoms are. Somedays I just focus on deep breathing or stretching, which is very important for pain control.

The most important thing I learned in the first few years after my diagnosis, in regards to exercise, is to start low and slow and to adjust your activities based on your symptoms at that specific moment. Somedays I have to completely change my exercise plans because my MG won't tolerate it, and that's okay, but I still try to do something that promotes my wellness.

MGFA: How do you get past fatigue?

Julia Naumes: I make sure to exercise multiple times a week, but at a level that works with my current symptom severity. I find that if I completely stop exercising my fatigue gets much worse. Also, with having a dedicated weekday off of work, I use that day to meal prep so I have healthy and easy meals available on work days when I come home exhausted. Finally, I prioritize getting sufficient sleep, both in regards to quantity and quality. The balance between all these things, and my medications, enable me to live a very active and fulfilling life, which helps me feel well!

Having a workout partner helps me stay accountable when the fatigue is telling me to go home and lay on the couch.



Julia Naumes and Dr. Charlene Hafer-Macko, MGFA Board Member

continued on page 29

Register For a Fall 2018 MG Walk TODAY!



**CELEBRATING 8 YEARS
OF RAISING AWARENESS
AND FUNDS FOR THE
MG COMMUNITY!**

2019 MG Walks

ST. PETERSBURG, FL:
February 23

COCONUT CREEK, FL:
February 24

TALLAHASSEE, FL: March 10

ATLANTA, GA: March 30

NEW ORLEANS, LA:
April 6

GREEN BAY, WI: May 11

**VIRTUAL:
ANYWHERE,
ANYTIME!**



**PLEASE GO TO
MGWALK.ORG FOR MORE
INFORMATION ON A WALK
NEAR YOU!**

**THE 2018 MG WALK SEASON
IS OFF TO A GREAT START AND
YOU CAN STILL JOIN US IN THE FIGHT TO STOP
MYASTHENIA GRAVIS! CONSIDER JOINING US AT
A FALL MG WALK, OR PARTICIPATE VIRTUALLY TO
HELP MGFA REACH ITS \$900,000 GOAL!**

We Need You! If you haven't already, now is a great time to reactivate your team from last year. New to MG Walk? It's quick and easy to start a team and join the MG community in this fight! To check out upcoming MG Walks or to register, visit MGWalk.org

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



STAY CONNECTED   

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



HELP US GROW THE MG WALK MEDICAL AMBASSADOR PROGRAM!

MG Walk Medical Ambassadors are medical professionals who provide leadership in their local communities in the fight against MG. At every MG Walk, we strive to recognize these passionate, dedicated professionals who help MG patients every day. Alongside these professionals, MGFA aims to reach more people affected by MG; aiding them in their MG journey with critical funds, resources and support.

Medical Ambassadors can be doctors, nurses, researchers, lab technicians or medical staff members. In 2018, we want to honor even more outstanding medical professionals like Dr. Gavin Brown:



GAVIN BROWN 2018 NATIONAL MG WALK MEDICAL AMBASSADOR

“I have been involved with the MG Walk for 5 years and my patients, fellow physicians, nurses and staff at the Laureate Medical Group and Northside Hospital have all embraced what the MG Walk means to the MG community. Each year I am honored to walk alongside the many persons with MG and their family & friends. I strongly encourage the MG medical community from around the country to support the MG Walk.”

— Dr. Gavin Brown, Laureate Medical Group, Northside Hospital

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

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



4 Easy Ways to Fundraise for Your MG Walk

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



“My advice for MG Walk fundraising is to tell your story. MG is the scariest disease that no one has heard of. I found that by telling our story and explaining MG, people were compelled to help through donations.”

— Heather Hilton
First Time Walk Captain,
North Carolina MG Walk

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

— Kimberly Wilson
First Time Captain, Northern
Wisconsin MG Walk

“I would say the best thing to do while fundraising is sharing on all social media and talking to businesses to help support you on the walk!”

— Kelsey Toon
First Time Captain,
National Kansas City
MG Walk



STAY CONNECTED   

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

Meet the Face Behind MGFA's Instagram: SARAH NOORI



I wanted to change the public opinion on MG and show a different narrative to the "MG Story," the positive, feel-good type of story that inspires people to push forward and live their best life



My name is Sarah and I was diagnosed with MG at the early age of two. My MG is primarily ocular so I've lived with the physical inconvenience of drooping eyelids practically my whole life. After a thymectomy at the age of seven, I grew up appreciating life a lot differently

than other kids my age. My parents raised me on the mentality that I didn't have a disability from my disease which pushed me to be independent at a very young age.

My journey with MG remains a constant battle between mind vs. body. Many life experiences later, and learning things the hard way, I've managed to take care of myself, physically, mentally, emotionally and spiritually. I gained the strength, courage and confidence to challenge MG. I didn't want MG running my life so I had to get comfortable with challenging myself in order to thrive. It takes a lot of self-discipline and hard work but with the right amount of dedication and strict lifestyle choices, I've been able to carry on with an active lifestyle, medication free.

Despite the young diagnosis, I've managed to pursue my dreams of running my own business and traveling the world. For me, living with MG is, 'normal.' There is no coping with the disease, it's a part of me and I have learned to live my best life. I'm thankful for my struggle because without it, I wouldn't have discovered my strength. Most of us don't realize our own strength or the power we have to make ourselves happy, to inspire, or to create positive change.

MG is such a rare disease; I had never met anyone else living with it (before my diagnosis). Growing up, social media wasn't a part of the culture yet. You couldn't just search a hashtag on Instagram, there were no Facebook groups or YouTube videos where you could instantly connect with other

patients. Every time I searched, "Myasthenia Gravis" it always led me to a sad story. That's what motivated me to get involved and help the

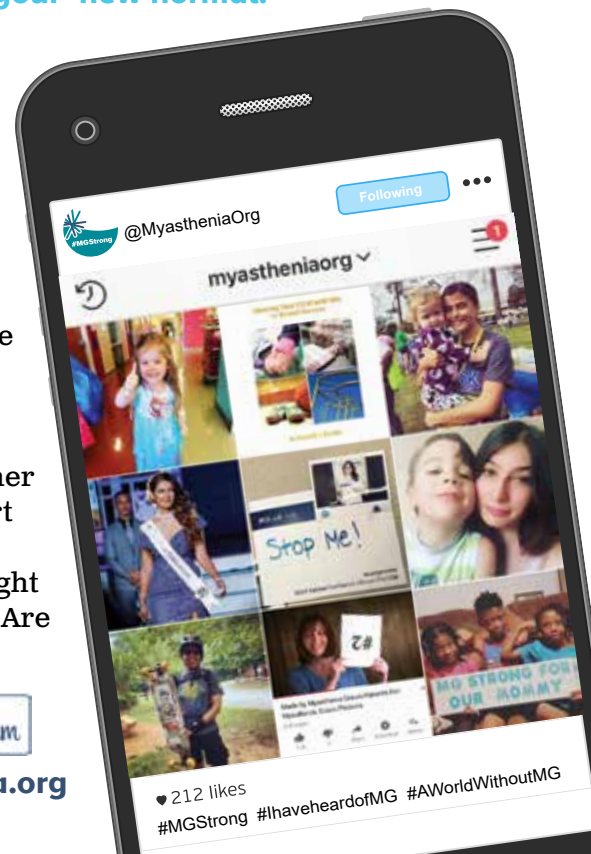
MGFA use Instagram as a platform to captivate an emotional connection with MG Patients. I've always wanted to be a liaison for bringing about positive change so my passion is really behind the patient stories shared on Instagram. I wanted to change the public opinion on MG and show a different narrative to the "MG Story"; the positive, feel-good type of story that inspires people to push forward and live their best life.

When you suffer from a disease like Myasthenia Gravis it's important to surround yourself with those who know MG and who can support your 'new normal.'

Sharing your story on Instagram is a great way to connect with like-minded people. Everyone's MG experience is unique and special. We're all on this MG journey together so let's support each other, educate and fight — because We Are MG! ✨



[@myasthenia.org](https://www.instagram.com/myasthenia.org)





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

By Sarah M. Jones, MD, Ikjae Lee, MD

3, 4-DIAMINOPYRIDINE ESSENTIAL FOR STRENGTH IN PATIENTS WITH LAMBERT-EATON MYASTHENIA

Lambert-Eaton Myasthenia (LEM) is a rare autoimmune disorder of the neuromuscular junction that results in muscle weakness. There are two types of treatments available: (1) symptomatic therapies that transiently improve strength without modifying the disease course, and (2) immunomodulatory drugs that impact the underlying autoimmune process. 3, 4-diaminopyridine (3, 4 DAP) is a symptomatic therapy to improve strength in LEM that has been used for decades.

Sanders and his colleagues¹ conducted a randomized, double-blinded, placebo-controlled study to provide additional evidence that 3,4 DAP helps to maintain muscle strength in LEM patients. Thirty-two patients with a confirmed

diagnosis of LEM taking 3, 4-DAP participated in the study. Participants were admitted to the hospital for two to three days and allocated into one of two groups: (1) taper and substitute the 3, 4 DAP for placebo or (2) to continue the same dose of 3, 4 DAP. Time

to stand from a chair, walk 10 feet, turn around, and sit down again (timed-up-and-go test; TUG test – a validated measure of leg strength) was used as the primary outcome. In this study the subjects were asked to do this three times in a row, and the average of these three “laps” was scored and called 3TUG (three timed-up-and-go). The primary endpoint was a deterioration of >30% of the 3TUG score during tapered drug withdrawal. Other endpoints included patient reports of the change in weakness, physician reports of the change in their weakness and change in the motor response on nerve conduction studies. During the study 72% of the subjects who tapered to placebo experienced a significant slowing of the 3TUG test versus 0% of the subjects who continued 3, 4 DAP. Over 90% of the subjects who tapered to placebo reported being weaker, while the majority in the continued group reported that their strength was essentially unchanged. Other outcome measures also indicated that the taper-to-placebo group was significantly more symptomatic than the continuous 3, 4 DAP group. 44% of the taper-to-placebo group had to be rescued due to severe weakness including significantly decreased oxygen saturation levels. None of the continuous 3, 4 DAP subjects had significant changes in their oxygen saturation levels. This study demonstrates that continuation of 3, 4 DAP is essential for those with LEM that have had symptomatic improvement from this treatment and that cessation of 3, 4 DAP in these patients could be life-threatening.

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RESOLUTION OF OPHTHALMOPARESIS AFTER STARTING IMMUNOSUPPRESSIVE TREATMENT FOR MG

Ophthalmoparesis refers to a weakening of eye muscles that control the eye movements, whereas ophthalmoplegia refers to paralysis. Weakness of the eye muscles is a common manifestation of myasthenia gravis and can include weakness of the eyelids (drooping upper eyelids; ptosis) or weakness of the extraocular muscles (EOMs), which may result in double vision (diplopia). Patients may find this to be a bothersome symptom and even disabling if it is severe. A recent prospective, observational, cohort study from South Africa by Europa and colleagues² followed eye muscle weakness in MG patients during their first year of treatment to examine how quickly these symptoms respond to immunotherapy. Patients with a confirmed diagnosis of MG and naïve to immunosuppressive therapy were included. Ophthalmoplegia score – a measure based on the examiner’s assessment of their eye movements – was used to follow the EOMs weakness. A four point grading system was used to follow ptosis severity. Patients were treated according to their local protocol by first starting anticholinesterase therapy. If their symptoms persisted after a few days they were then started on immunosuppressive therapies. Prednisone was typically the first to be started at a dose of 15-20 mg daily and increased as needed depending on the patient’s symptoms, weight, and tolerability. Non-steroid immunosuppressive therapies (e.g. azathioprine, methotrexate) were also used, and four patients were also enrolled in a thymectomy trial.

87 MG patients with persistent ophthalmoparesis and/or ptosis were included in the study. Among them, 76 had persistent ophthalmoparesis and these patients were given immunosuppressive treatments within days of diagnosis. Of these 76 patients, 37% had complete resolution of their symptoms in 3 months and 59% within 12 months of starting immunosuppressive treatment. The median time to resolution of ophthalmoparesis was seven months after the start of immunosuppressive treatments. Patients with fewer EOMs affected were more likely to have resolution within 12 months. Patients with an early diagnosis who were started on treatment within 12 months of symptom onset were twice as likely to have complete resolution of their

ophthalmoparesis. Of the 82 patients with ptosis at baseline, 70% had resolution within 12 months. Nearly three-quarters of these patients had their ptosis resolved within the first three months of immunosuppressive therapy.

In summary, this observational study demonstrates more than half of ophthalmoparesis and two third of ptosis can be successfully treated within 1 year of immunotherapy. The success rate was higher with early diagnosis and treatment.

These results should be interpreted with caution as the study has several limitations. Most importantly, the follow up and the treatment regimen varied among subjects. The results may not be directly applicable to the general MG population as there may be a genetic predisposition to treatment-resistant ophthalmoplegia in Africa. As the authors pointed out, this study was not designed to assess which dose of prednisone will be most effective and we need further controlled studies to answer this question.

TREATMENT REFRACTORY MG PATIENTS MORE LIKELY TO USE HOSPITAL RESOURCES

At least 10-15% of patients with myasthenia gravis (MG) are considered to have treatment refractory disease. Authors Engel-Nitz and colleagues³ attempted to assess (1) the rates of myasthenia crises and exacerbations as well as (2) the rates of hospitalizations and emergency room visits in patients with refractory MG versus those with nonrefractory MG by analyzing two national claims databases. Adults age ≥ 18 and two or more medical claims with an MG diagnosis code were included. Those with unknown gender or geographic region were excluded. MG patients were separated into 2 groups, refractory or nonrefractory. Subjects were considered to be refractory if they had a past and/or current use of ≥ 3 immunosuppressive therapies within a 24 month period, or ≥ 1 of the above therapies plus ≥ 1 more aggressive therapies (cyclophosphamide,

Nearly three-quarters of these patients had their ptosis resolved within the first three months of immunosuppressive therapy.



Compared to the control group, refractory patients were 4.4 times more likely to be hospitalized.

rituximab) or regular treatment with plasma exchange. Each subject was followed for one year.

A total of 403 refractory, 3,811 non-refractory, and 403 non-MG control patients were evaluated from the two administrative health plan databases. During the 1-year follow-up period,

patients with refractory MG were found to have 4 times higher odds of experiencing myasthenia crisis and 4.7 times higher odds of experiencing a myasthenic exacerbation when compared to non-refractory patients with MG. ER visits were twice more frequent and hospital admissions were 3.5 times more frequent in refractory patients when compared with non-refractory patients. Compared to the control group, refractory patients were 4.4 times more likely to be hospitalized.

This study had several limitations. The study was based off of diagnostic and procedural codes with an assumption that those were made correctly. Details of context surrounding the codes were unclear, for example, it was not clear from the claims data whether respiratory failure was due to a myasthenic crisis versus a non-MG condition. Despite these limitations, this study effectively demonstrated the disease burden in patients with treatment refractory myasthenia gravis as identified by higher rates of crises, exacerbations, ER visits and hospitalizations.

MG AND PREGNANCY

MG presents a risk factor for pregnancy and delivery, and can affect the newborn. In return, pregnancy can affect the course of myasthenia. This is a relevant issue as women with MG often develop the disease in their second and third decades. A recent review of the existing literature by Hamel and Cialfalonì⁴ highlights the implications that MG and its treatment may have on pregnancy. The following summarize the discussions in this article regarding fertility,

pregnancy planning, drug safety and postpartum management.

Prior to pregnancy, conversations between a woman with MG and her neurologist about fertility and pregnancy planning should begin early. Certain medications are contraindicated in women who try to get pregnant such as methotrexate and mycophenolate mofetil. Women treated with rituximab are advised to use contraception for 12 months after the last treatment. Thymectomy improves clinical outcome, reduces the use of immunosuppressive agents and is recommended for acetylcholine receptor antibody positive patients.



Treatment discussion between a patient and a neurologist should continue throughout the pregnancy to optimize treatment and avoid complications. Treatment of choice during pregnancy is pyridostigmine and corticosteroids. Starting of other immunosuppressive agents during the pregnancy is not recommended as the effect is often delayed by many months while there is a possible harm to the infant. For exacerbation of MG or crisis, intravenous immunoglobulin can be used safely. Plasmapheresis has a theoretical risk of shifting large hormones which may induce premature delivery, although there have been reports of successful use of plasmapheresis in pregnant patients with MG and other indications.

Delivery can be affected by MG. The most common complication is prolonged labor. Transient weakness in the newborn can be seen, which is called neonatal myasthenia gravis. This is caused



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by maternal antibody delivered to the fetus through the placenta. Monitoring of the newborn for at least 48 hours is important. Available information on drug safety during lactation is limited. The study suggests that a maternal dose of corticosteroids of less than 20mg/day in a breastfeeding mother results in low levels of the drug in breast milk and is not associated with side effects in the newborn. Breast feeding while taking azathioprine or cyclosporine is also considered low-risk. ✨

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3. Engel-Nitz NM, Boscoe A, Wolbeck R, Johnson J, Silvestri NJ. Burden of illness in patients with treatment refractory myasthenia gravis. *Muscle Nerve*. 2018 Feb 27.
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MGFA: What other advice would you give to fellow MG patients?

Julia Naumes: Good quality and quantity sleep. Exercising regularly. Eating well with lots of fruits and veggies. Scheduling rest days into my busy life. Taking my medications as prescribed. Taking various other vitamins, like B complex. Spending time with my friends and family.

Sometimes I throw a pity party and other days I just accept that that is part of this disease and I let myself rest and be cared for by my loved ones.

There are MANY different forms of exercise. You don't have to be running 5 miles or lifting weights for it to be considered exercise. Try different classes at your local gym to

“Respect your MG while getting out there and moving a bit more”

find out what type of exercise you like (sometimes the classes designed for elderly people are a good option because they are usually low impact and thus lower fall risk). The important thing is that you find something that you enjoy that gets you moving. It's also a lot more fun to exercise if you have someone to go with you, so see if a friend is interested in being your workout partner!

Respect your MG while getting out there and moving a bit more. It makes a world of difference in your overall health and wellness. ✨

SMILE FOR MGFA

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

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





PEOPLE MAKING A DIFFERENCE

Philanthropist Susie Johnson

Susie and Bill Johnson are not new to philanthropy. They have been prominent members of the Pittsburgh community for many years, supporting a variety of charitable causes. Bill led the Heinz Company for many years as their CEO and Susie served on the local boards for both the Make-A-Wish Foundation and the Ronald McDonald House Charities. As active community members and parents, life had been a whirlwind, allowing little down time. With Bill's retirement, and their two children all grown up, starting careers and families of their own, Bill and Susie were enjoying spending winters at their home in Florida and having time for both recreation and volunteer work. Together, they chaired a United Way campaign and Susie launched the Women's Leadership Council. They led campaigns for several disease-related charities, and leveraged Bill's deep ties to the NFL (his father was head coach for the Cincinnati Bengals) to start a charitable golf event. Bill also increased his corporate board responsibilities and became involved with private equity.



Susie and Bill Johnson

However, Susie began to feel unwell. Overwhelming fatigue and mysterious symptoms made it hard to participate in activities—and sometimes to get out of bed. Finally, there was a diagnosis: myasthenia gravis.

Like most people, the Johnsons knew nothing about the disease. A lifelong learner, Susie did her research and connected with MGFA through her physician, Araya Puwanant. Dr. Puwanant connected her with Dr. Robert Ruff and Dr. Suzanne Ruff, members of MGFA's Board of Directors and Medical / Scientific Advisory Board (MSAB). To learn more about MG, Susie and Dr. Puwanant traveled to Kansas City to take part in MGFA's 2018 National Conference. After meeting with prominent scientists and engaging with other people with MG, Susie decided to support the work of MGFA.

In August 2018, Susie generously committed to supporting research and programming to benefit those in the MG community. Bill and Susie's foundation made a multi-year commitment of 100K per year for three years to support MGFA initiatives. This pledge came at the perfect time; just as the MGFA Board had been asked to commit \$250,000 to support a groundbreaking grant application to the National Institutes of Health (NIH) to create a new MG Clinical Research Network. If approved this application would provide \$1 million a year for 5 years for MG Research!

The overwhelming generosity of Susie and Bill Johnson meant that MGFA could make this new research commitment with confidence, ensuring funding for multi-faceted programming while driving innovative and promising science towards a cure.

Like many of us with MG, especially those recently diagnosed, Susie continues to work with her medical team to find the right treatment regimen that will allow her to continue a full, active lifestyle. She and Bill work together to manage the changes in their life, and hope to inspire and support others with MG. Susie has made supporting MGFA a priority and we could not be more thankful for her commitment. Please join us in thanking them for their unprecedented generosity and dedication, which has brought us closer to a world without MG. ✨

2019 MG CONFERENCE CLUES!

Where's the next MG National Conference, hosted by the MGFA? Let's look at a few clues:

- Where was the "Standing Peachtree," a Native American trading post in 1762?
- Where was the Western & Atlantic Railroad started in 1836?
- Where's the home of Coca-Cola?
- Where does Delta Airlines call home?

If you replied Atlanta to all those questions, you've got it!

Now, when will the conference be held? This time you've got it easy, no quiz involved:

March 31st through April 1st 2019

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Put this on your calendar and plan to attend the conference and add a little R&R if you wish. Visit Lego Land; the Atlanta History Center or just stroll through the fabulous Lenox Square Mall. Or, you can take in an Atlanta Braves baseball game in SunTrust Park! Keep your eye out for future details. See y'all soon!





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

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

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



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

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