

FOCUS on mg

a publication of the MYASTHENIA GRAVIS FOUNDATION OF AMERICA

Fall 2022

MGFA Global MG Patient Registry: Join Now to Drive MG Research Results



The MGFA Global MG Patient Registry is a confidential

means for MG patients around the world to provide real patient data that will be critical to medical/research communities in the assessment of disease course, use of various therapies, and estimation of disease costs. The registry data helps MG researchers gauge the potential for trial recruitment and communicate with patients directly about potential research investigations, while respecting their privacy.

Researchers and clinicians need ACTUAL, REAL patient data in order to build their studies and trials. Your data is anonymous and secure in the registry and it provides researchers with accurate information that could help answer many open questions about MG biology and treatment efficacy. This fully-functional patient registry was created with our development partner, Alira Health, to ensure patients have easier, more efficient options for adding their data to our registry surveys.

Remember, your patient data will be in a secure, HIPPA-compliant repository with no direct access by any outside organizations.

We hope you join our MGFA Global MG Patient Registry in the near future so researchers have the most accurate, up-to-date information to find a cure. Please send any questions or inquiries to the MGFA at the following email address: mgfa@myasthenia.org.

Check back in mid-November when the MGFA Registry goes live at mgregistry.org.

Highlights in This Fall's Issue:

6 NEW MGFA Online Community

8 MGFA Community Health Fairs

12 Annual Scientific Session

13 Golf Events

14 Community Spotlights

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.

Table of Contents

- 2 Research Funding Update
- 3 Letter from the CEO
- 4 Meet New MGFA Board Members
- 6 MGFA Online Community
- 8 MGFA Community Health Fairs
- 10 MyMG Mobile App
- 12 Annual Scientific Session
- 12 National Patient Conference
- 13 Upcoming Golf Fundraising Events
- 14 Spotlight on the MG Community
- 20 Donate and Fundraising
- 20 MGFA Support Groups
- 23 MG Friends
- 23 MGFA Webinars
- 24 Contact information

FEATURED STORY

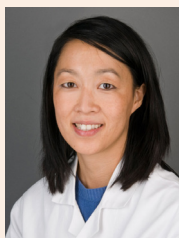
MGFA Funding the Most Promising MG Research for a Cure

Latest MG Research Announcements and News

Clinician and scientist investigators are engaged in groundbreaking myasthenia research all over the world. The MGFA funds promising research studies and clinical trials to discover potential new treatments and methods of living a better quality of life with MG. Here are some of the latest research results and resources.

INAUGURAL NANCY LAW IMPACT RESEARCH AWARD RECIPIENT

The Nancy Law Impact Award is an MG research funding opportunity named after former MGFA Board Chair and CEO, Nancy Law, who was a caring, close friend to so many people across the myasthenia community. The proposals for this grant award are focused on innovative patient outcome measurements, optimization of clinical research approaches/practices, and the application of translational biomarkers that will aid in further refining the current treatment paradigm.



Congratulations to the MGFA's first Nancy Law Impact

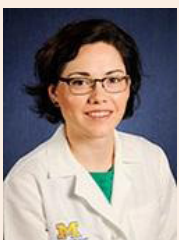
Research Award recipient Dr. Aimee Payne from the University of Pennsylvania. Her research project entitled "Preclinical models and biomarkers for predicting MuSK-CAART clinical outcomes" will be funded over 3-years (\$300,000).

Research Summary: MuSK MG is caused by MuSK autoantibodies that lead to life-threatening muscle weakness, so the ideal therapy

would be to eliminate autoantibody-producing B-cells while preserving healthy B-cells. CART cells in the body are currently being re-programmed to eradicate B-cell cancers, prompting researchers to explore whether this precision medicine can be used for other diseases like myasthenia gravis. The project researchers are testing a novel autoantibody receptor T-cell therapy designed to re-program MG patient T-cells to selectively kill anti-MuSK B-cells that cause MuSK MG. The research is designed to test the working hypothesis in hopes of leading to a safe and lasting disease response and develop protocols for the detection and characterization of MuSK-CAART to validate novel biomarkers.

Dr. Payne presented her ongoing work in this area during the MGFA Scientific Session at the 2022 AANEM conference in Nashville, TN on September 21st.

HIGH-IMPACT PILOT PROJECT AWARD RECIPIENT



The MGFA High-Impact Pilot Project Awards are pilot studies typically leading to new federal, pharmaceutical, or private foundation supported investigations. These grants are awarded annually.

Congratulations to Dr. Lindsey De Lott from the University of Michigan! Her research project entitled "Advancing patient-centered care and research for ocular myasthenia gravis: Validation of a novel patient reported outcome measure" will be funded over 1-year (\$50,000).

Research Summary: The ocular symptoms of Myasthenia Gravis (MG) are disabling and affect quality of life - the impact of double vision and droopy eyelids can be profound. We need to fully understand the extent of how ocular symptoms impact daily function. Patient-reported outcome measures (PROMS) are valuable tools for measuring the aspects of MG, such as double vision, that matter most to patients while enhancing patient-physician communication and support. However, there are no PROMs focused on the impact of the ocular symptoms of MG or OMG nor sufficient scales to measure OMG. Dr. De Lott aims to conduct a multicenter validation of the patient questionnaire as a standalone PROM for OMG so it can be deployed within future clinical research and support patient-centered care.

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.

FROM THE DESK OF THE CEO

Dear Friends,

As this year draws to a close and the seasons change, we feel grateful for our MG Community and the ways in which we have been able to connect this year. Just as we all learned how to adapt to significant challenges these past few years, we find ourselves once again in a transition as we return to in-person programs and events. We are eager to come together and to celebrate, and we also understand any hesitation in returning to in-person, and the health and safety of our community members will remain paramount in everything that we do as an organization.

In our Spring edition of Focus on MG, I shared that we had hosted our first in person program in two years, the MGFA International Conference, which brought together 450+ friends from around the world. This Fall, we hosted our second in-person program, our Scientific Session, as part of the AANEM Annual Conference in Nashville. The science that was delivered was outstanding and our speakers were top-notch and engaging, and certainly evoked tremendous discussion from their presentations. Our Scientific Session also doubled in attendance from the last time it was hosted in-person and we are excited to continue to grow this very important program, and to convene the scientific community.

This year has also been a time of inaugural events...we launched the new MGFA Community Health Fairs around the country! These Community Health Fairs have been hosted in-person in San Francisco, CA, Austin, TX, and Alexandria, VA with two more events in Atlanta, GA, and Tampa Bay, FL for November. We plan to expand these new community events in 2023 and continue to provide this forum to come together and offer education on health and wellness. We also hosted a new golf classic in Orange County, CA. This event was in addition to existing golf classics hosted by our amazing volunteers in both New Jersey (thank you Gershwin family!) and Florida (thank you Jeff Abramson!). We simply could not grow, and continue our critical mission work, without the support and partnership of so many...and our volunteers are the best! We feel so fortunate to be able to work with so many amazing people who want to make a difference....and it is so wonderful to finally be able to meet some of you in

person!

Perhaps one of the most outstanding achievements to share from 2022 is progress with our grant program and the research that MGFA has funded. This year, we increased our funding yet again and will fund nearly \$1M in innovative research. This funding included the inaugural Nancy Law Impact Award, which was MGFA's largest grant award in the organization's history at \$300,000. We also were able to increase funding due to the very generous investment made by some of our donor families. Given this commitment to increasing our support of research, we now offer two funding cycles instead of one which allows us to review and consider more proposals and support an increased number of projects. Finally, we announced Dr. Kevin O'Connor as our Chief Research Advisor and Dr. Richard Nowak as our Chief Medical Advisor, both of Yale University School of Medicine, to assist MGFA in advancing our research agenda and priorities.

Whether it be board members, community volunteers, donors, or our strategic partners and sponsors, we are surely in very good company. We are so grateful and we look to the future with encouragement and promise.

Sincerely,



A handwritten signature in black ink that reads "Samantha Masterson". The signature is fluid and cursive, matching the name of the person in the portrait above.

Samantha Masterson | President and CEO



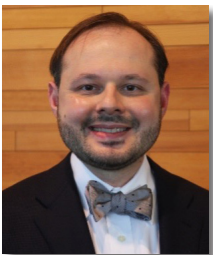
MGFA Welcomes New Board Members to the National MGFA Board of Directors

We welcome Dr. Sangeeta Sawhney, Dr. Richard Nowak, Robert Thomas, and Adreja Lajoy Ann Boutté to our Board of Directors. We are excited about their support and dedication to the MGFA and the entire MG Community.



Adreja Lajoy Ann Boutté, JD

Adreja is a Louisiana litigator with more than 20 years of experience on both sides of the courtroom as in-house counsel and as a commercial litigator defending cases on behalf of a Fortune 500 company and various insurance companies across the nation. With a strong background in leadership in legal organizations (statewide and nationally), in compliance matters (with a focus on cyber risk), and as a life-long advocate of diversity objectives; Adreja regularly offers trainings and presentations to individuals and companies. Adreja is also a MG patient.



Richard J. Nowak, MD, MS

Dr. Richard Nowak currently serves as Chief Medical Advisor to the MGFA. He is a neuromuscular fellowship trained neurologist and a faculty member in the Department of Neurology at Yale University School of Medicine. He is the founding Director of both the Program for Clinical & Translational Neuromuscular Research (CTNR) and the Yale Myasthenia Gravis (MG) Clinic. In this leadership capacity, he has successfully established and built a translational neuromuscular immunology program. He has been integral in establishing the recently NIH-funded Rare Disease Network for Myasthenia Gravis (MGNet) with his collaborators at Duke University and George Washington University. Dr. Nowak is not only a skilled academic neurologist but also a seasoned, senior investigator as demonstrated by continuous NIH grant funding.



Sangeeta Sawhney, MD

Sangeeta Sawhney has more than twenty years of experience in clinical drug development including IND, NDA, and MAA submissions. She is experienced in strategic planning, design and execution of clinical projects across multiple therapeutic areas. She has deep knowledge of regulatory requirements in key therapeutic areas and direct clinical experience in general medicine. She currently serves as vice president of Intercept Pharmaceuticals and has worked in multiple, additional roles providing leadership and oversight for a variety of projects.



Robert Thomas

Robert Thomas is currently the Founder, President & CEO of NUEnergy Payroll HR. Previously, Robert served in executive leadership roles at Fidelity, ADP, Hewitt, and Bank of America. He has an extensive background in chief executive management for large corporations, as recent Chief Benefits Officer for Strategic Benefits Administration, Strategy, Operations & HRIS at the City of Houston, and past roles as Executive in Residence at the Houston Technology Center, Mentor/Advisor to SURGE Accelerator companies, past Advisory Board Member to the Dean at University of Houston's College of Technology, and Advisory Council Member to the Dean of University of Texas' school of Health Sciences. He earned an MBA from University of Phoenix and completed Executive Development Programs at Harvard Business School and the Haas School of Business, University of California Berkeley.

To learn more about our new board members, please visit www.myasthenia.org/About-Us/Our-Leadership

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 AlexionMGEvents.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[®]

ALEXION and the Alexion logo are registered trademarks of Alexion Pharmaceuticals, Inc.
Copyright © 2021, Alexion Pharmaceuticals, Inc. All rights reserved. US/UNB-g/0192 03/21

Introducing the MGFA Online Community

Imagine stepping into a completely one-of-a-kind virtual neighborhood where the MG Community can join together, connect, share ideas and discoveries, and access MG-specific educational materials such as live broadcasts, webinars, and information libraries – all in one place!

This graphically-oriented online space will display all the charm of a small town with the combined power of the MG Community through chatting, networking, and learning. It is a dynamic virtual neighborhood that is constantly changing. New materials and resources are regularly posted – so there is always something new to experience.

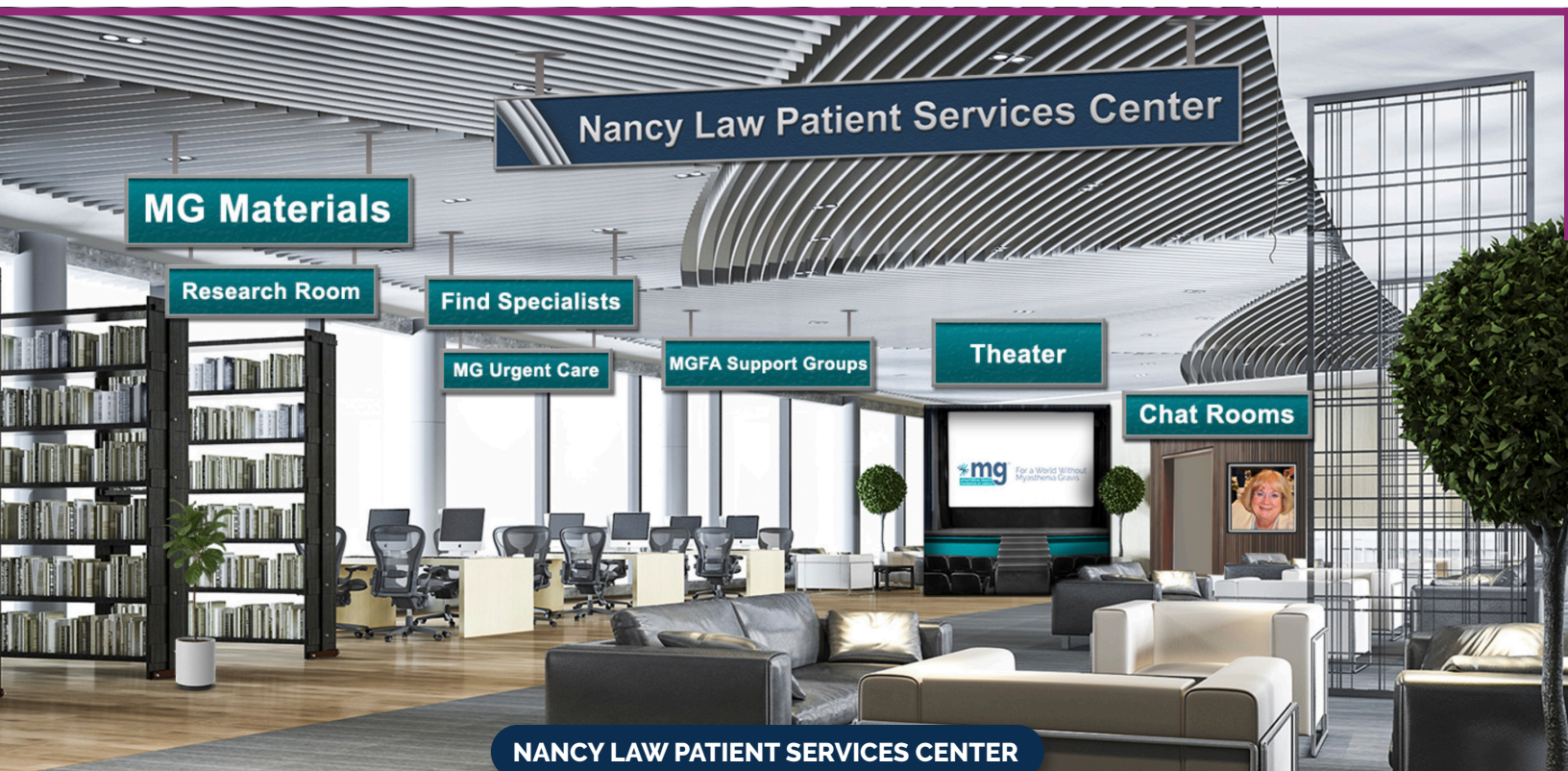
Become a member and enter unique online buildings such as a Wellness Center to access nutritional information and physical fitness tips or a Town Hall to learn how to get involved with the MG Community. Learn about the history of the MGFA in the onsite Museum or access a whole host of educational resources in the Nancy Law Patient Services Center.

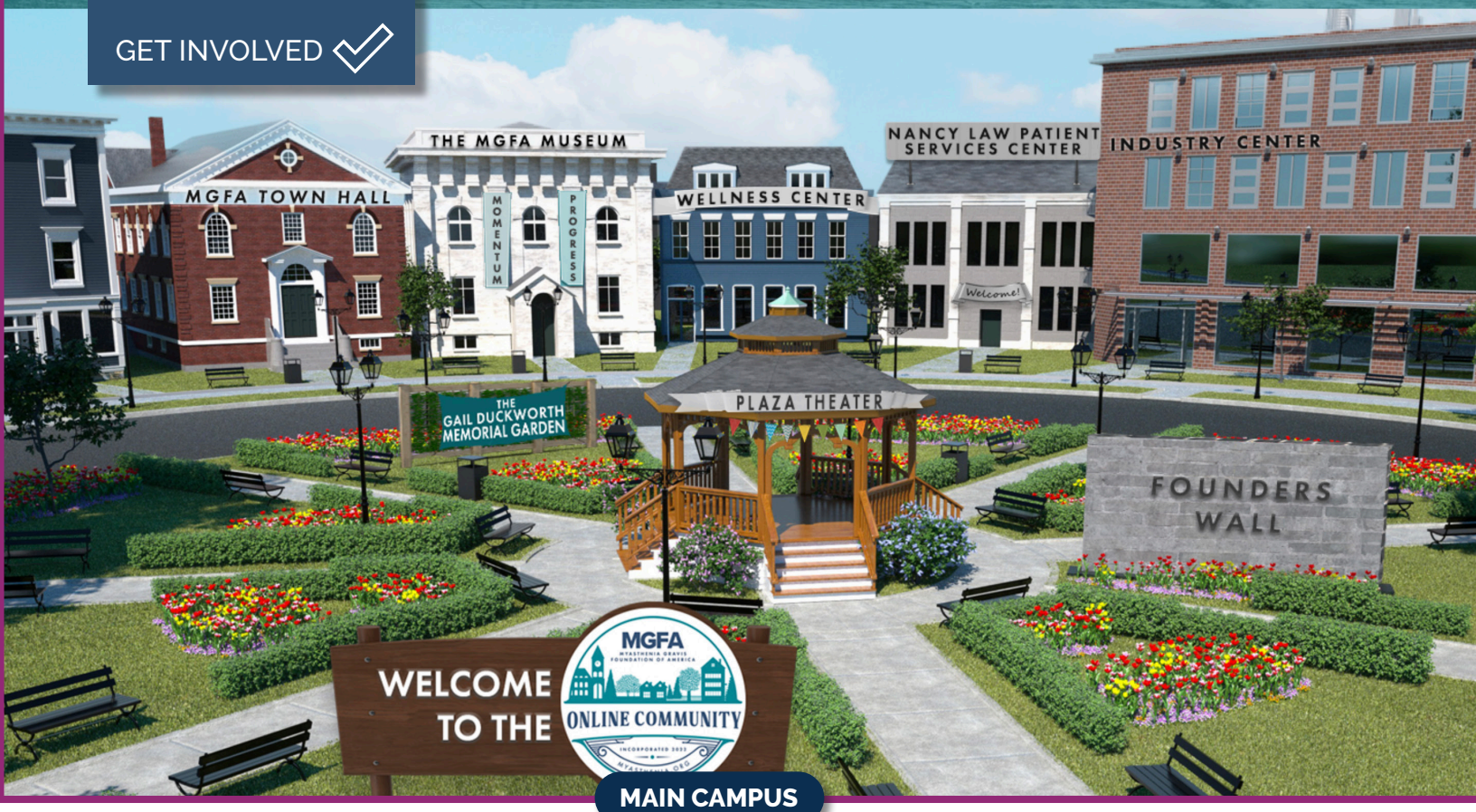
Become part of the Founders Wall, view live events in the Plaza Theater, or honor a loved one in the Gail Duckworth Memorial Garden. MGFA corporate partners can “own” real estate within the Industry Center to display and offer educational materials and informational links to all members of this online community.

Each building in the MGFA Online Community contains rooms with resources, chat areas, videos, and educational materials. Click around and discover what’s in the indoor and outdoor spaces.

All you have to do to join the Online Community is register. Use the link below to provide your contact information and to read and accept our code of conduct. Then we’ll send you the link to visit our Town Hall, which is your first stop when exploring the Online Community.

www.myasthenia.org/MG-Community/MGFA-Online-Community

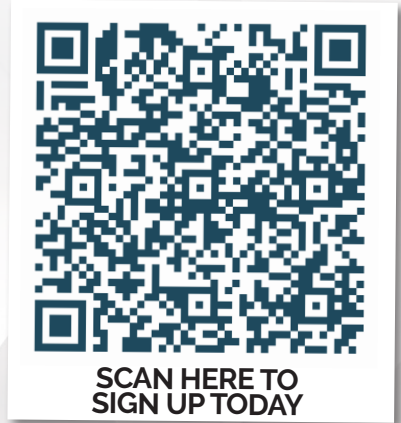




Areas to Explore

- MGFA Town Hall
- The MGFA Museum
- Wellness Center
- Nancy Law Patient Services Center
- Industry Center
- Founders Wall
- Plaza Theater
- The Gail Duckworth Memorial Garden

We hope you enjoy your Online Community experience!
Register at <https://bit.ly/3s4SFmo> or scan the QR code.



Bringing the MG Community Together for In-Person Education

The MGFA introduced its first-ever local, in-person Community Health Fairs in 2022! These events are a great way to **CONNECT** to members of the MG Community, to **SHARE** stories and guidance, and to **LEARN** more about managing MG.

Earlier this fall, MGFA conducted our first Community Health Fairs in San Francisco, Austin, and Alexandria, and they were all a huge success. Attendees actively engaged with patients, caregivers, medical professionals, MGFA industry partners, and specialists across the MG Community and beyond.

We have two more Community Health Fairs coming:

The Greater Atlanta Area

Location: Georgia Tech Institute Exhibition Hall
 Address: 460 4th St NW, Atlanta, GA 30313
 Date: November 6, 2022
 Time: 10:00 AM - 1:00 PM

The Greater Tampa Bay Area

Location: St. Petersburg Marriott Clearwater
 Address: 12600 Roosevelt Blvd. North, St. Petersburg, FL 33716
 Date: Nov. 12, 2022
 Time: 2:00 PM - 5:00 PM

MGFA COMMUNITY HEALTH FAIRS

CONNECT • LEARN • SUPPORT

At the fairs, you can...



Interact with MG patients and medical experts to get questions answered.



Learn more about MG research and treatment developments from MG experts and corporate industry leaders.



Connect with local businesses and companies that cater to MG patients and specialize in their needs.



Simply get together, in person, to share stories and gain support.



WE STILL NEED YOUR HELP to keep the momentum going and make sure our next Community Health Fairs rock!

We are currently seeking new volunteers and attendees to provide a really rich experience. In addition, we need vendors or consumer goods providers who can cater to the MG community, volunteers and local sponsors who will be attending this exciting event. Vendors benefit from offering their products or services to an in-person audience of committed MG Community members.

If you or someone you know would like to be a part of an upcoming MGFA Community Health Fair, please register at the following website:

www.myasthenia.org/Events/Community-Health-Fairs

Or contact [Tasha Duncan](mailto:tduncan@myasthenia.org) at the MGFA at tduncan@myasthenia.org or 423-827-5445.

We look forward to seeing you at these various locations, with more to come in the future. Register today!



New Features in the MyMG Mobile App Make it Easy to Track Your MG



Continual improvements add value to the MyMG Mobile App - new text verification process, facial recognition, and symptom tracking.

MGFA recently introduced its completely brand new MyMG

Mobile App for your Apple iPhone or Android phone. This state-of-the-art mobile app provides a host of new features that will enable patients to help manage and track their myasthenia symptoms and treatments while helping anyone across our community access critical MGFA resources including webinars, brochures, research information, events and blogs, and MG assistance and guidance.

Manage and learn about your myasthenia gravis in a new and personal way – from the palm of your hand. The MyMG Mobile App reflects the features that you...the MG Community...asked for in a fully-functional mobile solution. We reached out to patients and community members in surveys and discussions over the past year to find out what you would like to see in our mobile app. MGFA listened and we took our time to build a mobile app that does what you asked for.

MGFA launched our new MyMG Mobile App a couple of months ago, and we've already added new features and functions to make it easier for the MG Community to use it to help manage your myasthenia.



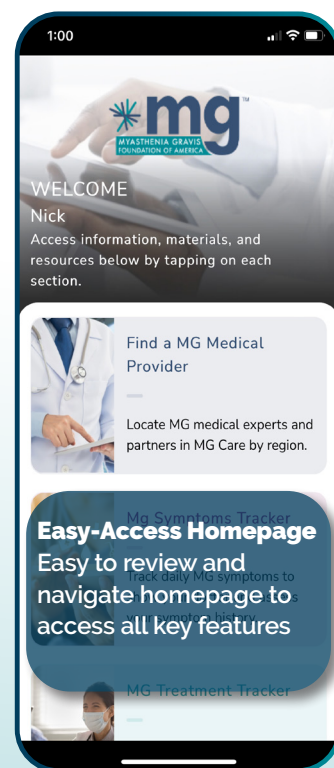
Update your MyMG Mobile App on your smartphone and you will experience these new features:

- Facial ID and touch ID recognition for automatic login for Apple and Android users.
- International registration and support begins in November.
- Easier and more automated verification process including lengthened time to verify. 6-digit verification in the app.
- SMS text (and email) verification for immediate registration verification and log in to the system.
- Notification reminders on your phone to log symptoms and treatment data as well as new content availability.
- Notifications when new content, such as blogs, events, webinars, or educational materials are available.

Patients have already been able to quickly and effectively track their daily symptoms and treatments on the MyMG Mobile App. You can also enjoy access to patient education materials and helpful resources, blog articles and patient experience stories, clinical trial and research updates, wellness and research webinars, all MGFA events, brochures, and introducing Apple Health Apple Watch application synchronization – so you can keep track of your health app information on the MyMG Mobile App.

Just go to the Apple App store or Android store to download the MGFA MyMG Mobile App on your phone or go to <https://myasthenia.org/Newly-Diagnosed/MyMG-Mobile-App> on MGFA website to upload the app.

If you have not completely registered your app yet or need to verify, update the app in the Apple App Store or Google Play and register to realize all the benefits of MG management in the palm of your hand. And stay tuned for other new features throughout the fall season.





www.janssen.com

SPONSORED CONTENT



www.horizontherapeutics.com

SPONSORED CONTENT



Latest MG Research Presented at Annual Scientific Session - In-Person



The Annual MGFA Scientific Session took place in-person on Wednesday, September 21, 2022 at the AANEM meeting in Nashville, TN at the Gaylord Opryland Resort & Conference Center. The Scientific Session is one of the premier scientific forums in the U.S. related to the pathogenesis, immunology, diagnosis, and treatment of MG and related disorders of the NMJ.

The session brought together some of the world's foremost MG experts, researchers, and clinicians as well as industry executives, medical professionals, and patient advocacy organizations to experience the latest data and informational results concerning clinical trials and studies. The

MGFA also hosted a luncheon for its Partners in MG Care; a peer network of MG healthcare providers throughout the U.S. To learn more about the MGFA Partners in MG Care program, please contact the MGFA at mgfa@myasthenia.org.



The session was kicked off by MGFA President & CEO Samantha Masterson and Program Chair Dr. Shruti Raja, then attendees were treated to Dr. Carolina Barnett-Tapia's keynote titled "Development and Validation of MG-specific Outcome Measures." Throughout the morning,



some of the top, worldwide MG research experts and clinicians presented on very important MG research topics including new groundbreaking discoveries, new and upcoming treatments, risks and considerations, and seronegative and MuSK MG.

The in-person event was a great opportunity for researchers and medical professionals to meet and shake hands and collaborate – face-to-face. Also, a number of industry partners and leading treatment manufacturers attended to answer questions and showcase the incredible work being done to improve MG patients' quality of life.

Thank You to our MGFA Scientific Session Steering Committee:

Shruti Raja, MD – Chair – Duke Health

Ali Habib, MD – University of California, Irvine

Diana Castro, MD – Founder of Neurology and Neuromuscular Care Center, Founder of Neurology Rare Disease Center

And, another thank you to MGFA staff member **Dova Levin**, and the full team at the MGFA.

To learn more about the full Scientific Session program and to view a video of the session, please visit: www.myasthenia.org/Events/mgfa-scientific-session-at-aanem

National Patient Conference

Annual National Patient Conference

Sunday, March 26th – Tuesday, March 28th 2023

The Annual MGFA National Patient Conference is the largest and most complete gathering of the MG Community. Every year, attendees include amazing MG patients, generous caregivers, and MG experts including researchers, clinicians, and specialists. The conference features MG research information and updates, heartfelt and informative patient stories, updates on MG treatments and discoveries, and many exciting educational topics to help you and your family better manage your MG journey.

In 2023, the Conference will be held IN PERSON, starting on Sunday, March 26th for a special MGFA volunteers training, and then, will resume on Monday, March 27th through Tuesday, March 28th 2023. We will all meet in the historic, uniquely American city of New Orleans, Louisiana at the lovely Astor Crowne Plaza Hotel at 739 Canal Street near Bourbon Street.

Registration will be open and accepting attendees by November 1, 2022, and the program of sessions will be published soon, For more information please visit: www.myasthenia.org/Events/mgfa-national-patient-conference-2023.

If you have questions, please contact Dova Levin at dlevin@myasthenia.org or call us at 1-800-541-5454.



Regional Golf Events

Annual Fundraising Golf Tournaments Support the MGFA's Mission

There are so many incredibly generous volunteers in the MG Community who are willing to step up and plan community or regional events to raise funds to support MG research and the MGFA's mission. Many volunteers are now starting up golf tournaments because they are extremely fun and a great way to bring people together. We have already seen several tournaments this fall, and some of these fundraisers have been supporting the MGFA for years. Here is just a small list of fall 2022 events.

30th Annual Helen & Leonard A. Golden Memorial Golf Classic to benefit MGFA

Monday, August 15, 2022 (Past Event)
Crestmont Country Club
750 Eagle Rock Avenue West Orange, NJ 07052

The Helen & Leonard A. Golden Memorial Golf Classic, which continues to honor the legacy of my grandparents and their incredible efforts on behalf of myasthenia gravis (MG), serves as a hugely important fundraiser for the Myasthenia Gravis Foundation of America. Our tournament, now in its 30th year, has been recognized as the largest grossing golf event in the country that raises money for MG.

Jason Gershwin, Chairman
The Helen & Leonard A. Golden Memorial Golf Classic
To purchase a sponsorship or entry offline, please email jason.gershwin@gmail.com.
To Learn More: <https://bit.ly/3eErMT6>

South County Classic Golf Tournament

Wednesday September 21st (Past Event)
Tijeras Creek Golf Course
29082 Tijeras Creek Rd. Rancho Santa Margarita, CA.

The South County Classic - Presented by the William Ross Family Foundation is a partnership event benefiting the Myasthenia Gravis Foundation of America as well as the Roosters Foundation of Orange County. We have combined a National specialty disease organization with the premier specialty non-profit for supporting children's charities in Orange County. This Scramble format event will include on course competitions, BIG BOARD RAFFLE opportunities, drinks and treats on course as well as a dinner. All the fun begins with registration at 11:30 AM and a 1:00 PM shotgun start to the South County Classic.

William and Elaine Ross - Ross Family Foundation
Craig Strenger - National VP of Development MGFA
Kirk Adams - President, Roosters Foundation
To Learn More: <https://bit.ly/3TbtVVd>
Facebook Photo Album: <https://bit.ly/3MFMn67>

Annual Fall Golf Tournament Hosted by the Bell Company

Saturday, September 24th (Past Event)
Mattaponi Springs Golf Club
22490 Penola Road, Ruther Glen, Virginia 22546

This annual golf tournament is sponsored by the Bell Company and supports MG Research. Prizes include a new golf putter, YETI coolers, packs, and a new car.

Celebrating Five Years of The Patti Abramson Golf Outing

Wednesday Friday, October 21st (Past Event)
Heritage Oaks Golf & Country Club
4800 Chase Oaks Dr, Sarasota, FL 34241

In 2018, Jeff Abramson started The Patti Abramson Golf Outing in memory of his wife who had myasthenia. Together, with friends in his community, he established this event to raise both awareness and funds for the Myasthenia Gravis Foundation of America.

Over the past five years, this tournament has raised more than \$130,000. Participants have the opportunity to play golf and attend a lovely dinner afterwards with both a silent auction and raffle to support the MG community. This year, the raffle had over 45 items and the silent auction included special sports memorabilia.

The Patti Abramson Golf Outing is one of the highest grossing third-party events led by a volunteer. We are so grateful to Jeff and his amazing volunteers who put this event together in celebration of Patti's life.

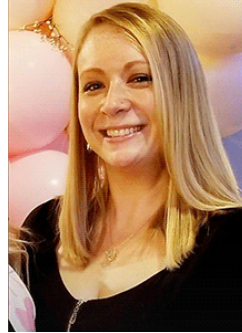
To Learn More: <https://bit.ly/3eBwO2G>



Managing MG: A Nurse's Perspective

By *Kate Stober*

Managing a chronic illness is difficult – even when you're a medical professional. For nurse Melissa Edmonds, having myasthenia gravis has impacted every aspect of her life.



"I've had to slow down... MG will do that to you, whether you want to or not," Melissa shares.

A nurse in a critical care setting when she experienced her first symptoms, she soon found she couldn't care for ICU and step-down unit patients on 12-hour shifts. She had to reduce her hours and accept more flexible nursing opportunities as her symptoms set in.

At 32, she'll sometimes use a rolling walker at night, when her muscles are most fatigued. Long nights out with friends are taxing. Chasing her two little girls around isn't always feasible.

Despite the upheavals Melissa and her family have gone through, she remains upbeat. She's developed a mindset that serves those with chronic illness so well:

Take it day by day.

"Just recently I had to take a few days off because I was tired. In my head, I was beating myself up. I had to tell myself, 'Stop. Don't worry about it. Don't worry about being productive all the time. Don't beat yourself up about it. Just be up front about what you need.' It's the new normal."

Getting to her MG diagnosis was also a challenge that required patience, flexibility and determination. Despite working in a hospital, she faced roadblocks to diagnosis and treatment that are familiar to many MG patients.

Her initial symptoms of muscle weakness were misunderstood as somehow her fault – she wasn't taking care of herself, she needed to get more sleep, she was having an anxiety attack. Melissa already suffered with chronic pain, so the doctors

compounded that issue with her MG symptoms.

A bevy of tests proved nothing definitive. The neurologists she saw initially said it was nothing.

"That was my first dose of reality as a patient. I felt like I was being judged because they were giving me pain meds and anxiety meds." Her doctors weren't putting everything together.

Many times she arrived at the ER, people didn't believe her symptoms, telling her she was having panic attacks.

In the end, it was three years before a new provider, reviewing her chart and symptoms with a fresh set of eyes, diagnosed her with MG.

Because of her professional and personal experience with medical crisis, Melissa has become an advocate for patient education. When she was in MG crisis not long ago, she pulled out MGFA pamphlets to share with the EMTs and the nurses at the hospital. She wears a medical alert bracelet so medical professionals will know what to do.

"MG symptoms are so different for each person – it's a 'snowflake disease,'" Melissa says. An EMT might assume stroke if they see facial drooping and the patient is unable to speak well enough to explain. Providing the care team with a clear picture of your disease can be lifesaving.



MG has also changed the way Melissa practices medicine. She is a more thoughtful listener, more willing to think outside the box. She has more patience with chronic pain

patients because she has been in their shoes.

"It makes me a better advocate for prescribing meds to them and taking care of them with more compassion," she says.

To other MG patients, Melissa offers this advice:

"Be kind to yourself. No matter what your symptoms are, it's exhausting. Whether it's a fatigued muscle or a fatigued mind, whether you're 32 or 62, just remember to slow down. We all should slow down sometimes."



Biking For Mg Awareness: Lucero's Brian Venable Takes On The Tour Divide

By Kate Stober

Brian Venable is used to being on the go. As the guitarist for the alt-country band Lucero, he tours constantly. He fields phone calls from a dozen music journalists every time the band drops a new album. On the side, he paints and designs t-shirts to sell on the band's website.

So it shouldn't be a surprise that his idea of a vacation is biking over 2,600 miles from Canada to New Mexico.

Described as "a painstaking test of endurance," the Tour Divide starts in Banff, Canada, and traces a path along gravel roads and trails, through grasslands, the Rockies, and the high desert. The ride ends in Antelope Wells, New Mexico, near the Mexican border. There are no prizes for finishing except sore legs, blisters, and the satisfaction of having spent weeks on the open road and survived to tell your tale.

Brian readily admits he has no idea how this whole thing will turn out.

"That's the humor in it. I grew up riding bikes, being a punk rock kid. But I have no training."

His lifelong friend, Chuck, is a bike enthusiast and convinced they'll do 100 miles a day — with stops along the way to see certain rock formations (Chuck's a geologist). But if they don't make their goal, that's okay. The ride is not a race in the traditional sense. While some riders will go hard, forgoing sleep and showers to complete the course as fast as the can (the record is 13 days, 22 hours and 51 minutes), everyone takes it at their own pace. Brian looks forward to enjoying the scenery, the fresh air. The simple act of peddling, away from the daily grind of band life and household activities.

"I'm camping and hanging out with my buddy, that's how I look at it," Brian shares. "This is the first time in so many years that I've gone somewhere that didn't involve the band or my family."

Brian has another mission on the Tour Divide: raising money and awareness for the Myasthenia Gravis Foundation of America.

His good friend, Meredith, was diagnosed with MG in November 2021. He watched as she, a young woman who "had it all together," experienced a confusing array of scary symptoms without an understanding of what was causing her health problems. He admires her strength, and that of her husband Derek, as they've navigated her illness.

Raising funds to support MGFA's mission is important to Brian, but so is using his platform as a well-known musician to shine a light on MG.

"A lot of our fans are like family. When I bring up something, my people step up. It's crazy how many people MG affects but how so few people know about it."

For Meredith, having a friend's love and support through a hard journey has been invaluable.

"When you're first diagnosed, your friends and family respond in myriad ways. It's easy to find yourself wondering whether they're embarrassed or uncomfortable with some of the changes you're undergoing. But the level of support Brian has shown has been amazing."



When she first heard that Brian wanted to raise funds and awareness for MG through his ride, she cried.

"I believe my exact words were, 'Crud! There goes my mascara!' But in all seriousness, I am both humbled and proud of his choice to use the Tour Divide to support MG awareness, and I can

confidently say that such a selfless and loving act is entirely keeping with Brian's character. I couldn't be more thrilled for him to undertake this adventure.

"Over the years, he's taught me so much about the freedom in living authentically, and with my diagnosis in particular, he's inspired me to not let preconceived limitations slow me down. He's given me the courage to keep going in my MG journey, and in return I've given him a large can of Bear Spray to keep him going in his!"

The Tour Divide begins June 10. More information about the race can be found [here](#). Brian aims to raise \$10,000 during the month of June - you can make a gift [here](#).



My MG Story:

Felicia Jeffries

By *Kate Stober*

I am a 42-year-old business woman who was diagnosed with Myasthenia Gravis almost 10 years ago. It landed me on life support on Christmas Day, 2018, made me a stigma amongst former friends, and contributed to the end of my marriage, but I do not let that stop me. I've been blessed to become a successful business owner who helps many underprivileged business owners get funding, and I help disabled people start businesses of their own. My focus has been on informing people of the mental effects of having Myasthenia Gravis.

I feel blessed to be a voice of this illness, to share my story with others and bring awareness of what people with MG experience.

Tell us about your MG journey.

It was rough! It started out with one incident - I went to a friend's house one Sunday night, ate a cookie, and a few minutes after that my eyelid drooped. I couldn't see properly out of my eye. I went to the ER, and they admitted me to the hospital. At the time, I was studying to be a paralegal, and it was finals week. Since the doctors had no idea what was wrong, I stayed in the hospital almost a week.

My eye went back to normal for about a year. Then my voice started messing up. I started having a hard time swallowing. I remember sitting at the Thanksgiving table eating some turkey, and my chewing was off. It was laborious trying to chew a

piece of meat. I told my then-husband and friend, "Something is wrong with my mouth. I can't chew right."

My then-friend who happened to be my managing attorney told me I was crazy. I would go to the doctor, and they didn't know what was wrong. I went to one doctor, who supposedly was a specialist, and she told me I needed jaw surgery. I got up and walked out of her office.

That's when I started to do my own research. By this time a few years had passed. I had lost about forty pounds from not being able to eat well. I went to the ER one night - I couldn't talk, could barely cough or sneeze, and I had a notepad and pen with me with some research I had done. I asked a resident doctor, a Black lady, to test me for myasthenia gravis. I'll never forget it - the look she gave me when the test came back positive for Myasthenia. For some reason, she was the only one I noticed who was empathetic about the situation.

I started taking medicine. The medicine helps when it wants to. I would go into the hospital every year, twice a year - springtime and wintertime. I would get sick with an allergy or a cold, and it would take all the strength I had. I couldn't close my eyes, could barely swallow, couldn't cough or sneeze. It was like I was becoming a vegetable. I couldn't smile, and my looks had totally faded.

In 2018 I had a big crisis. I remember going to the spa with my friend and son. I was very weak. I went home and felt my strength literally leave my body each minute. I asked my daughter to bring me soup, but I couldn't swallow it. My muscles in my esophagus had begun to shut down. My chest felt heavy from shortness of breath, and although I didn't want to, I





knew I had to go to the hospital. December 24, 2018, I went to the hospital and passed out trying to use the bathroom. I woke up in a hospital bed on December 25 with an oxygen mask on. It was so uncomfortable.

I remember looking at the clock to see what time it was, and everything looked blurry. I remember barely being able to turn my head, and my arms felt like they had concrete weighing them down. I tried adjusting the mask and accidentally pulled the hose from the machine. I tried to take a breath, and nothing happened!

So I lay there trying to muster up the strength to push the button to call the nurse, all while suffocating. This African nurse walked in, and said, "What's wrong, honey!" I couldn't talk, couldn't breathe, and was using what little strength I had to try and point. She saw the hose had been disconnected. She hurried and plugged it back into the machine, and I remember scribbling on my tablet, "LIFESUPPORT" right before passing out.

I woke up on a cold table, surrounded by medical staff, and bright lights over me, with a nurse putting a catheter in me. I couldn't move or turn my head. I kept my tablet and pen by me the entire time and chose to remain cognitive. I wanted to know what they were doing to me while I was intubated. I remember the respiratory therapist had to come in several times a day and push this apparatus down the tube to remove the mucous.

I don't wish intubation on my worst enemy. I was intubated for two weeks while I went through treatment. It was my first time having the Plasmapheresis done. I had to write things like, "Please turn my head, please lower my bed, please turn me, please wipe me." I was a baby all over again. I still have that notepad from that time in my life. I'm surprised the nurses could read my writing. I was writing with my left hand, and it was so weak, I could barely hold the pen. The entire time, I continued scribbling my morning meetings with God and telling myself, "This too shall pass." I remember, a nurse came into my ICU room, and I could tell she had more experience than the others. She came in to clean the incision in my neck that had the tube in it for the treatment. She tilted my bed back at about a 45-degree angle and went in. The pain was excruciating from the pressure of cleaning that area. I couldn't yell, couldn't move, I just had to take it.

Interestingly, I had planned a trip to Australia, and I didn't figure I would make it. So, I wrote a request for the doctors to write me a letter to cancel the trip; it didn't happen. I got out of the hospital a week before the Australia trip. I said a prayer and decided to go. I told my neurologist, and he was like, "You're going down under by yourself!" I said, "Yes, I'm going to have my angels with me." I requested special accommodations at the airport and boarded a business class flight to Melbourne, Australia. I wasn't about to lose 40% of my money for canceling that trip. And I am so glad I went! YAHWEH, blessed me with a smooth trip that I'll never forget. It was so inspiring that I wrote my first book, a children's book, "Diary of Your Favorite Animals Near Extinction Volume 1." I visited protected animals on a safari, and they reminded me of myself - saved from extinction.

I did so well after that. It's like I was me again. I got my smile back. I gained my weight. My business really took off, and I was able to do things humans are supposed to do like run, eat a meal, laugh and smile. I felt my emotions change. It's like my joy had literally been taken away. And after the life support and treatment, it returned. From my experience, I can tell MG does something to you emotionally.

A friend of mine got upset with me because I went to Australia, and I never heard from her again. That was disappointing. The steroids caused me to gain an excessive amount of weight, and since the Plasmapheresis is temporary treatment, I started losing my voice again, and the symptoms came back.

I searched for a doctor that I knew about when I was a child. He's a functional medicine doctor. I know we are all different, but the doctors have a cookie cutter method for handling this disorder, and I'm not satisfied with that. So, I have dug deeper to see what deficiencies I have and correct them. I last went into the hospital in October of 2021. I read that low levels of Vitamin D can cause autoimmune symptoms. I asked the doctor to check my levels and they were excessively low. I see a neurologist, a functional medicine doctor and a primary care doctor. I can feel myself get better and better each day. It's a process, and I believe in a power far higher than any human. Almighty God has the last say over my health.

Why is it important to you to be an advocate?

People with MG are ostracized. It takes away your smile. Because of this illness, I have had a hard



time with my weight, difficulty swallowing. I've had people say I was drunk due to my slurred speech. I struggle going out with friends because I've had such difficulty eating a meal. A lot of people don't understand the strength it takes sometimes just to hold up my hand or put on a shirt. It's an invisible illness, so I want more people to understand the difficulty - the social difficulty - of having MG. It takes a toll on you emotionally and can cause you to feel low self-esteem.

What do you wish others knew about having MG?

It takes empathy to view a person with MG. Picture your muscles just giving out after trying to work out. When that personal trainer says, "just one more!" And you know you don't have one more; your muscles are exhausted. That's what it's like for people with MG. We're not pretending.

It is even a bit traumatic, because if you have a career and a social life, that can become non-existent if you have a hard time finding the right treatment. This is what I'll say to help you understand a bit better. Picture the last baby you took care of. Picture how that baby is when it's learning to walk. Its muscles are weak, it can barely stand at times. If you let it go, it will fall flat on its face! Put a plate of chicken in front of that baby, it won't be able to eat it. Its chewing muscles are weak. Well, thankfully due to medication, MG isn't that bad unless a person goes into crisis like I did, but the muscles still get very weak from time to time, and sometimes the medication doesn't help. Be patient with people who have MG. Don't allow them to overwork themselves. They are down for days if they do. Help them as much as possible and show them love.

Tell me about your professional life.

I'm a business and bankruptcy paralegal who founded a business consulting firm, Moore Financial Services, in Dallas, Texas. I've been at this for almost 12 years. We help people start businesses properly. We help disabled people start businesses of their own. We work with professional athletes to start their businesses properly. We also serve disabled pro athletes who have suffered injury on the field. They want to start businesses to supplement their income, and we help them start their businesses properly. I have authored five books since 2019, and I'm writing a sixth one about the journey I have been on with Myasthenia Gravis. It should be completed in November of this year.

If you had one piece of advice for other MG patients, what would it be?

Love yourself, no matter what happens. It's not your fault. I know it's hard sometimes because you don't even look the same at times, and you have difficulties doing things you love, but we have a better hope for the future. I believe in God's word, and it promises at Isaiah 33:24, "No resident will say I am sick."

"Fantastic Things" Helps Children Understand MG

By Kate Stober

Elyse Bruce is a prolific writer, artist, and musician. She has written dozens of books, including *Fantastic Things*, a novel that addresses myasthenia gravis. *Fantastic Things* is the first middle-grade reader chapter book that explains what MG is in easy terms that children, teens, and adults can understand.



Her own personal connection to MG - both her brother and son have been diagnosed - inspired her to create awareness about this rare disease through her creative work.

She shares more about her book and her "why" in this interview.

Tell us more about *Fantastic Things*.

Fantastic Things is about nine-year-old Missy Barrett deciding she's old enough to ask her 15-year-old brother, Josh, about myasthenia gravis (he was diagnosed as a child) so she can figure out what to do when her brother is having difficulties because of his MG. The book begins with Missy sitting on the front step of her house with her two brothers, who are playing a one-on-one game of driveway basketball, and Missy is doing her best at being a color commentator. When the game concludes, Missy suggests that she and Josh head over to Icy Delights (a fictional ice cream store) because she



wants to get the downlow on what MG is and how it affects her brother as well as how to help him when he needs help.

What inspired you to write it?

My late brother was diagnosed with myasthenia gravis as a young teen back in the 1970s. When he first exhibited symptoms, my parents would ask him point blank if he was experimenting with drugs (he wasn't). Finally, they took him to see a neurologist who diagnosed him with MG. He had a thymectomy, and immediately after healing from the surgery, his MG went into remission. He was fortunate in that, as my son also had a thymectomy, but unfortunately didn't go into remission.

My son was diagnosed with myasthenia gravis when he was 12 years old after exhibiting symptoms consistent with MG. Because my son was diagnosed with autism as a toddler, for years medical professionals chalked up symptoms that were consistent with MG to autism, which is why his MG went undiagnosed for so long. But even after he was diagnosed, it was shocking to find out how little people knew and understood about MG, and how much disinformation and misinformation was easily accessible online.

My son was excluded from participating in a number of activities through various special needs groups because the organizers didn't want to take chances dealing with a kid who had a disease they didn't really understand. The world can be cruel that way, and I wanted to find an impactful way to share how a child or teen diagnosed with MG is just a child or teen who just happens to have MG. MG doesn't define them; it's something they have to deal with. The more people know about what MG is and how to help a person with MG, the less fearful they will be of interacting normally with people diagnosed with MG.

As a character, Missy Barrett has a pluckiness and an innocence. She has a way of taking away a lot of the negative aspects of life because of her outlook. Seeing this disease through her eyes allows readers to understand the disease in a different light. Missy learns about her brother's MG but doesn't catastrophize it. She understands that Josh is still Josh.

Before *Fantastic Things* and all my other Missy Barrett books, Missy was a main character in a

great many stories I made up and told to my son when he was either in the hospital or undergoing IVIg treatments. It kept his mind off what he was going through at the hospital, and he always had questions about Missy and her world.

How do you hope your book will support the MG community?

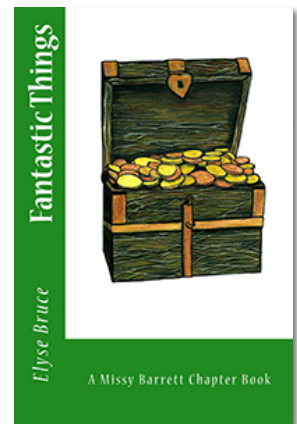
For me, it's hard to come to the realization that myasthenia gravis is still so poorly understood, since it's been 50 years since I first heard about MG. The more people know and understand about MG, the more understanding and accepting society will be towards those with MG, and diagnosed individuals and their family members won't feel so isolated from society.

Tell us more about your creative work.

Being creative is how I supported my family of two as the single parent of a special needs child. I am a self-taught artist and a classically trained pianist. I have written sound scores for stage productions as well as documentaries.

And I write ...

I am currently working on the 20th Missy Barrett book. The first time Missy showed up as Missy she was a secondary character along with her brothers, Josh and Aaron, but readers enjoyed her antics so much, they asked me to write books where Missy was the main character. I write as myself (Elyse Bruce), as my other self (E.B. Taylor), and under various pseudonyms.



Prescribing Information



GENERALIZED MYASTHENIA GRAVIS

*doesn't get to make
these plans*

VYVGART is a first-of-its-kind, FDA-approved treatment for adults with anti-AChR antibody positive generalized myasthenia gravis (gMG)

AChR=acetylcholine receptor
Visit VYVGART.com/glossary for a glossary of terms.



Talk to your neurologist and **scan the QR code** to learn more or call **1-833-VYVGART (1-833-898-4278)**.

What is VYVGART™ (efgartigimod alfa-fcab)?

VYVGART is a prescription medicine used to treat a condition called generalized myasthenia gravis, which causes muscles to tire and weaken easily throughout the body, in adults who are positive for antibodies directed toward a protein called acetylcholine receptor (anti-AChR antibody positive).

IMPORTANT SAFETY INFORMATION

What is the most important information I should know about VYVGART?

VYVGART may cause serious side effects, including:

- **Infection.** VYVGART may increase the risk of infection. In a clinical study, the most common infections were urinary tract and respiratory tract infections. More patients on VYVGART vs placebo had below normal levels for white blood cell counts, lymphocyte counts, and neutrophil counts. The majority of infections and blood side effects were mild to moderate in severity. Your health care provider should check you for infections before starting treatment, during treatment, and after treatment with VYVGART. Tell your health care provider if you have any history of infections. Tell your health care provider right away if you have signs or symptoms of an infection during treatment with VYVGART such as fever,

chills, frequent and/or painful urination, cough, pain and blockage of nasal passages/sinus, wheezing, shortness of breath, fatigue, sore throat, excess phlegm, nasal discharge, back pain, and/or chest pain.

- **Undesirable immune reactions (hypersensitivity reactions).** VYVGART can cause the immune system to have undesirable reactions such as rashes, swelling under the skin, and shortness of breath. In clinical studies, the reactions were mild or moderate and occurred within 1 hour to 3 weeks of administration, and the reactions did not lead to VYVGART discontinuation. Your health care provider should monitor you during and after treatment and discontinue VYVGART if needed. Tell your health care provider immediately about any undesirable reactions.

Before taking VYVGART, tell your health care provider about all of your medical conditions, including if you:

- Have a history of infection or you think you have an infection
- Have received or are scheduled to receive a vaccine (immunization). Discuss with your health care provider whether you need to receive age-appropriate immunizations before initiation of a new treatment cycle with VYVGART. The use of vaccines during VYVGART treatment has not been studied,

and the safety with live or live-attenuated vaccines is unknown. Administration of live or live-attenuated vaccines is not recommended during treatment with VYVGART.

- Are pregnant or plan to become pregnant and are breastfeeding or plan to breastfeed.

Tell your health care provider about all the medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal supplements.

What are the common side effects of VYVGART?

The most common side effects of VYVGART are respiratory tract infection, headache, and urinary tract infection.

These are not all the possible side effects of VYVGART. Call your doctor for medical advice about side effects. You may report side effects to the US Food and Drug Administration at 1-800-FDA-1088.

Please see the full Prescribing Information for VYVGART and talk to your doctor.



VYVGART is a registered trademark of argenx.

© 2022 argenx US-EFG-22-00048 V1 03/2022

Look for the MGFA Annual End of Year Appeal and Giving Tuesday



Support the MGFA's research and programs starting on Giving Tuesday, November 29th.

Every year, International Giving Tuesday occurs on the first Tuesday after Thanksgiving in the United States. In 2022, the MGFA will use Giving Tuesday on November 29th to kick off its annual End of Year Appeal to support MG research funding and our many programs and educational resources to help those living with myasthenia. The MGFA plans to fund nearly \$1 million dollars in new research grants this year – a record high for us! We cannot commit to this level of critical funding without YOUR support and generous giving. As you know, the MGFA also provides a robust set of educational resources and programs including webinars, video sessions,

conferences and events, brochures and informational materials, and so many tools that the MG Community depends on. We could not provide all these resources and expertise without you and your support of the MGFA.

Please visit myasthenia.org to make an impact. There are so many ways to invest in the MGFA – participate in events and fundraising, include the MGFA in your monthly financial planning or legacy gift, or simply make a donation.

To learn more about all the ways to donate, visit: www.myasthenia.org/Make-an-Impact/Donate

And, if you want to get involved in fundraising or plan your own event, check out: www.myasthenia.org/Make-an-Impact/Fundraise

MGFA Support Groups Back to In-Person

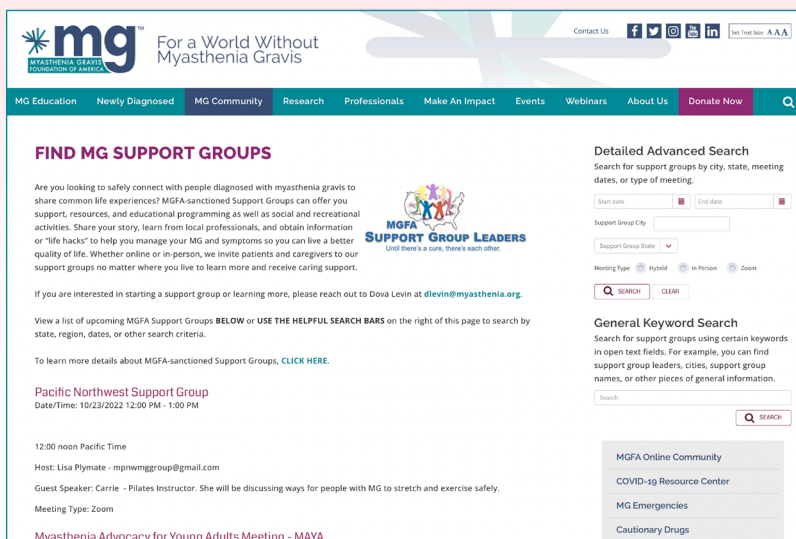


In-Person and Online Support Groups are open to all MG patients and caregivers. Many support groups are meeting in-person now and MG Community members are enjoying a return to face-to-face interactions. Yet, there are support group leaders who are still conducting their support groups over the Zoom virtual meeting platform. No matter how your local support groups leaders are bringing people together, you should definitely join us and share your experiences.

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 valuable information. But also look for support groups in your home city or close by. We hope you will consider joining the MG Community in-person soon.

Now, the MGFA has provided a much better, more accurate and more efficient method of searching for support groups near you.

Visit www.myasthenia.org/MG-Community/Find-MG-Support-Groups on the MGFA website, and you can now conduct a detailed or general word search to find support groups in your state, city, by month or date, and even by whether a meeting is in-person, online, or a hybrid meeting. Check it out and quickly find a list of relevant MG support groups – and join today.



The screenshot shows the MGFA website's search interface. At the top, there's a navigation bar with links for MG Education, Newly Diagnosed, MG Community, Research, Professionals, Make An Impact, Events, Webinars, About Us, and Donate Now. The main heading is 'FIND MG SUPPORT GROUPS'. Below this, there's a detailed search form with fields for Start date, End date, Support Group City, and Meeting Type (Hybrid, In Person, Zoom). A 'SEARCH' button is visible. To the right, there's a 'Detailed Advanced Search' section with a 'General Keyword Search' field. At the bottom, there's a list of search results for the 'Pacific Northwest Support Group' meeting on 10/23/2022 at 12:00 PM. The meeting details include the host (Lisa Plymate), guest speaker (Carrie - Pilates Instructor), and meeting type (Zoom). A sidebar on the right contains links to 'MGFA Online Community', 'COVID-19 Resource Center', 'MG Emergencies', and 'Cautionary Drugs'.



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 \[ucbCARES@ucb.com\]\(mailto:ucbCARES@ucb.com\) or 844-599-2273](mailto:ucbCARES@ucb.com) to learn more.



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

Ra Pharma now a part of UCB

2020 UCB, Inc., Smyrna, GA 30080. All rights reserved.
US-P-DA-2000069. September 2020.

Catch Up With The **MG Community**

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

www.myasthenia.org



YouTube



You've Got A **(MG) Friend**

Do you need support managing your myasthenia? MG Friends are here to help! Our free peer-to-peer phone support program helps you get the information and support you need, when you need it.

While support groups serve an important purpose for our community, not everyone can access a group or feels comfortable sharing in a group setting.

The MG Friends Program connects you to a trained volunteer who can provide practical advice, an understanding ear, and emotional support from someone who is also facing the challenges of a life with MG. The service is available to MG patients, caregivers, and family members anywhere in the United States and is free of charge.

Request to connect with an MG Friend at bit.ly/3x6KpEn



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](https://www.myasthenia.org/MG-Community/Wellness-Strategies/Wellness-Series)

What's New in MG Research? <https://www.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.





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.

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

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

Non-Profit Org.
U.S. Postage
PAID
N. Reading, MA
Permit No. 211



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 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.

Make a bequest in your will, name MGFA as a beneficiary, or consider other estate gift options. Contact Craig Strenger at cstrenger@myasthenia.org today so we can answer any questions you have or help you set up your gift.

