FOCUS on mg

a publication of the MYASTHENIA GRAVIS FOUNDATION OF AMERICA

SPRING/ SUMMER 2022

MGFA Funding the Most Promising MG Research *for a Cure*

Former MGFA board chair and CEO **Nancy Law** was one of a kind — warm hearted, passionate, supportive, optimistic, uplifting, and above all a champion of those in the rare disease community. Her passing on September 23, 2021 has been felt by all who knew her and worked with her. Recipients of her friendly phone calls felt instantly at ease, whether they were recently diagnosed with MG or had been in the MG community for decades. She brought tremendous energy to her role as a leader in the MG and rare disease community, tirelessly organizing, making connections between people and organizations, and always advocating for patients.

Her legacy will live on through those lives she touched, and through this organization - the MGFA - that she stewarded so well.

In her honor, we're proud to launch the Nancy Law Impact Award: High Impact Clinical Research and Scientific Projects on Myasthenia Gravis and Related Neuromuscular Junction Disorders (Link: https://myasthenia.org/Professionals/Research-Grants).

This grant award will provide up to $300,000 over three years for applicants who are researching questions related to MG patient outcomes, innovative patient outcome measurements, optimization of clinical research approaches or practices, or the application of translational biomarkers that will aid in further refining the current treatment paradigm.

Through this research, we hope to get closer to our goal of a world without MG – something Nancy spent years working toward with her advocacy, leadership, and incredible spirit.

MGFA will be announcing the names of the recipients in the summer of 2022. Stay tuned.

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.

New Vyvgart Treatment Promises Better Quality of Life for MG Patients

Neonatal Fc receptor (FcRn) blockers

The U.S. Food and Drug Administration (FDA) has approved argenx's Vyvgart (efgartigimod alfa-fcab) for the treatment of generalized myasthenia gravis (gMG) in adult patients who are anti-acetylcholine receptor (AChR) antibody positive. This is an amazing and truly welcome new treatment for the generalized myasthenia community and is the first new treatment in years. Approval was granted in December, 2021.

Vyvgart is a prescription medication and the first FDA-approved treatment that uses a fragment of an IgG antibody to treat adults with anti-AChR antibody positive generalized myasthenia Gravis. It is given in treatment cycles with a break between each cycle. A treatment cycle consists of a 1-hour infusion each week for 4 weeks (4 infusions total). The treatment is specifically designed to attach to and

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VYVGART™ efgartigimod alfa-fcab)

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block the neonatal Fc receptor (FcRn), resulting in the reduction of IgG antibodies, including the harmful AChR antibodies that cause gMG symptoms.

Receptors called "FcRn" extend the life of IgG antibodies. In gMG, this allows harmful AChR antibodies to continue causing gMG symptoms. But IgG antibodies, including harmful AChR antibodies, that cannot attach to an FcRn are removed by the body. When harmful AChR antibodies that cause gMG symptoms are removed, they can no longer disrupt nerve-muscle communication.

"Today is the start of a new era for argenx and the gMG community as we honor our commitment to bring forward an innovative treatment option for people living with this debilitating disease. The approval of VYVGART represents many achievements: our first approved product; the first-and-only FDA-approved neonatal Fc receptor blocker; and the first approved therapy designed to reduce pathogenic IgGs, an underlying driver of gMG," said Tim Van Hauwermeiren, Chief Executive Officer of argenx. "Importantly, we want to thank the patients, supportive caregivers, investigators and study teams who participated in the ADAPT trial, as well as our partners and dedicated employees for their hard work and collaboration – all of whom made this milestone possible.

"The gMG community has long awaited the FDA approval of VYVGART, especially for those patients who struggle with basic personal tasks such as speaking, chewing and swallowing food, brushing teeth and hair, and in some severe cases, breathing," commented Samantha Masterson, President and Chief Executive Officer of the Myasthenia Gravis Foundation of America. "We thank argenx for its continued commitment to the gMG patient community, which led them to deliver this much-needed new treatment option with the potential to change the lives of many gMG patients."

"People living with gMG have been in need of new treatment options that are targeted to the underlying pathogenesis of the disease and supported by clinical data," said James F. Howard Jr., M.D., Professor of Neurology (Neuromuscular Disease), Medicine and Allied Health, Department of Neurology, The University of North Carolina at Chapel Hill School of Medicine and Principal Investigator for the ADAPT trial. "Today's approval represents an important new advance for gMG patients and families affected by this debilitating disease. This therapy has the potential to reduce the disease burden of gMG and transform the way we treat this disease."

The approval of VYVGART is based on results from the global Phase 3 ADAPT trial, which were published in the July 2021 issue of The Lancet Neurology. The ADAPT trial met its primary endpoint, demonstrating that significantly more anti-AChR antibody positive gMG patients were responders on the MG-ADL scale following treatment with VYVGART compared with placebo (68% vs. 30%; $p<0.0001$). Responders were defined as having at least a two-point reduction on the MG-ADL scale sustained for four or more consecutive weeks during the first treatment cycle.

This treatment is offered by argenx and you can learn more by visiting the following: www.vyvgart.com.

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

THE CEO'S LETTER

Dear Friends,

What a very busy and exciting first half to the year we have had at MGFA! We are so pleased to share all that has been going on, as well as what is to come. In this second year of our strategic plan, there are some major strategic priorities that have been in development that are coming to fruition.

As we began the year, we anticipated the continuation of virtual interactions. In February we hosted our Annual National Patient Conference – virtual once again. What a program and how you all respond! Thank you so very much for your support and participation. This conference is so special and such a testament to the power of community. Hosting the National Patient Conference is part of our promise to connect patients to premiere resources and education to help inform and navigate their healthcare journey, as well as to connect patients to each other. Each year, attendance for this conference grows, we introduce new experts in the field of MG, and we highlight patient stories. Thank you for your very positive feedback that you enjoy the new format and thank you for showing up time and time again. During the National Patient Conference, we announced our national volunteer awards. I would like to take this opportunity to share the names of our recipients, so turn to page 17 to read about them.

In March, we launched our new and improved MyMG Mobile App! Many of you may recall that this app did already exist, but due to your feedback it was obvious that it needed some serious revamping. The new and improved MyMG Mobile App has significantly better functionality, most importantly a symptom tracker to make it easier for patients to have an informed dialogue with their care providers. The MyMG Mobile App is a prime example of our priority to leverage technology to help improve the lives of those living with MG.

In May, we hosted our first in-person event in two years...and we went BIG...for our first event in two years, we hosted approximately 450 friends from around the world in Miami at our MGFA International Conference. It really was an amazing experience to have a front row seat to the top talent in both the clinical and research spaces for MG as they reported on and shared their findings, conclusions, and ongoing work. What a phenomenal conference and it nearly doubled in size! The MGFA International Conference is the best example of our commitment to serve as a convener and to expand our global footprint. Together we can absolutely inform clinical trials and move research forward.

This month, in June, we celebrate MG Awareness Month...or as we refer to it, MG Action Month by turning Awareness into Action!! We hope that you will join us in the many activities that we share on our website to encourage participation and support. Please visit www.myasthenia.org and upload a photo of yourself to our global Interactive Online Map and join others who are #MGStrong!

Also, in celebration of MG Awareness Month, we have a very special unveiling that will take place later in June. We will be launching our new, one-of-a-kind, MGFA Online Community! This virtual space will serve as a place for MG community members to learn, share thoughts and experiences, and, most importantly, to connect with others. There will be MG educational resources, videos, and interactive chats. Community members can visit a multitude of spaces including, but not limited to, the MGFA Town Hall, the Nancy Law Patient Services Center, the MGFA Museum, the Wellness Center, and even enjoy a video on the Town Common. There will, also, be an Industry Center where visitors can gather and learn from our partners about clinical trials and MG treatments. The ribbon cutting will be late June. We hope that you can join us for the unveiling of this awesome new virtual space to the MG Community!

The Second half of 2022 promises to be just as busy with the launch of our new MGFA Health Fairs in select cities, our Scientific Session, and more regional conferences. We sincerely hope to hear from you and to see you at our programs and events. We always look forward to connecting and partnering with our MG Community!

Sincerely,

Samantha Masterson

Samantha Masterson | President and CEO

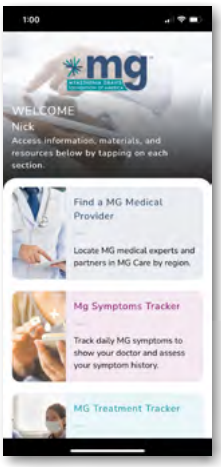
Meet A New MGFA Team Member

The Myasthenia Gravis Foundation of America continues to grow and take on an increased number of critical tasks to improve the lives of the MG Community. We have added a new team member, and we wanted you to meet him in this issue of Focus on MG. We are excited to welcome Nick Patrone.

NICK PATRONE - Visual and Web Design Manager

Nick joined the MGFA team with more than 15 years of graphic design and web development experience. He drives creative and web design projects and digital media as well as focusing on brand management and content communications across a multi-channel framework. Prior to joining the MGFA, he worked for a community development non-profit in Cleveland, OH for seven years, leading all of the organization's marketing design initiatives. He has also held a freelance design position and a web-based, creative design opportunity in the printing and fulfillment industry. Nick brings his passion for technology and design to help advance all types of communication, education, and engagement for the MG community.

Brand New MyMG Mobile App
Puts Your MG at your Fingertips



Manage and Learn About Your Myasthenia Gravis in a New and Personal Way – from the Palm of Your Hand

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.

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.

JUST LOOK AT THIS FULLY-ROBUST SET OF FEATURES:

- **Easy-Access Homepage** - Easy to review and navigate homepage to access all key features.
- **Find MGFA Support Groups** - Search for MGFA Support Groups in your area.
- **Track MG Symptoms** - Enter your ongoing MG symptoms and track severity over weeks and months. Helps you keep track of your daily symptoms or show the graphs to your health providers.
- **Track Current Treatments** – Enter time frames, usage, and dosage.
- **Apple Watch integration** - Use Bluetooth to sync up your Apple Watch Health app with the MyMG Mobile App to track your health stats.
- **Learn about MG Materials** – Gain access to hundreds of educational and information resources, brochures, blogs, webinars, and research materials to help you manage your MG and hear from MG experts and patients.
- **MG Friends** – Sign up to talk with an MG Friend or become one.
- **Find MG Experts** – Search for medial providers in your area.
- **Get Involved with the MGFA** – View events, volunteer, fundraise, and make an impact on the MG Community.

Available on the App Store
GET IT ON Google Play

Visit the Apple App store or Google Play store to download the MyMG Mobile App on your phone.

June is Time to Turn MG Awareness *into* **Action**

mg AWARENESS ACTION MONTH

Turn awareness into action this June!

June is MG Awareness Month around the world! Every June, the MG community comes together to create a unified voice for MG advocacy and education. This year, we're TURNING AWARENESS INTO ACTION.

Take action to make sure people understand the challenges and opportunities faced by those diagnosed with myasthenia gravis and their caregivers. MGFA is offering a number of creative ways to show that **WE ARE MUCH MORE THAN OUR MG**.

Shine Bright for MG
If your community has a monument or building that lights up with different colors to acknowledge different causes, encourage them to go teal for MG awareness.

Give Presentations
Think civic associations, hospitals, religious groups, schools, and more. If public speaking makes you queasy, enlist support from a fellow MG volunteer. Get creative with your presentation – one of you could interview the other, or tag team giving MG facts and personal anecdotes.

A Little Goes a Long Way
Take 15 minutes to call or write to your local Senator or Congressperson and ask for their support on initiatives that support the rare disease community. Resources are on the MGFA Patient Advocacy page.

WWW

Volunteer
Visit www.myasthenia.org/Make-an-Impact to find out how you can Volunteer for the MG Community.

Get Crafty
Use sidewalk chalk to create an #MGStrong mural in your driveway or on the sidewalk in your neighborhood.

MGFA AWARENESS TOOLS

Proclamation Request and Format – Sample

City of_____/ Town of_____/ State of _____

WHEREAS, myasthenia gravis is a disorder causing extreme muscle weakness whichcan impact a person's ability to see, smile, walk, talk and breathe, and it is often misdiagnosed. It's controllable by medication and other treatments formost MG patients, and although rare, it can prove fatal; and

WHEREAS, because of its rarity (approximately 100,000 people are living with MGin the United States today), many Americans are often undiagnosed; and

WHEREAS, the Myasthenia Gravis Foundation of America, Inc. (MGFA) is a not-for-profit organization founded in 1952; and

WHEREAS, the MGFA's mission is to facilitate the timely diagnosis and optimal careof individuals affected by myasthenia gravis and to improve their lives through programs of patient services, support groups, public information, medical research, professional education, advocacy and patient care.

NOW, THEREFORE, BE IT RESOLVED that I,_____, Mayor of the City of/Chairman, Board of Selectmen of the Town of/Governor of the State of_____,do hereby proclaim June 20XX, as:

MYASTHENIA GRAVIS AWARENESS MONTH

in the City/Town/State of__and urge all residents to join with me, during the period, in an attempt to focus attention on the need for education, treatment,research, and ultimately, a cure, for this currently incurable disease.

IN WITNESS WHEREOF, I hereunto set my hand and cause the Seal of the City of/Town of/State of_, to be affixed this_____day of_____ in the year of our Lord, Two Thousand XXX.

Mayor/Chairman, Board of Selectmen

Contact:

MGFA National Office Address:
290 Turnpike Road, Suite 5-315, Westborough, MA 01581

[April/May] XX, 20XX

TO:

Board of Selectmen ***OR:*** Mayor or Governor

Town of:_____ City of or State of: _____

The Myasthenia Gravis Foundation of America, Inc. (MGFA) is pleased to designate June as Myasthenia Gravis Awareness Month. Myasthenia gravis (MG),is a disorder causing extreme muscle weakness that can impact a person's abilityto see, walk, talk, breathe and even smile.

Please join with other municipalities in issuing a proclamation for **MyastheniaGravis Awareness Month** in your **[town, city, or state].** Attached is a sample proclamation that is being declared in several other communities nationwide.Thank you for your attention to this important matter.

Local contact: _____

Name:_____

Phone number: _____

MGFA AWARENESS TOOLS

Sample Pitch Email for Media

New Message

To Cc Bcc

Subject [Town] Resident Inspires Community

Hello,

On [date] at [location], [resident] is [conducting activity, such as: "hosting a virtual gathering" or "organizing a vehicle parade"] and can share her experiences with how the incurable, autoimmune neuromuscular disease myasthenia gravis (MG) inspired her to become an advocate in her community. We hope you can cover this event on [date/time].

[Add more details, particularly any visual components.]

More information about MG and the Myasthenia Gravis Foundation of America are included below my signature. Please let me know if you are interested in covering this event or have questions.

Thank you,

[Signature and phone number] [Include Media Alert – see below]

Send

Media Alert

A media alert is similar to an invitation for newspapers, radio and TV news outlets to attend and cover an event. When creating this document, be sure to highlight the local impact of what you are doing and note the community/city where the event will take place. We included brackets around the items you may want to tailor to your event. Here is an example:

[City] Resident Highlights MG Awareness Month by [Activity]

WHAT: On [date], residents of [city/town] will take part in the [event name] to raise awareness about myasthenia gravis (MG). MG is a disorder causing extreme muscle weakness that can impact a person's ability to see, walk, talk, breathe, and even smile. It strikes people of all races, genders, and ages. [Add 1-2 sentences about the event.]

WHEN: [DATE] and [TIME]

WHERE: [LOCATION] and [ADDRESS]

CONTACT: For more information, please contact [NAME, NUMBER, EMAIL]

WHY: Myasthenia gravis is rare and non-contagious. In MG, the body's immune system attacks the connection between the neurons and the muscle fiber, which limits the ability of the brain to control muscle movement. The degree of muscle weakness can vary from person to person, and day to day. Due to the high number of misdiagnoses, the precise number of people with MG is unknown, but MG is estimated to affect approximately 100,000 Americans. There are effective treatments for most, but not all with MG. There is currently no cure.

[Insert 2-3 sentences describing a personal story, if applicable.]

Photo and interview opportunities available.

MGFA AWARENESS TOOLS

How to Write an Opinion Editorial

Opinion Editorials (Op-eds) are articles written by local citizens, organization leaders, experts, or others who are knowledgeable about an issue. The topic of an op-ed is the writer's choice; of course, more relevant and timely op-eds are more likely to be published. By submitting an op-ed you can call attention to your issue. Check out your local paper for requirements regarding length and where to submit. Here is an example:

Title: RAISE Awareness and Take Action

My husband, Bob, lives every day with a debilitating disorder called myasthenia gravis, a disorder most people have never even heard of. Myasthenia gravis, a disorder causing extreme muscle weakness that affects all races, genders and ages, has no cure.

This disorder can strike anyone and can attack without warning. MG has weakened Bob so that he's unable to pick up our 4-year old daughter or participate in activities he used to love, such as running. Myasthenia gravis (MG) causes weakness in muscles that control some of our most basic movements: seeing, walking, talking, breathing and even smiling.

MG is frequently misunderstood and under diagnosed, and because of this, it took nearly two years and seemingly endless doctor's appointments to get Bob the proper diagnosis. During this time, I was forced to put my career on hold and it opened my eyes to the impact this disease was having on our entire family, and the importance family caregivers have once a loved one becomes ill. I am asking for your help to raise awareness and take action.

AT THIS POINT INSERT A TIMELY REASON FOR YOUR LETTER, FOR EXAMPLE, SEE THE FOLLOWING PARAGRAPH OR, PROVIDE CONTEXT FOR YOUR LETTER BY MENTIONING JUNE IS MG AWARENESS MONTH, FOR INSTANCE.

[RAISE (Recognize, Assist, Include, Support, and Engage) Family Caregivers Act (Senate Bill 1719; House Bill 3099) has passed the Senate but still needs to pass the House. This bipartisan legislation calls for the Secretary of the U.S. Department of Health and Human Services to develop, maintain and update an integrated strategy to recognize and support family caregivers. I urge you to take a few minutes to contact your Congressman/woman and urge him/her to support this legislation. It's the first step in better recognition and help for family caregivers. Note: You can confirm the status of the legislation at the Congress.gov website: https://www.congress.gov/bill/114thcongress/senate-bill/1719

To find your representative visit: http://www.house.gov/representatives/find/. Thank you for your help in advocating for increased attention to the needs of family caregivers.

NOV 12 2022

Join the MGFA Coast-to-Coast 2740 Walk Challenge

Begin Fundraising Today

National Fundraising Event Takes Place on November 12, 2022. Register Your Team or Yourself Today and Raise Funds to Help the MG Community.

The Coast-to-Coast 2740 Challenge virtual walk is MGFA's annual fundraiser that enables participants to walk no matter where they live, and also, raise critical funds for the MG community. It provides hope for the thousands of families who face the challenges caused by myasthenia gravis (MG).

It takes place online on Saturday, November 12, 2022, and is the virtual recognition of all our participants' and teams' hard work. We will be highlighting various walk teams, our partners and patients all across the country. We will recognize our top fundraising teams and individuals, as well as celebrate all that we have accomplished together for the MG community.

In the weeks leading up to the walk, participants are encouraged to fundraise spreading the word about MG and how it affects those living with MG, and also their families, friends, careers and all aspects of their lives. These conversations shed light on what MG is, and the need for the MGFA to receive vital funding for programs to find a world without myasthenia gravis.

The money raised through the Coast-to-Coast - 2740 Challenge is used for research to find a cure for MG, improve treatment options, and provide support for people with MG through community programs and advocacy.

Go to bit.ly/39e2sRd to register or please contact Tasha Duncan at tduncan@myasthenia.org or at +1.423.827.5445 See you on November 12th.

Hear From Volunteers

After over a decade of misdiagnosis, I finally had some answers--and in the process found a cause in need of one more voice. One of the first things she discovered in my research into myasthenia gravis was the MG Walk. I created a team and joined right away, knowing that the more awareness and funds I could bring, the better! With creative fundraising techniques, a wonderful support system, and a lot of hope for the future, I am still here five years later...now helping to helm the Coast-to-Coast Challenge as the volunteer Chair!

Chair – Drea Carbone

My name is Jessica Milanes and I was diagnosed with Myasthenia Gravis in 2006. I currently lead the San Francisco Support Group and Myasthenia Advocacy for Young Adults (MAYA). I didn't meet another person with MG until I joined the Stanford Support Group in 2016, and the 2016 San Francisco MG Walk was the first MGFA event I ever participated in. I had felt very alone and isolated prior to joining the support group and walk so it was amazing to see how big and supportive the MG community was. Both of these events have made a significant impact on my life and especially how I live and deal with MG, and I am very thankful for the MGFA!

West Coast Co-chair – Jessica Milanes

My name is Priscilla Forrester, and I was diagnosed with Myasthenia Gravis March 2020. This diagnosis came after years of doctors trying to figure out what the cause of my symptoms were and my struggling in silence. The first outlet I went to was the Myasthenia Gravis Foundation of America. There I came across the page for various city walks to spread awareness and raise money for research for a cure. I figured this would be a great way to help spread the word about this rare condition, in hopes that others like me would not have to suffer in silence for years like I did. I am looking forward to doing it all again on the Coast to Coast 2740 Challenge and hope you will join in on the journey with us.

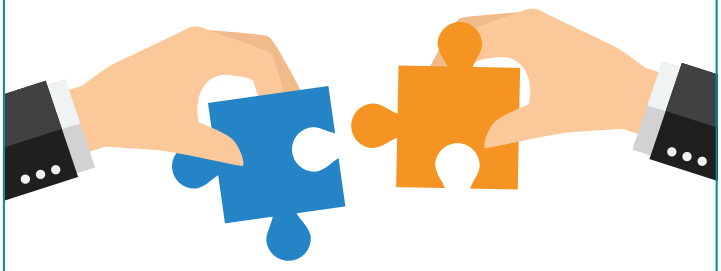
East Coast Co-chair - Priscilla Forrester

MGFA Helps You Donate and Fundraise with New Tools
Making It Easy to Make an Impact

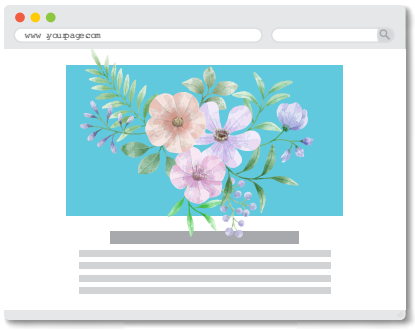
We all want a world without MG. Your support brings us one step closer.

Making a gift or hosting a fundraising event ensures crucial funding for MG patient support, advocacy, and research. We've made it easy with tools, event how-tos, and a friendly fundraising department ready to answer any questions.

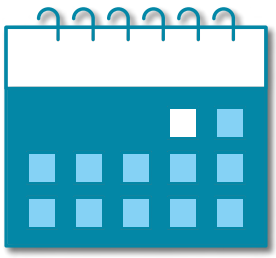
Make a gift online, send in a check, include MGFA in your estate plans – there are many giving options to suit your needs.



Does your company offer matching gifts? If so, you can double your impact.



Honor a loved one or caregiver with an MGFA tribute page.



Host your own fun event and raise funds and awareness at the same time! Don't limit yourself to a walk or fun run – we've had volunteers host golf scrambles, paint 'n sip events – even a rubber ducky derby!

Make an impact for all those affected by MG and bring your fundraising vision to life with our help. Through your creativity and our fundraising tools, we will work with you every step of the way to make an impact.

Visit myasthenia.org/Make-an-Impact/Donate or connect with Director of Development Caroline Gaylor at cgayler@myasthenia.org to learn more.

Gather and Connect at our new **MGFA Community Health Fairs**

MGFA kicks off its first-ever local, in person Community Health Fairs in 2022 to bring the MG Community together in various locations around the country while more effectively supporting those diagnosed with myasthenia and their caregivers. Join us in Alexandria, VA, Atlanta, GA, Austin, TX, Tampa Bay, FL, San Francisco, CA. Our goal for these Community Health Fairs is to attract increased numbers of attendees and more actively engage with patients, caregivers, medical professionals, and people across the MG Community and beyond. We want you to CONNECT with each other to SHARE stories and guidance, to LEARN more about managing MG.

MGFA COMMUNITY HEALTH FAIRS

CONNECT • LEARN • SUPPORT

This is the perfect way to reach the community while educating all of you on all facets of MG care and treatment – and we hope you will join us.

At the fairs, you will engage in so many rewarding and educational experiences including:

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

Obtain information and educational materials.

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.

Join the "MG Experience" to learn new methods of sharing MG challenges.

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

If you want to become a sponsor or donor, **please contact Tasha Duncan at tduncan@myasthenia.org** or at **+1.423.827.5445** or contact your local Community Health Fair leader. You can register to attend at a location near you at: **www.myasthenia.org/Community-Health-Fairs**

AstraZenenca/Alexion's Ultomiris Treatment Approved in the US for Adults with Generalized Myasthenia Gravis

Ultomiris showed early effect and lasting improvement in activities of daily living and has potential to reduce treatment burden with dosing every 8 weeks. AstraZeneca, and its Alexion rare disease group, announced that the United States Food & Drug Administration (FDA) has officially approved the Ultomiris (ravulizumab-cwvz) treatment for adult patients with generalized myasthenia gravis (gMG) who are anti-acetylcholine receptor (AChR) antibody-positive, which represents 80% of people living with the disease.

This FDA action marks the first and only approval for a long-acting C5 complement inhibitor for the treatment of gMG.

According to Alexion, the medication works by inhibiting the C5 protein in the terminal complement cascade, a part of the body's immune system. When activated in an uncontrolled manner, the complement cascade over-responds, leading the body to attack its own healthy cells. Ultomiris is administered intravenously every eight weeks in adult patients, following a loading dose.

Samantha Masterson, President & Chief Executive Officer, Myasthenia Gravis Foundation of America (MGFA), said: "gMG takes a physical and emotional toll on those living with the disease. We are grateful for continued innovation and research into new treatment and dosing options to meet the needs of more patients and reduce the treatment burden. With the approval of Ultomiris, we're excited that MG patients now have another option to consider as part of their personalised treatment strategies that may offer more convenience and improve muscle weakness."

You can read more about this critical new treatment at https://www.astrazeneca.com/media-centre/press-releases/2022/ultomiris-approved-in-the-us-for-adults-with-generalised-myasthenia-gravis.html.

UCB Announces Positive Data in Myasthenia Gravis With **Zilucoplan** Phase 3 Study Results

UCB, a global biopharmaceutical company and collaboration partner with the MGFA, recently announced positive topline results from the RAISE trial evaluating its investigational treatment called zilucoplan for generalized myasthenia gravis.

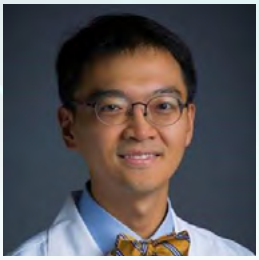
The results show zilucoplan was well-tolerated and no major unexpected safety findings were identified compared to earlier zilucoplan studies.

Zilucoplan is a self-administered, subcutaneous (SC) peptide inhibitor. The primary endpoint of this phase 3 study was met - a clinically meaningful and statistically significant improvement from baseline in Myasthenia Gravis-Activities of Daily Living Profile (MG-ADL) total score at Week 12. All key secondary endpoints were also met.

This is a very positive sign that may see a future new treatment for those diagnosed with MG. The results show a favorable safety profile and good tolerability. UCB plans to proceed with zilucoplan regulatory submissions later this year

For more information about the trial visit https://clinicaltrials.gov/ct2/show/NCT04115293.

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



Sarah M. Jones, MD
Dept. of Neurology,
University of Virginia

Ikjae Lee, MD
Dept. of Neurology,
Columbia University

EMR data supports that COVID-19 Outcomes are worse in patients with Myasthenia Gravis who are older or have trouble swallowing

There is a concern that persons living with myasthenia gravis (MG) may be more vulnerable or have worse outcome due to COVID-19 infection. Kim and colleagues examined outcome of COVID-19 infection in patients with myasthenia gravis and compared to those without myasthenia gravis by using Optum®'s electronic health record database of more than 700 hospitals.[1] Patients were included if they had laboratory confirmed COVID-19 with positive SARS-CoV-2 PCR test between March 1, 2020 and Jan 31, 2021. MG patients were identified based on diagnostic medical codes. Among those without MG, rheumatoid arthritis (RA), systemic lupus erythematosus (SLE) and multiple sclerosis (MS) were further identified with corresponding diagnostic codes. Through this process, 5 groups of patients namely MG, RA, SLE, MS and Non-MG groups were identified. Outcomes of COVID-19 infection including hospitalization, ICU admission, ventilator use and death were compared between groups, adjusted for age, sex, race, comorbidities, treatments, presence of swallowing and breathing difficulties and month of COVID-19 diagnosis.

A total of over 400,000 individuals were included, with 377 individuals in the MG group and over 97% of patients falling into the non-MG group without any of the aforementioned conditions. Compared to Non-MG group, individuals in the MG group were older, more frequently Caucasian and had higher prevalence of comorbidities. MG patients with COVID-19 infection were more frequently hospitalized (38%) compared to RA, SLE, MS, and non-MG groups (26%, 24%, 24%, 14% respectively). Risk of ICU admission in the MG group was higher than the other groups after adjusting for covariates. Ventilator use (3.7%) and death (10.5%) were more frequent in the MG group compared to the non-MG group, however, these differences were not significant after adjusting for covariates. Within the MG group, age 75 years or older and trouble swallowing were significantly associated with the risk of death after accounting for other differences. Symptomatic treatment, chronic immunosuppressive therapy or IVIg within the 6 months prior to COVID-19 infection did not affect the outcomes significantly in the MG group.

This study used large population-based dataset to compare COVID-19 infection outcome between MG and other disease groups as well as identifying risk factors for worse outcome among MG patients. The authors acknowledge limitations of the study including retrospective study, unknown validity of using diagnostic code to identify MG patients, inability to identify MG disease severity or dose of medications. The study findings nonetheless can further guide decision making and counseling on vaccination, maintenance treatment, and initiation of new treatments during pandemic.

Safety of COVID-19 vaccines in persons with MG

People with autoimmune diseases are often concerned of disease exacerbation triggered by a vaccination. In the observational study conducted by Farina et al.ii, 104 subjects with MG who had received at least one dose of SARS-CoV-2 vaccine were evaluated to see if vaccination worsened MG symptoms. MG worsening was defined as reoccurrence of MG symptoms lasting at least 24 hours within the 4 weeks after SARS-CoV-2 infection or vaccination. MGFA classification and post intervention status (PIS) classification was used to measure symptoms before and after vaccination. Data was gathered from medical records and interviews.

Among 104 subjects, 94% had at least two doses and 64% had the third "booster" dose. 79% had acetylcholine receptor antibody, 8.6% had MuSK antibody and 11.5% were antibody negative. At the time of vaccination, most patients (83.6%) had minimal or no MG symptoms and at least 80% of the patients were taking immunotherapy. The mean disease duration was 16 years and patients were followed for 91 days in average.

The most frequent symptoms after COVID-19 vaccination were pain and fever. MG symptoms worsening was observed in eight cases (7.7%), more frequently in those with MuSK antibody. Most of the worsening was considered mild and spontaneously resolved in 75% of cases. Overall, there were no differences in disease severity class when MGFA-PIS was compared before vaccination and at the last follow up.

This study supports the safety and tolerability of COVID-19 vaccination. Limitations of this study include its retrospective design, which may result in underreporting of symptoms. Still, the very low numbers of reported complications in this population are reassuring and in-line with what is expected given the safety of other vaccines for patients with MG. The cohort measured in this study had a rather long disease duration and most of the subjects had well controlled MG symptoms, so the generalizability of this data may be limited.

Patient Reported Experiences as reported by an International MG Patient Council

In a unique analysis led by an international group of professional MG advocates who also have MG themselves, Law et al.[iii] sought to identify common experiences as described by patients who are diagnosed with MG, with the hope that it will enhance the understanding of MG. Data on patient reported experiences was gathered from three different resources: prospective interviews between Nov 2019 & Jan 2020, a Patient Council meeting report from September 2019, and 32 peer-reviewed research publications that present patient-reported outcomes or experiences of living with MG. The collated insights and quotes were organized based on how the Patient Council members considered them to represent the patient perspective of MG. Domains were constructed at the start of analysis and adjusted during the analysis to help consolidate common themes identified in the patient insights. The authors clarify that care was taken to accurately represent source data, minimize researcher interpretation and avoid changing the meaning of the insights. Quotes were used to explain the insights.

114 insights and 50 quotes were recorded from 54 people affected by MG. This included 48 people with generalized MG and six caregivers. Nine domains were identified: physical; psychological; social; reproduction and parenting; activities and participation; controlled and not controlled; flare-ups and myasthenic crises; treatment burden; and unmet needs. The Patient Council identified five themes that best represented the patient experience: (1) living with fluctuating and unpredictable symptoms, (2) a constant state of adaptation, continual assessment and trade-offs in all aspects of life, (3) treatment inertia, often resulting in under-treatment, (4) a sense of disconnect with healthcare professionals, (5) feelings of anxiety, frustration, guilt, anger, loneliness and depression. The Patient Council also identified several positive outcomes observed in patients with MG, including opportunities for personal growth, better coping strategies and the opportunity to help others through peer-support.

While the Patient Council took extra steps to maintain accuracy and limit researcher bias, they acknowledge that the inherent nature of the study design may limit the variability of responses and decontextualize insights during data extraction. The small number of patients included in the study may also limit generalizability of the study. Nonetheless, the authors' hope is that this novel, patient-led patient reported experience summary may lead to better understanding of what it is like to be living with MG.

The long awaited BeatMG study results: Rituximab for AChR Antibody positive generalized Myasthenia Gravis did not show benefit in achieving favorable outcome compared to placebo

Rituximab has been used for many antibody mediated illnesses, including neuromuscular diseases. In this phase 2 controlled clinical trial,[iv] the BeatMG study team sought to clarify if administration of rituximab for AChR antibody positive generalized MG would lead to more frequent achievement of favorable outcome defined as tapering of prednisone and improvement of disease severity. Participants

were randomized to receive rituximab or placebo, with stratified randomization based on baseline prednisone and concomitant immunosuppressive therapy so that participants in both groups have similar baseline treatments. The treatment group was given a dose of four weekly rituximab infusions followed by a second cycles of four weekly infusions six months later while the placebo group received vehicle components (without true medicine). If the patient had stable or improved disease based on the Myasthenia Gravis Composite (MGC) score at week 8, prednisone dose was tapered. The primary outcome was the proportion of participants with greater than or equal to 75% reduction in mean daily prednisone at weeks 49 to 52 compared to the baseline without disease worsening. Another primary outcome was the safety of rituximab treatment. The trial used a futility design to determine whether larger phase 3 trial is warranted or not.

Total 52 participants were randomized, 25 to rituximab and 27 to placebo groups. Participants were enrolled at 16 centers across the United States between August 2014 and July 2016 and followed for 52 weeks. Mean age was 55 ranging from 21 to 90. Baseline immunosuppressive therapy was well matched between groups. Disease severity was predominantly mild (MGFA class II by approximately 60% in each group). Placebo group had significantly lower disease burden at baseline compared to rituximab group based on disease severity scales and proportion of participants with minimal symptom. The primary outcome of effective steroid taper with stable disease was achieved in 60% of subjects in the rituximab group versus 56% in the placebo group. Since the groups responded similarly, the futility endpoint was achieved ($p = 0.03$). This result means that it is unlikely that the subsequent larger trial would demonstrate a clinically meaningful steroid sparing effect of rituximab.

Despite this negative trial, researchers have learned many valuable lessons. The trial design and the milder disease severity of participants may have limited the ability to measure a clinically significant response. The dramatic response rate and disproportionate fraction of individuals with milder disease in the placebo group were unanticipated and likely affected the study results. Although most of the primary and secondary outcomes were comparable between groups, the rate of MG exacerbation requiring rescue therapy was threefold higher in the placebo group when compared to the rituximab group, when baseline differences were accounted for. This observation suggests that the disease course was more stable in the rituximab group compared to the placebo group while tapering the prednisone. Safety profile was similar between rituximab and placebo groups. Further studies including the ongoing observational post-intervention study are needed to define role of rituximab in generalized AChR MG treatment.

[1] *Kim Y, Li X, Huang Y, Kim M, Shaibani A, Sheikh K, Zhang GQ, Nguyen TP. COVID-19 Outcomes in Myasthenia Gravis Patients: Analysis From Electronic Health Records in the United States. Front Neurol. 2022 Mar 28;13:802559. doi: 10.3389/fneur.2022.802559. PMID: 35418937; PMCID: PMC8996116.*

[2] *Farina A, Falso S, Cornacchini S, Spagni G, Monte G, Mariottini A, Massacesi L, Barilaro A, Evoli A, Damato V. Safety and tolerability of SARS-Cov-2 vaccination in patients with myasthenia gravis: A multicenter experience. Eur J Neurol. 2022 Apr 7. doi: 10.1111/ene.15348. Epub ahead of print. PMID: 35390184.*

[3] *Law N, Davio K, Blunck M, Lobban D, Seddik K. The Lived Experience of Myasthenia Gravis: A Patient-Led Analysis. Neurol Ther. 2021 Dec;10(2):1103-1125. doi: 10.1007/s40120-021-00285-w. Epub 2021 Oct 23. PMID: 34687427; PMCID: PMC8540870.*

[4] *Nowak RJ, Coffey CS, Goldstein JM, Dimachkie MM, Benatar M, Kissel JT, Wolfe GI, Burns TM, Freimer ML, Nations S, Granit V, Smith AG, Richman DP, Ciafaloni E, Al-Lozi MT, Sams LA, Quan D, Ubogu E, Pearson B, Sharma A, Yankey JW, Uribe L, Shy M, Amato AA, Conwit R, O'Connor KC, Hafler DA, Cudkowicz ME, Barohn RJ; NeuroNEXT NN103 BeatMG Study Team. Phase 2 Trial of Rituximab in Acetylcholine Receptor Antibody-Positive Generalized Myasthenia Gravis: The BeatMG Study. Neurology. 2021 Dec 2;98(4):e376–89. doi: 10.1212/WNL.0000000000013121. Epub ahead of print. PMID: 34857535; PMCID: PMC8793103*




Living with Generalized Myasthenia Gravis (gMG)?

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

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

Ra Pharma now a part of UCB

Annual MGFA National Patient Conference
Features Latest MG Guidance

The annual National Patient Conference is the largest and most complete gathering of members of the MG community, including patients, caregivers, MG experts, medical professionals, researchers, and industry partners.

This two-day event is open to anyone worldwide and featured presentations by prestigious medical professionals and MG experts, dedicated volunteers, and consultants who provide wellness and financial guidance to attendees.

This year the conference was held on February 10 and 11, 2022. The conference featured research information, patient stories, updates on MG treatments and discoveries, and many exciting and informative topics to help you and your family navigate your MG journey.

Topics included:

- Navigating the ER and other emergencies
- Navigating an MG crisis as a caregiver
- Insight into rare forms of MG
- A Q&A on pediatric MG
- New treatment options and clinical trials

If you weren't able to make it, you can watch recordings of all sessions for free by registering via the event portal at bit.ly/3GKjpz3. Take a look at the agenda at bit.ly/3miWpxr.

MGFA Volunteer Awards
Recognize Dedicated MG Community Members

Congratulations To The 2022 MGFA Award Recipients:

Volunteer of the Year
Tom Larsen
Volunteer and MG Patient

Impact Award
Paul Strumph
Volunteer, Board Member, and MG Patient

Ellsworth Award
Nancy Law
(posthumously)
Former Volunteer, Board Chair and CEO

Medical Professional of the Year
Dr. Jefferey Guptill
Associate Professor of Neurology at Duke University School of Medicine

Ambassador of the Year
Adrejia L.A. Boutté
Volunteer and MG Patient

Emerging Leader Award
Toni Gitles
Volunteer, MG Patient, and MG Caregiver

Outstanding Service Award
Michael Lifshitz, Dr. Jeffrey Guptill, and Annette Zampelli
Ending Board Members Terms

Strategic Partner of the Year
argenx
Pharmaceutical Company

At the annual patient conference in February, MGFA recognized some of our shining stars - our volunteers and partners.

These special people and organizations were honored for their deep commitment to MGFA and the MG community through patient advocacy, unprecedented medical advancements, and positive impact on those living with MG, their caregivers, and others across the community.

"Our conference brings hundreds of people together from around the world and across the entire MG community, and I can't think of a better forum to recognize these wonderful recipients and shine a spotlight on their commitment to anyone living with or fighting against myasthenia gravis," said MGFA President and CEO Samantha Masterson. "It is also with great sadness that we posthumously recognize Nancy Law to showcase her one-of-a-kind legacy and leadership as our past board chair, CEO, and an invaluable advocate for MG patients everywhere. Congratulations to all our award winners."

VYVGART®
(efgartigimod alfa-fcab)
Injection for Intravenous Use
400 mg/20 mL vial

Picture your life in motion

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.

argenx

Bringing the MG Medical World Together for the 14th MGFA International Conference

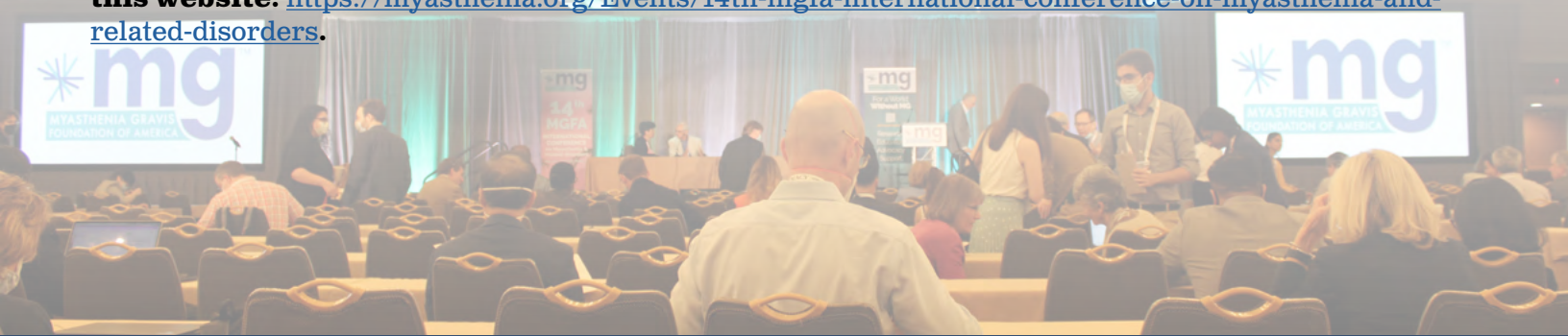
Every three years, medical professionals and researchers from around the world come together to share myasthenia research, progress, and new discoveries at the MGFA International Conference. This year, we gathered in Miami, Florida at the 14th MGFA International Conference held on May 10 – 12.

This conference is the premier space for MG experts to discuss their latest findings, promoting global scientific collaboration and discovery – and what made it even more exciting is the fact that attendees met in person for the first time in several years.

We were excited to welcome Angela Vincent, a giant in the field of neuroimmunology, as our keynote speaker. Dr. Vincent's research over the past 35 years has contributed to our understanding of the role of antibodies in neurological disease. Among other work, she defined and characterized a new form of myasthenia gravis associated with antibodies to a receptor tyrosine kinase, MuSK, that performs an important maintenance role at the neuromuscular junction.

Other critical topics included the latest therapeutics, biomarkers for MG, autoantibodies, updates in MG management, pediatric MG, and patient case studies. Presenters joined us from 50 countries around the world and included some of the top MG experts from MGNet, Partners in Care, and the most prestigious university medical centers and healthcare institutions/hospitals.

You can read the many intriguing abstracts and presentations as well as the run of show on this website: https://myasthenia.org/Events/14th-mgfa-international-conference-on-myasthenia-and-related-disorders.



MGFA Support Groups

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

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

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

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

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

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

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

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

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

Female Chief of Cherokee Nation Lived with MG

Watch for the new American Women Quarters Series from the US Mint featuring Wilma Mankiller, first female chief of the Cherokee Nation who lived with Myasthenia Gravis. Learn more about this upcoming opportunity at the following link:

www.usmint.gov/coins/coin-medal-programs/american-women-quarters/wilma-mankiller

www.janssen.com

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Coast-to-Coast Challenge "ROOKIE OF THE YEAR" Finds Power in Sharing Her Story

By Kate Stober

For newly diagnosed MG patient Priscilla Forrester, participating in the 2021 Coast-to-Coast Challenge was more than a chance to raise much-needed funding for the MGFA's mission. It was a way for her family and friends to truly understand what having myasthenia gravis is all about.

Priscilla's MG diagnosis was confirmed just as the pandemic hit the U.S. in March 2020. She spent most of that year inside her apartment, adjusting to her diagnosis, her new medications and the reality of pandemic life. After receiving her COVID-19 vaccine, she began to venture out.

"I hadn't been outside much to see how my medication had been helping me," Priscilla shares. "Before I started the medication, I could hardly walk a block without getting spent."

During this time, she found out about the Coast-to-Coast Challenge. She liked the idea of giving herself a training goal and seeing if she was up for the challenge of a short walk.

She also liked the idea of speaking publicly about what she was going through. Although Priscilla was diagnosed with MG in 2020, she had been suffering confusing and debilitating symptoms for five long years.

"I can recall one time, I was going to a holiday party and I was carrying trays of food in my hands, and my arms just couldn't hold the weight of it - it was just a couple of pounds. All this food I cooked almost dropped to the floor. I could feel my arms getting weaker and weaker."

For a time she brushed off her muscle weakness and exhaustion, assuming these symptoms were related to her busy and stressful job. When she finally sought help, she found doctors were dismissive of her concerns. MRIs and other tests were normal or inconclusive – her neurologist suggested physical therapy.

It was three years before a functional medical doctor ran an extensive panel of bloodwork and found her acetylcholine levels were high – a hallmark of MG. Even with these test results in hand, her neurologist was reluctant to believe the evidence. It finally took a switch to a new neurologist who specializes in MG to get the diagnosis and the care she needed.

"I felt like I was suffering in silence during that five year span. I wasn't even talking to friends and family because I didn't have words to put to it. I wasn't really telling anybody."

For that reason, being part of the MGFA Coast-to-Coast Challenge mattered to Priscilla. Participants invite friends and family to join their team and walk with them, in addition to fundraising online. Participating is an opportunity to share with your community that you have MG – and tell them how the disease impacts you.

"As soon as I started posting about it, the outpouring of responses from family and friends was overwhelming. Concern, of course, but people really asking about what I was going through. That was very comforting and healing to me. Going on this journey of raising the money and being vocal about it really helped family and friends understand what to do, what the symptoms are – they check on me."

A cousin helped Priscilla develop an online presence to share her MG story on social media platforms, especially Instagram.

When the 2021 in-person Coast-to-Coast Challenge was canceled because of the pandemic, Priscilla created her own three-mile loop on the waterfront near her home in Washington, D.C. She invited friends and family to join her, and about 15 came from far and near to walk. She streamed the walk live, so her donors could participate virtually.

Priscilla's team was a top-ten fundraising team – a huge accomplishment considering it was her first time participating in the Coast-to-Coast Challenge. She was asked to speak at the virtual Coast-to-Coast Challenge event, sharing her story for others in the MG community.

"Priscilla was our unofficial Rookie of the Year," says Tasha Duncan, national director of field development at MGFA.

Priscilla says that her decision to do the challenge has motivated her through her healing process, both physically and mentally.

"It's continuing to open doors that I didn't even know I wanted to open. One of my friends said, 'You're doing work that you didn't know you needed to being doing, and it's making a difference.'"

My Doctor Says "Always Try to Get the Patient Back to Water Skiing".

By Jane Marla Robbins

To the MGFA,

Thank you for being there. I am happy to share this poem I have written, as it seems to give some hope and make people happy.

Gratefully. Sincerely,

Jane Marla Robbins

WATER SKIING INTO THE NEW YEAR

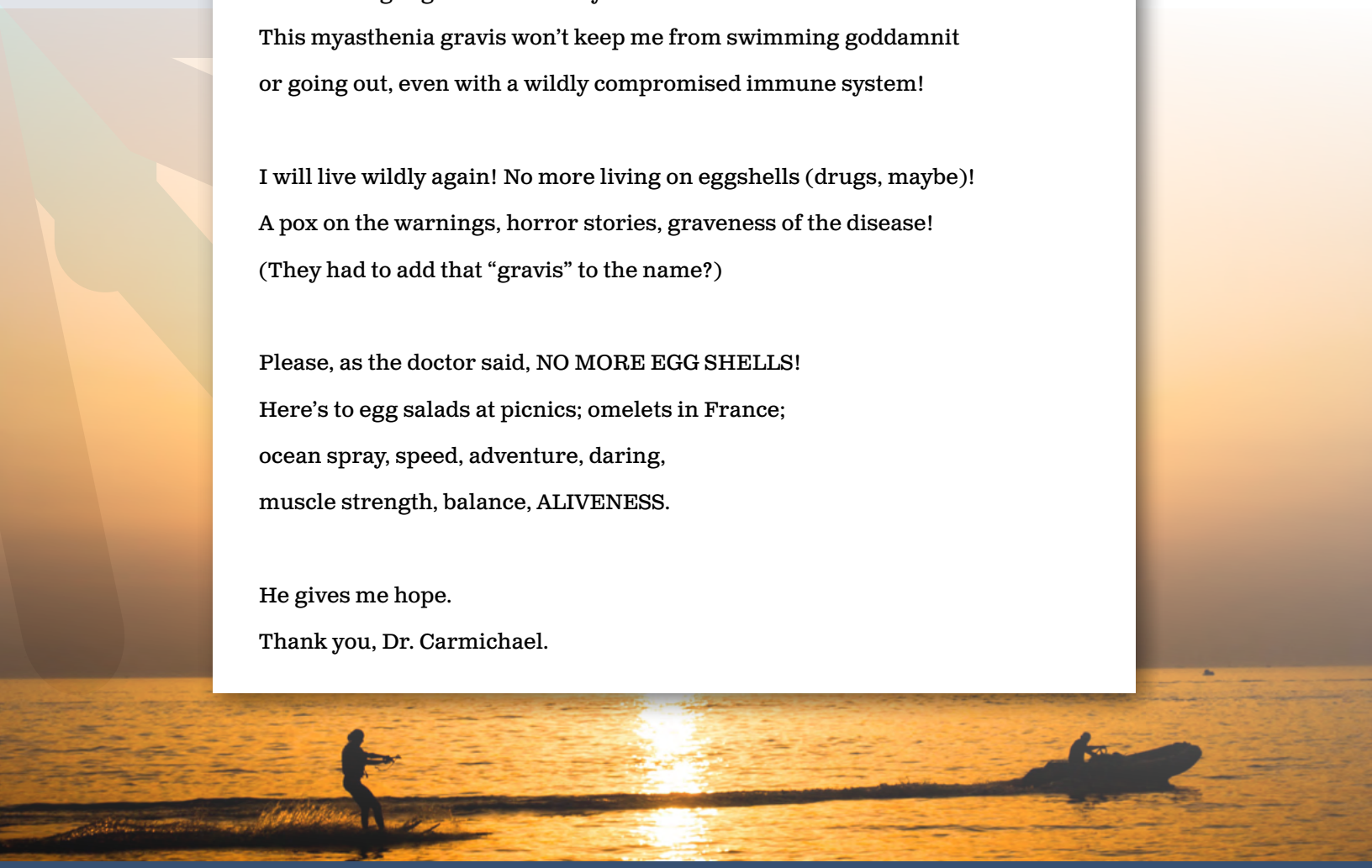
"The goal with myasthenia is always to get the patient
back to water skiing." Dr. Stanley Carmichael

Water skiing! Again? Wind in my face! Aliveness!
This myasthenia gravis won't keep me from swimming goddamnit
or going out, even with a wildly compromised immune system!

I will live wildly again! No more living on eggshells (drugs, maybe)!
A pox on the warnings, horror stories, graveness of the disease!
(They had to add that "gravis" to the name?)

Please, as the doctor said, NO MORE EGG SHELLS!
Here's to egg salads at picnics; omelets in France;
ocean spray, speed, adventure, daring,
muscle strength, balance, ALIVENESS.

He gives me hope.
Thank you, Dr. Carmichael.



MY MG STORY: DIAGNOSED AS A TEEN, EMILY'S MG IS IN **REMISSION** THANKS TO THYMECTOMY

By Kate Stober

While myasthenia gravis can strike at any age, it's not as common in children - only one in 10 cases are diagnosed in children under 10 - and symptoms may present differently than in adults.1 Because of this, young people with MG face an especially difficult time getting an accurate diagnosis.

Emily Boyle was only 14 when she began exhibiting symptoms.

"She mentioned to me that she was having trouble smiling," says Emily's mom, Betsy. "I thought it was weird, but I kind of ignored it."

Over the next several weeks, Emily's difficulty moving her facial muscles became more and more noticeable to her family. Betsy took her to the pediatrician, who immediately referred them to a pediatric neurologist. That doctor - and others they saw that spring - were stumped.

After a volley of tests to rule out more common diseases and disorders, her doctors began to suspect MG.

She was started on Mestinon, a common MG medication to combat muscle weakness. The medication helped control her symptoms, but they didn't go away entirely.

"I don't feel that I was impacted that much because I was so young," shares Emily. "Except numbness in my bottom lip — I wanted to be able to smile. I wanted to feel more normal. I remember a lot of people looking at me and trying to figure out what was wrong."

By the time she started high school that fall, her symptoms had worsened dramatically and were impacting her quality of life. It became hard for her to eat and talk, as she lost control of the muscles in her face, jaw, and throat. If she got a cold, she'd struggle to breathe because she couldn't cough.

Betsy and her husband, Tom, began a deep-dive into MG, exploring every corner of the internet in their quest to help Emily. In their online travels, they found MGFA and its resources and supports.

"I remember reading little stories and realizing more what myasthenia was," says Emily. "I did a lot more research, and it was eye opening to see that all of these other people have myasthenia. To me, it was comforting."

Finding Treatment

Betsy and Tom called specialist after specialist trying to find a treatment that would work for Emily.

"I was making calls all over the place trying to get appointments with people," says Betsy.

After several months of searching, Emily secured an appointment at Johns Hopkins Medicine in Baltimore, Maryland. The experts there were able to conduct a same-day test on site to definitively confirm Emily's diagnosis.

Their neurologist recommended increasing Emily's Mestinon dosage and undergoing a thymectomy, which is the surgical removal of the thymus. This gland plays a role in the production of antibodies and, when producing antibodies beyond childhood, can trigger myasthenia. Removing the thymus has improved symptoms in some patients and is a strategy for long-term disease remission.

Her parents were nervous, as any parent would be when considering surgery for their child. Betsy says their doctor convinced them that this approach would give Emily the best chance of dramatically reducing or even eliminating her symptoms.

"I was very relieved when we got to Baltimore," Emily says. "I was ready to get the surgery and move on."

Her surgery went well, and within just a few days she was able to be discharged. While Emily remembers the pain and discomfort of recovery, she also remembers feeling more like herself within a few weeks.

The surgery and continuing on Mestinon for several years made a huge difference in Emily's symptoms. She is now in remission and no longer on medications.

"The thymectomy changed everything for the better. I would highly recommend it."

Emily is now a high school Spanish teacher and spends her days standing in her classroom, talking to her students — a career that might have been impossible without this life-changing treatment.

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Betsy agrees.

"It was a remarkable godsend that we will forever be grateful for and we can't express in words," she says.

"We're eager to give back in some way now, including supporting MGFA and trying to make it easier for newly diagnosed patients to learn more about thymectomy. It changed the whole course of Emily's life. It's worth pursuing and asking multiple neurologists about it."

1- Source: https://www.chop.edu/conditions-diseases/myasthenia-gravis

A PATIENT'S PERSPECTIVE ON MUSCLE CRAMPING

By Rebecca Molitoris

I've been living with myasthenia gravis for 66 years now, 26 of those years without a diagnosis. Muscle cramping was always a consistent symptom that I never associated with MG. In fact, early in my diagnosis when I asked my neurologist about my frequent cramping, he stated that he didn't think it was part of MG and that none of his other patientzs complained about them (sigh).

Just to be clear, I'm not talking about the occasional Charlie horse that everyone gets now and then, but a crippling kind of cramping that contorts my feet, hands, legs, and sometimes even my tongue into a shape that I would be unable to do otherwise. Sometimes the cramps last for a few seconds or minutes, but sometimes they go on for hours, inflicting a special type of exhausting pain that is both frustrating and agonizing.

When I started to talk to other MG patients, I found that they do indeed complain about muscle cramping. In fact, almost everyone of them had experienced the type of severe muscle contortions I was living with. In the support groups I lead, it is the second most talked about problem, following closely behind general weakness.

This fact led me in search of answers. Some of the common causes of muscle cramps are dehydration, electrolyte imbalances (sometimes caused by high-dose prednisone), Mestinon™ (pyridostigmine bromide), and overuse. Since I had experienced this cramping even before I was diagnosed and placed on Mestinon™ and steroids, and most of my muscle cramping occurs after extended muscle use, I believe my major source of the cramping is overuse.

The problem is that I can't tell, even now after all these years, how much use is overuse. Some days I can type for hours, or bike a few miles on my stationary bike, or stand for a long time with nary a cramp. Other days a quick drive to the grocery store or doing some drawing or knitting will provoke hours of cramping. I try to set limits for myself and my energy so that I don't get so weak that my muscles complain. I've learned that sometimes I must stop in the middle of a project and leave the rest for another day to avoid the dreaded cramps and accompanying weakness. I also try and drink enough water to avoid dehydration which can certainly aggravate the cramps.

As with any type of advice given here or at a support group, this is what works for me. It may not work for you. Check in with your own doctor before trying anything to cure your cramps. Please consult your treating physician, especially if you are frequently experiencing the contortion type of muscle cramping as your doctor may want to check your electrolyte levels. I hope you can find something that works for you.

Looking to connect with others

in the generalized myasthenia gravis (gMG) community?

Making Connections

Education and support for
generalized myasthenia gravis

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

Register at AlexiongMGEvents.com

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

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

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

ALEXION

Catch Up With The **MG Community**

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

www.myasthenia.org

GET INVOLVED

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

MGFRIENDS
PEER-TO-PEER CONNECTIONS

MGFA WEBINARS SERIES

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

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

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

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

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

MYASTHENIA GRAVIS FOUNDATION OF AMERICA

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

www.myasthenia.org

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

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

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