mg™

MYASTHENIA GRAVIS
FOUNDATION OF AMERICA

Broading our Impact
in the MG Community

FY '21 Annual Report

FY21 Annual Report
Leadership Letter

Dear Friends,

We would like to start this letter with an expression of sincere thanks for your trust and collaboration during these dynamic times. Creating a sustainable path to an evolving organization that expands patient and community services, funds impactful research, and that connects our global MG Community can only be achieved through our collective partnership…and our partnership has never been more appreciated. Together we have achieved solid results in 2021 and strengthened our financial stability for the future, as well as our trajectory of growth.

For MGFA, 2021 was marked by the clear objective to support and provide services to our MG Community consisting of education, advocacy, and funding critical research. We did not waiver from these key areas of focus, and we have achieved results by serving as a convener, thought leader, and as the preemptive source of information for patients, clinicians, and the research community. In 2021, MGFA continued to serve a critical role as the leading patient advocacy organization solely focused on MG nationwide. We are extremely pleased to share the expansion of, and growth in, the following areas.

- MGFA funded more than $700,000 in critical research, marking the largest contribution to research in the organization's history
- MGFA expanded programming through additional patient and community services including educational webinars and advocacy efforts
- MGFA continued to build a strong operational structure with high-caliber talent to support the important work of our strategic plan

We are excited to continue our journey of successful and sustainable collaboration with you for years to come. Thank you for your confidence and trust.

With best personal regards and thanks.

Sincerely,

Brian Gladden
Chair
MGFA Board of Directors

Samantha Masterson
President and CEO

Volunteers Who Make an Impact Around Global MG Community

MGFA in 2021: Strength & Growth in the Face of Adversity

What a challenging year it's been… and yet we achieved so much!
At the end of 2020, when we looked ahead to 2021, the pandemic made short-term planning impossible - too many unknowns and what-ifs. So we focused on what we could control and change for the better - building more ways to serve our MG community virtually, developing our organizational infrastructure, and making more funding available to support MG research. We also embarked on developing new programs as well as launching events and campaigns.

By dialing in on the fundamentals, we've been able to continue moving our mission forward and growing the MGFA despite the upheavals of COVID-19. It is truly amazing that we have achieved this level of growth during the COVID era when so many other organizations have faltered. This is a testament to the MGFA's staff and board leadership as well as the many dedicated, committed MG volunteers and partners.

2021 was the year of the COVID-19 vaccine. Data from the MGFA CARE-MG Registry, which recorded COVID-19 infections, symptoms, and outcomes for patients with MG, drove informed recommendations from top scientists that MG patients be prioritized for the SARS-CoV-2 vaccination. Physician-reported data in the registry demonstrated that patients with chronic autoimmune neuromuscular disorders who were on immunosuppressants were more likely to be hospitalized for and die from COVID-19 infections.

We also drove a brand new COVID vaccine survey with hundreds of responses from the MG Community that provided the latest data about the MG Community's usage and perceptions of the COVID vaccines. All this data and information served to help inform medical professionals and everyone across the MG space while strongly recommending that patients obtain the vaccine.

MGFA continued to be a resource for the MG community as we all navigated the post-vaccine world. COVID-19 diagnosis rates plummeted…only to come roaring back not once but twice in 2021. As immunosuppressed people sought support, our medical professional partners provided research-backed guidance around masking, social distancing, and vaccination. MGFA shared stories of those who had received the vaccine, as well as those who had contracted the virus, to help the community better understand the way the virus affects our community.

Serving our MG community virtually has brought surprising advantages.
We've reached people through virtual support groups who weren't well enough to attend an in-person group or able to find one in their area. **A volunteer support group leader launched a Spanish-language group over Zoom, which now welcomes MG patients and their caregivers from Spanish-speaking countries around the world.** We also saw the launch of a new care givers support group and a new seronegative support group. Online technology has helped us to reach a wider set of community members across the world in order to provide the support and guidance they need. In total, MGFA provided guidance for nearly 90 virtual support groups in the United States in 2021.

The MGFA National Patient Conference also touched more patients, caregivers, and medical practitioners as a virtual event. As in 2020, we welcomed **1300 people** through a two-day online experience sharing practical, patient-centric information about MG treatment, research, wellness best practices, and more.

We launched our first-ever Coast to Coast 2740 Challenge virtual fundraising program and drove team participation and fundraising for months leading up to the event. We engaged in an amazing and heartfelt family-led end of year appeal that featured members of the MG Community.

Thanks in part to these programs and the extreme generosity of the MG Community, MGFA received incredible support from donors, foundations, and corporate partners in 2021. Our development team diversified ways to increase revenue to support programs, patient and caregiver education, and research funding. As a result, giving and program revenue increased over $1 million compared to 2020.

MGFA awarded
$764,067
in research
funding in 2021.

+$127,166 **more**
than in 2020.

MGFA awarded $764,067 in research funding in 2021 – creating more opportunities to drive MG research. We prioritized only the most promising, high impact research projects. This level of growth means that more resources will be provided to clinical researchers and medical professionals around the world to find better treatments and potentially a cure for MG in the future. At the same time, we have seen more FDA-approved treatments for MG in 2021 – several of which started by critical involvement by MGFA and funding to drive milestone results and outcomes that led to new discoveries.

Looking into the future...

Growing our internal operating capacity was crucial to MGFA's ability to increase services in 2021. We brought on board Caroline Gayler as national director of development and Tasha Duncan as national director of field development, as well as Amy Peterson as project manager supporting our education, advocacy, and research efforts. Our new national director of finance Daryl Lee also helped to build new internal processes that helped MGFA more accurately target new opportunities. With their leadership, passion, and drive, we're providing more programs and building new fundraising and donor stewardship programs.

2021 also brought leadership changes. We lost our good friend, committed advocate, and board chair, Nancy Law. Nancy passed away in September 2021, and the entire MG community felt the loss. Brian Gladden stepped in to honor her commitment to service and became our new board chair. We welcomed several new additions to our executive board in 2021 as well.

We honored Nancy's long and fierce commitment to the MG community by creating the Nancy Law Impact Award. This grant awards up to $300,000 over three years for research related to MG and other neuromuscular junction disorders. 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. We'll award the first grants in 2022.

When we look back on the year, we can't help but feel proud of all that we've accomplished despite challenging circumstances. It was a year of growth and change, and a year of struggles and loss. Together with our incredible group of volunteers, collaborators, and supporters, we continue to make strides, to come together, and to pursue our important mission.

The Myasthenia Gravis Foundation of America at a Glance

The Myasthenia Gravis Foundation of America (MGFA) is the largest, leading patient advocacy organization solely dedicated to finding a cure for the rare neuromuscular disease myasthenia gravis (MG) while improving the lives of people living with MG. MGFA is focused on funding the most promising research discoveries for better treatments and a cure while providing impactful programs, guidance, and education to help support members of the MG Community.

More than

70,000+

people are diagnosed and living with MG in the United States alone

We provide more than

85 MGFA-sanctioned support groups,

led by patients and caregivers, to help those with MG navigate the challenges of the disease

We service and communicate with more than

90,000 contacts

around the world

MGFA conducts

12 **Wellness Webinars**

6 **research-based update webinars per year**

MGFA utilizes **Facebook, LinkedIn, Twitter, YouTube, and Instagram** to communicate our programs and events to

more than 24,000 fans and followers

We issue **12** **monthly eNewsletters per year**

2 **Focus on MG magazines**

In 2021, MGFA funded more than

$750,000 **in research grants**

We maintain the ***only*** U.S. MG Patient Registry that has grown to include over

3,500+ participants

MGFA offers:

- **an Annual National Conference**
- **Scientific Session**
- **5 Regional Conferences**
- **an International Conference every 3 years**

We provide more than **25** **different educational and informational brochures on treatments, cautionary drugs, MG facts, and MGFA-related information.**

MGFA's website **myasthenia.org** contains extensive educational content and news as well as materials, a blog, resources and guidance that drives more than **850,000 pageviews and 686,000 unique pageviews per year.**

We distribute

100+ national emails

each year.

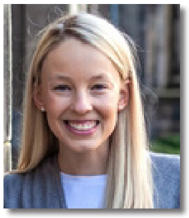
Foundation News

MGFA Staff Grows and Evolves

This year we expanded our professional bench of talent and expertise.

Tasha Duncan - National Director of Field Development

Tasha brings more than 15 years of non-profit development experience to MGFA as a multi-faceted fundraising professional. She has served as a frontline fundraiser for two different multi-million-dollar capital campaigns. She brings a wealth of experience in development operations, such as corporate sponsorship support, peer to peer fundraising and event management. Prior to her time at MGFA, Tasha was the Director of Major Gifts at Lutheran Medical Center – SCL Health, and before that she served as the Director of Regional Development, Southwest for the National Brain Tumor Society. As the National Director of Field Development for the MGFA, Tasha will be working directly with donors, volunteers and staff, leading strategic fundraising initiatives throughout the country to support MGFA's mission and goals.



Caroline Gayler - National Director of Development

Caroline is the Director of Development for MGFA. Her passion is understanding the interests of each donor she works with, and learning how best to connect their passions with investing in our mission. She has worked for multiple health-related non-profit organizations in development, including her most recent role at March of Dimes, and has served as a global health consultant for various international organizations. Caroline has a master's degree in Global Health Implementation with a focus on reproductive health highlighted through her research work. As the Director of Development at MGFA, Caroline works directly with donors to share the impact of their giving and aid donors in reaching their philanthropic investment objectives.

Daryl Lee - National Director of Finance

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

Amy Peterson - Project Manager

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

MGFA Board of Directors

Experiences Change and Evolution

In Memory of Nancy Law

Our dear friend Nancy Law passed away on September 23rd, 2021. She touched us all in so many meaningful ways. It is impossible to express how significant this loss was, as she was someone who truly cannot be replaced. Everyone was always so thankful whenever we had the opportunity to speak to or engage with Nancy.

She was a cheerleader for the MGFA, for MG patients, and for the entire MG Community. You did not need to know her for long to feel her warmth and caring. She made complete strangers feel like old friends. Everyone was important to her. She will be missed for her knowledge of MG and the history of MGFA. But most of all, she will be missed for her incredible personality and spirit that was always positive and uplifting.

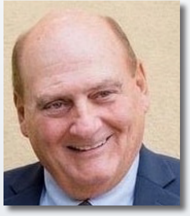
Nancy served as CEO for the Myasthenia Gravis Foundation of America from March 2016—February 2020 and was appointed Board Chair in 2020. She was a board member for the organization for 8 years prior to accepting the CEO position. Nancy retired in 2015 from a 28 year career with the National Multiple Sclerosis Society, where she served as an Executive VP. Diagnosed with MG in 1996, Nancy wa ed consultation to the pharmaceutical industry on program design and strategies to enhance patient/physician communication.

Thank you to those who left a message on our website Tribute Wall in honor of Nancy. Your lovely tributes are a testament to just how remarkable she was and how deeply she is missed. See the wall using the link below. https://myasthenia.org/MG-Community/In-Loving-memory-of-Nancy-Law

Board Update

With the unexpected passing of Nancy Law, the MGFA Board of Directors experienced change and continued to evolve by bringing in a new member while shifting responsibilities and roles of other Board members.

Brian Gladden now serves as Chair of the MGFA Board of Directors, and is the Chief Financial Officer for Zelis, a Bain Capital and Parthenon Capital sponsored healthcare technology company.



Bill Sauerwine is the Vice Chair of the MGFA Board of Directors. After more than 30 years of serving as President and CEO of W.J. Sauerwine Custom Homes, Inc., Bill retired in 2017.

Justin Stachtiaris joined the MGFA Board of Directors in 2021. He is currently an Associate at Bain Capital in their Healthcare Private Equity Group.

2021 GIVING CIRCLE DONORS

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Lynn Trahan
Marcia Campbell
Pat Shea
Paula and Kert Sorber
Rodney Pope
Tim Reynolds

Thank you to all of our donors. With your generous gifts, we are able to contiue supporting the MG community while also investing in research to find a cure.

If you would like to learn more, or become a donor, please contact Caroline Gayler at CGayler@myasthenia.org.

Generating New MG Research Funding and Rewarding the Most-promising Studies

Research Agenda

We support research that will improve the lives of patients with myasthenia gravis and related neuromuscular junction disorders. The committee has identified five broad research priorities:

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

Grant Programs Summary

We support research that will improve the lives of patients with myasthenia gravis and related neuromuscular junction disorders. We have identified five broad research priorities:

1. Biomarkers
2. Disease Mechanisms
3. Targeted Therapies
4. PatientOutcomes
5. Pediatric Treatment

Grant Funding Areas

- High-Impact Pilot Project Awards: pilot studies leading to new federal, pharmaceutical or private foundation supported investigations
- Transformative Research Awards: focused, innovative investigations that are highly likely to produce fundamental alterations in understanding myasthenia gravis
- Targeted Research and Special Projects Awards: further greater understanding of MG and its impact on quality of life
- Awards to Engage and Support Young Investigators and Clinicians: recognize the importance of good clinical research and encourage young investigators’ involvement in clinical studies

2021 MGFA Research Grant Recipients
Congratulations to Our Researchers!

The use of Survivin as a Diagnostic Marker for for Myasthenia Gravis

Dr. Linda Kusner M.D.
The George Washington University
(Committed $55,000 per year for 2 years)

Nine percent of patients with myasthenia gravis (MG) cannot have a clinical diagnosis confirmed by laboratory testing for detectable antibodies, designated seronegative MG (SNMG). We have found the expression of survivin in circulating lymphocytes to correlate with the diagnosis of acetylcholine receptor antibody-positive (AChR+) MG. We have also found survivin expressed in circulating lymphocytes from patients with muscle specific kinase antibody-positive (MuSK+) and rigorously defined SNMG patients, demonstrating the potential of survivin positivity as a diagnostic marker for MG. We propose to confirm positive survivin expression in circulating lymphocytes for the context of use as a diagnostic adjunct for MG.

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

Dr. Laura Mandik-Nayak M.D.
Lankenau Institute for Medical Research
(Committed $55,000 per year for 2 years)

Myasthenia gravis (MG) is widely recognized as a B cell-mediated disease, with autoantibody production critical to its development and progression. While there has been intense interest in the development of therapies that deplete B cells or prevent B cell activation, these therapies are not effective in all patients and there is a continued need for new therapies. In this proposal, we will use a preclinical model of MG, together with a novel IDO2-targeting approach, to explore IDO2 inhibition as a novel therapeutic strategy to treat MG. In the short term, our studies will provide an initial step in the preclinical evaluation of IDO2 as a therapeutic target in the treatment of MG. If successful, the potential longterm impact of this project would move the concept of IDO2-directed therapy into development as a novel strategy to treat human MG.

MGFA Conferences

Moved Ahead Despite the COVID Pandemic

MGFA Coast-to-Coast 2740 Challenge

Combining the Power of MG Walks with Fundraising to Find Better MG Treatments and a Cure

In the face of COVID-19, the MGFA established the unique Coast-to-Coast 2740 challenge. It is 2,740 miles from Los Angeles to New York City – a journey no one person can take alone. Members of the MG Community came together and raised funds for the November 13th event.

MGFA's Annual National Conference Showcases Momentum Against MG

The annual MGFA National Conference is a time to bring members of the MG Community together for the largest gathering of MG patients, caregivers, myasthenia specialists, MG-focused organizations, and volunteers in the world. It is similar to a reunion of friends and colleagues who truly enjoy coming together and engaging in all things MG.

Yet, like the 2020 edition, this year's conference in April was held online and in the middle of the continuing COVID-19 pandemic. But that did not stop the more than 1300 registered attendees from joining and experiencing a packed agenda of medical experts, volunteers and patients, consultants, and industry presenters. Though our attendees could not come together in person, they enthusiastically chatted, shared stories, discussed symptoms and guidance, and listened to three days of presentations that informed and inspired them. The conference truly offered multiple examples of Momentum Against MG.

Our attendees are always extremely excited about MGFA's Award recipients. The award presentations are consistently one of the major highlights of the conference each year. This year, the awards were revised and new ones were created to recognize and acknowledge the incredible, selfless achievements that our volunteers strive for each year. These award winners show their love and passion for the MG Community through

their partnership and support of the MGFA and everyone who is living with MG.

Congratulations

To All Our 2021
Award Winners!

Volunteer of the Year
Pierre Clement

Ambassador of the Year
Kim Eldridge

Emerging Leader Award
Jessica Milanes

Medical Professional of the Year
Dr. James “Chip” Howard

Outstanding Service Award
Denise Rossi

Corporate Partner of the Year
UCB Pharmaceuticals

Impact Award
Brian Gladden

Ellsworth Award
Marc Kalish

MG Awareness Month 2021

Turning Awareness into Action

June is MG Awareness Month around the world. It is an important time to Take Action and create awareness and understanding of the challenges and opportunities faced by everyone in the MG Community. This year, we actually changed the theme of MG Awareness Month to “MG Action Month – Turning Awareness into Action” - and offered specific calls to action for the MG Community and beyond to find creative ways to show that **WE ARE SO MUCH MORE THAN OUR MG.**

MGFA created an online Action Toolkit this year and a number of tools were made available this year including sample PROCLAMATIONS and advocacy tools, LIGHT UP THE WORLD IN TEAL, MEDIA COVERAGE OF MYASTHENIA, PAINT N’ SIP Night, the MGFA COOKBOOK CHALLENGE, the MGFA T-SHIRT DESIGN CHALLENGE and SOCIAL MEDIA streams.

Shine Bright for MG

Give Presentations

Volunteer

Get Crafty

A Little Goes a Long Way

*mg™

~~AWARENESS~~

ACTION

MONTH

Turn awareness into action this June!

Patient Stories from our MG Community

GOLFING FOR GOOD

In three years, Jeff Abramson's DIY golf tournament in memory of his wife Patti has raised over $70,000 for MGFA.

When he decided to host a charity golf tournament for MG awareness, Jeff Abramson had never organized a major event before. His wife, Patti, had recently passed away, and a friend suggested that a tournament would be a meaningful way to channel their grief. Jeff and Patti had recently retired to a golf community in Sarasota, Florida, where they'd visited and played regularly over the previous eight years.

Though a novice organizer, Jeff approached the staff at the golf community about hosting the tournament. Their support encouraged him and his friend Liz Kinnisten to pursue the idea. Patti's father, Bob Medlar, and brother, Dave Medlar, who also live in Florida, were on board. Friends and family helped out tremendously.

"The first year was word of mouth through the clubhouse, and family and friends came down from New York," Jeff said. "We took home $17,000. We were really shocked about that. It's pretty much a mom and pop operation."

The second year, they raised an incredible $29,000 to support MGFA's mission.

This year was different. At first Jeff wasn't sure they could host the tournament because of the pandemic. He felt strongly that if they didn't, they'd lose the momentum they'd built among their community the previous two years. With support of the golf pro and other staff, the community's board of directors let them proceed with a smaller tournament with adjustments for health and safety.

"We usually have a shotgun so it goes faster, but we had different tee times," Jeff said, allowing the groups to socially distance. Only 18 foursomes were allowed to play — short of the 100 golfers who'd participated the previous year. Fun activities like 50/50 raffle, putting contest, longest drive award, raffles, beer and snack stops on the course, and the post-tournament dinner proceeded as usual.

Despite the circumstances, the tournament's dedicated donors help them raise $24,000 to support MGFA.

And that's what matters to Jeff.

Patti passed away from stomach cancer, but she suffered from MG her entire life. To Jeff, raising awareness of the disease that Patti fought and conquered — she was a successful controller and small business owner who didn't let her illness define her — is the most important part of the event.

"Nobody really understands or knows what MG is. When we first did this, 95% [of the participants] had no clue what MGFA was." Now, hundreds of players and donors know what MG is and how MGFA makes a difference.

The 2020 golf outing ended just as those in 2018 and 2019 had — sending up balloons in the MGFA colors, and thinking of Patti.

The next Patti Abramson Golf Outing is scheduled for October 22, 2021. If you live in the Sarasota area and would like to attend next year's outing, please contact mgfa@myasthenia.org. Registration is $100 per golfer and includes dinner. A sponsorship fee of $500 includes four golfers and a tee sign.

My Mg Story: Diagnosed As A Teen, Emily's Mg Is In **Remission** Thanks To Thymectomy

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.

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."

Hungarian Mg Patients

Use Social Media To Connect Across The Miles

Hungary is a country of about 10 million people, and there are only 2,000 people diagnosed with myasthenia gravis. If you're diagnosed with MG in Hungary, there's a slim chance you'll never run into another MG patient.

But thanks to the magic of social media, connecting with others is just a click away.

Hungarians living with MG have gravitated to a Facebook group called Myasthenia Gravis Positive Vibes started by Zoltan Lelkes, an MG patient who has been living with the disorder for about 30 years. Zoltan is an example for other patients to follow because, with lifestyle changes, he's been symptom free for a long time - even running a marathon. The support group serves as a place for patients to share symptoms, treatments and how the disease has affected them and their families. Those who are feeling strong check in on - and give hope to - those who are not. They share photos of the places where they live and travel, and they talk about other common interests, like children and work.

The group has become a lifeline for Andrea Ujj, who was diagnosed with MG in June of 2019.

She found out she had myasthenia after collapsing at work one day. The emergency responders who treated her thought it was stress-related — it was the end of the fiscal year, and Andrea shouldered a lot of responsibility as the CFO of a multinational company. But after symptoms persisted, she was admitted to the hospital, where neurological and other tests confirmed she had MG.

"I was shocked," she shared. "I was shocked because I didn't think when I collapsed it was something serious. My thinking was that it could just be burnout. I will never forget the doctor's words: 'It is a rare, incurable disease, but with treatments can be maintained quite well. We can have better quality of life now.'"

After the diagnosis, which was a very difficult time, Andrea joined the Facebook group and got to know Zoltan and many others. She found the discussion extremely helpful as she sought to understand her MG diagnosis.

As part of the learning journey, she also discovered MGFA, and attended several webinars and the virtual conference. She would translate the sessions, sharing valuable information with the Hungarian MG patient Facebook group. She learned that the annual MGFA Walk, which raises awareness and funds for MGFA's mission, was being held October 10, 2020.

"I would like to be part of this event, but I couldn't figure out how to do that because I couldn't travel to America. I had the idea that we could connect virtually," Andrea said.

She raised the idea with the Facebook group,

and received an enthusiastic response. Because it was 2020, and pandemic restrictions were in place, members of the group would walk at the same time, but on their own.

Because of the pandemic, they couldn't make matching t-shirts, but everyone did their own version of official MG walk apparel… from homemade buttons and badges to hand-illustrated t-shirts. Andrea reached out to former colleagues at the printing company where she worked years ago, and within a day they had printed a patch for her, which she sewed on to her shirt.

She travelled with her husband and son to Lake Balaton, a beautiful lake ringed by volcanic mountains. The "Hungarian Sea" is the people's name for this 50-mile-long lake with silky, green-yellow water in the middle of Transdanubia. There are picturesque vineyards in the region. Andrea and her family walked 10 kilometers.

Others in the group walked in their own locations, whether in a park, on a trail, or just in their neighborhoods. Walkers included Istvan Gergely, Bettina Szalai, Zoltan Lelkes, Erika Kiss, Maria Szabo, Krisztina Kohalmy, Csilla Burkus. Vivien Rezes, a Hungarian expat, joined from Hawaii. They were joined by spouses, children, and dogs.

"Everyone shared photos in the group," Andrea said. "There are a lot of people who can't do a walk because they are in bad conditions, but they were happy to see others do the walk. It gave them hope for their own improvement."

Group members shared that being part of a collective experience was important and meaningful. Seventy-year-old Istvan Gergely walked with his wife in a park near their apartment.

"It was an amazing feeling to belong somewhere."

Many others shared that walking is a daily ritual, an important part of their care regime.

"I've been walking for years," said Bettina Szalai. "Every patient has to do some kind of movement."

Zoltan Lelkes agreed.

"Walking makes me feel better. With lifestyle changes, and movement, we can support our bodies. We can have better life conditions as well."

Andrea, Zoltan, and the other members of the group hope they can do another walk in 2021, but in person, together. They also plan to get together for a summit, where they can talk to each other about their illness and connect personally.

For Andrea, the impulse to organize the MG walk in Hungary came from the heart. She was called to be part of a community, to do something to raise awareness for this extremely rare disease.

"My advice would be, if you are not an MG patient but you have the chance to support people with MG, do it - it's great. Please be resilient and help others to live with MG easier. MG patients should not be alone to fight against this hard illness. For others, who are living with MG, please never give up. Hope always! Sometimes down, sometimes up, be hard in soul and never give up our common dream to achieve the long-awaited remission time."

We're Not Alone:
Creating A Spanish-Language Support Group

For the Spanish Translation of this blog titled No Estamos Solos: La Creación de un Grupo de Apoyo en Español, please click here or scroll down.

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

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

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

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

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

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

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

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

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

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

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

Two Myasthenia Patients

Proudly Rolled Up Their Sleeves For Covid-19 Vaccination

On December 23, 2020, Roseann Devlin proudly pulled up the sleeve of her MG Walk t-shirt to receive her first COVID-19 shot. A certified oncology nurse at Little Company of Mary Hospital in Torrance, California, Roseann was eligible to receive her vaccination as part of the first wave of health care workers. She is diagnosed with myasthenia gravis and has lived with the disease for a number of years.

Though she has MG and is taking immunosuppressant drugs, she did not hesitate to get the vaccine. As a nurse, she has seen many patients with severe COVID-19 symptoms and wanted to avoid any serious complications. Though there is some debate in medical circles about vaccine efficacy levels for people with autoimmune diseases, "it's still worth it to me to be vaccinated because getting full-blown COVID is absolutely terrifying to me," she says.

She knows firsthand and has a unique perspective… because she contracted COVID-19. On that day in December when she received her first shot, Roseann was unexpectedly exposed to a COVID-19-positive patient at work. Seven days later, she developed symptoms - a racing heart, joint pain, fatigue, dry cough, and a low-grade fever. She tested COVID-19 positive the next day.

"It takes your body about three weeks [after a vaccination shot] to create antibodies against the thing you're trying to prevent," Roseann shares. The vaccine had not yet done its job of creating protective antibodies in her blood at the time of her exposure to the virus.

She spent the next two weeks feeling exhausted, weak and feverish, and she had to isolate from her loved ones.

"My boyfriend would drop off a plate of food outside my door. I'd eat on the bed. I could feel the joints in my jaw - even eating was painful." After the worst of her symptoms ended, she still felt tired - "like I'd done some kind of boot camp exercise club."

She says she understands why people with MG might have concerns about taking the vaccine. It has not yet been widely tested on people with autoimmune disorders or other chronic diseases. People may be worried about side effects, or the likelihood of the reduced efficacy.

But she hopes that her story can encourage others in the MG Community to take the vaccine.

"My experience with the vaccine was that my arm was very sore, but that pales in comparison to the joint pain and headaches I had for days with the real coronavirus. When I get any vaccination, like the flu shot, I tend to have that fatigue, a little more eye droop the next day. But, I can plan for that and manage it effectively."

She also stresses that lower efficacy is better than no efficacy.

"If it saves you from the agony of full-blown COVID - and instead you have a light case that you could manage at home - it's absolutely worth it to get the vaccine."

Her colleague, Job Clay, agrees.

Like Roseann, Job is a registered nurse at Little Company of Mary Hospital. Also like Roseann, he has MG. The medical cardiology telemetry floor where he normally works has been converted into a COVID ward, so he has treated many COVID patients since the pandemic began.

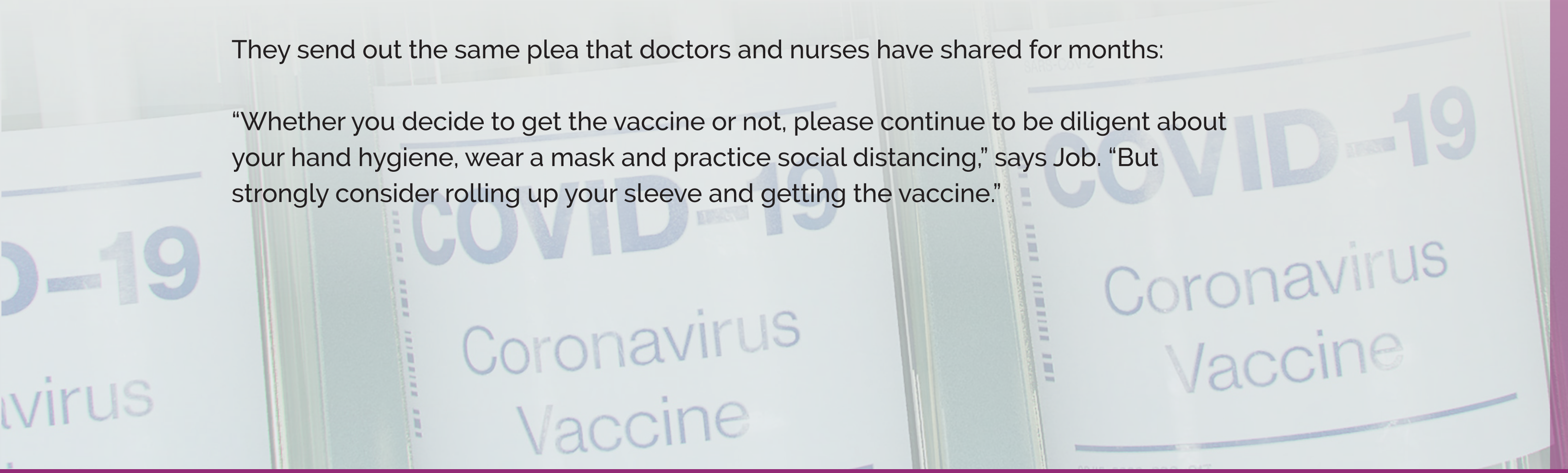
"The decision to get vaccinated is ultimately up to you – with guidance from your doctor - but I am working every day in the face of COVID, and believe me, the vaccine's side effects are way more appealing than the symptoms that come with full-blown COVID," he says.

Job received his first dose of the Pfizer vaccine on December 23, and his second on January 7. While side effects from the second shot were worse than the first and lasted about 48 hours, "they were not bad enough to prevent me from going to work those two days."

As COVID infections begin to decline after a devastating winter wave, and vaccines offer hope for the future, health care workers like Roseann and Job still face crushing patient loads.

They send out the same plea that doctors and nurses have shared for months:

"Whether you decide to get the vaccine or not, please continue to be diligent about your hand hygiene, wear a mask and practice social distancing," says Job. "But strongly consider rolling up your sleeve and getting the vaccine."



MGFA Partners with Rare Across America to Advocate for MG and Other Rare Disease Patients

During the week of March 1, 2021, ten MG advocates volunteered their time to participate in RARE Across America hosted by the EveryLife Foundation for Rare Diseases. The volunteers had meetings with United States senators and representatives to discuss key advocacy issues in the rare disease community. Meetings were held virtually, and advocates were paired with other advocates from their state or local district.

Key Legislative asks included:

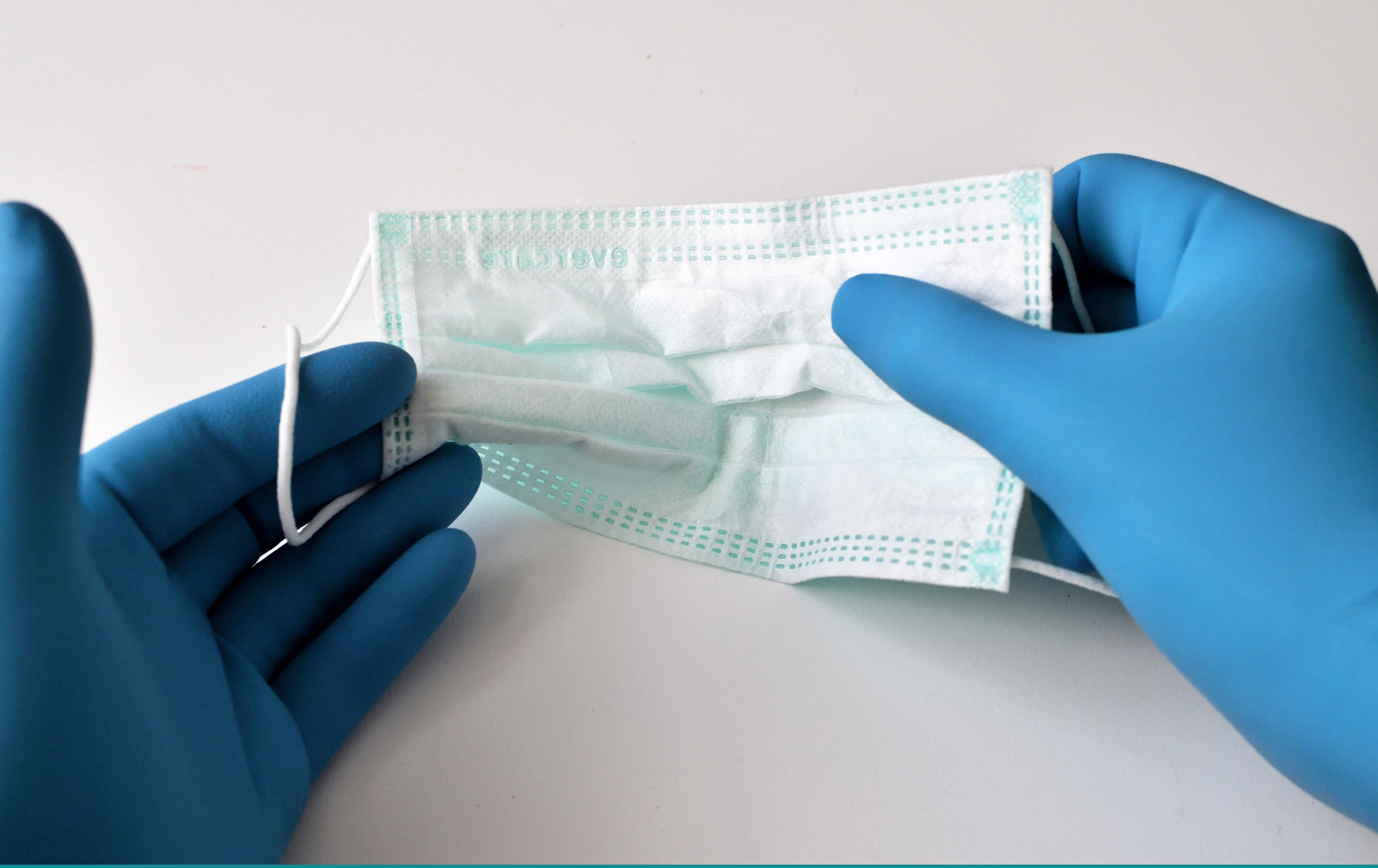
- Cosponsor the Speeding Therapy Access Today (STAT) to strengthen rare disease patient access to FDA-approved therapies.
- Support Rare Disease Programs Appropriations to improve the accuracy of diagnosis of rare disease, increase funding for rare disease infrastructure and expand support.
- Cosponsor the Newborn Screening Saves Lives Reauthorization Act, HR 482.

COVID-19 Resource Center Provides Guidance to Patients

Early in 2021, MGFA launched the COVID-19 Resource Center. People living with MG have had unique concerns during the COVID-19 pandemic. Many MG Community members were worried about how the virus would affect them or their treatment plans if infected, and the resource center addressed questions about the vaccines. MGFA's COVID-19 Resource Center https://myasthenia.org/MG-Community/COVID-19-Resource-Center is here to help. The resource center is a hub of information for MG patients. It is updated frequently so members have the latest studies, data, and advice at their fingertips.

RARE ACROSS AMERICA

EVERY VOICE, IN EVERY DISTRICT, MATTERS

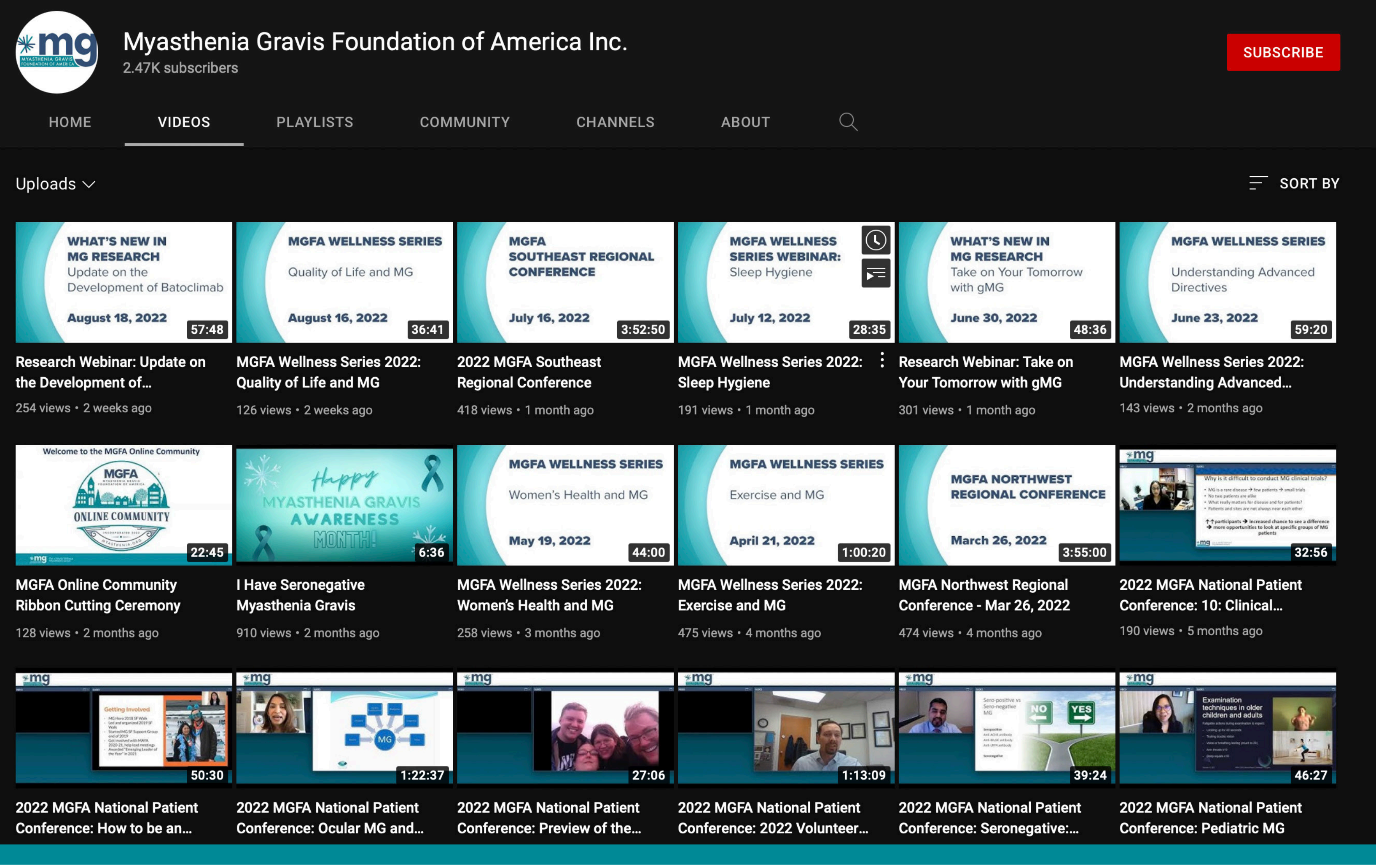


Continued Educational Programming, Webinars, and Regional Conferences

MGFA continued to offer our monthly Wellness Webinars and the What's New in MG Research webinars as well. This important programming attracts many patients and community members, highlighting an array of medical professionals and MG experts from across the country. MGFA also provided "Virtual Town Hall" meetings to offer the latest information and developments from the MGFA and the MG Community. We also conducted 5 Regional Conferences that were online with registrants from all over the United States.

Latest MG Treatment is approved by the U.S. Food & Drug Administration

The MGFA community played a key role in the development of a new myasthenia gravis treatment, approved by the FDA in December. Vyvgart (efgartigimod alfa-fcab), produced by argenx, is the first and only FDA-approved neonatal Fc receptor (FcRn) blocker for adult patients who are anti-acetylcholine receptor (AChR) antibody positive.



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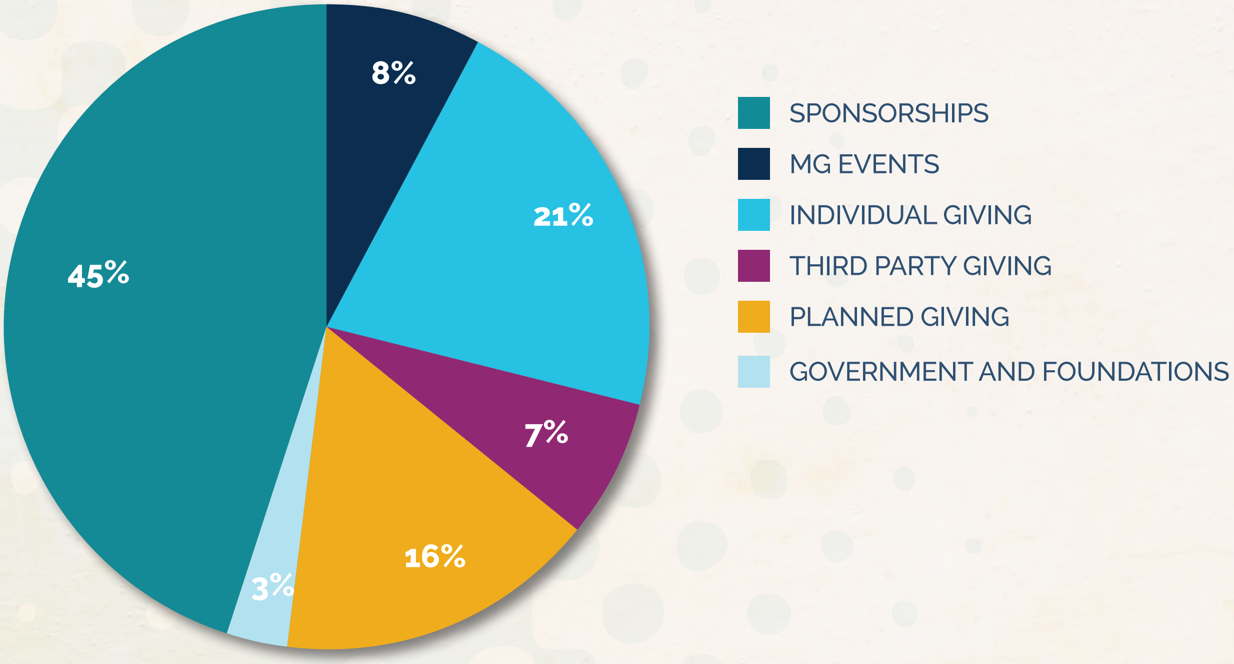
Financial Information

PUBLIC SUPPORT:	**2019**	**2020**	**2021**
Individual Giving	413,818	626,734	603,374
Third Party Giving	161,481	171,348	196,434
Planned Giving	44,067	1,126,496	455,143
Government and Foundations	203,146	58,619	82,754
Sponsorships	365,050	937,250	1,314,030
MG Events	950,367	361,862	251,624
Total Public Support	**2,137,929**	**3,282,309**	**2,903,359**
REVENUE:			
Research studies	106,360	30,078	189,501
Conference and Other Fees	71,075	5,387	157,922
Total Revenue	**177,435**	**35,465**	**347,423**
Total Support and Revenue	**2,315,364**	**3,317,774**	**3,250,782**
PROGRAM EXPENSES:			
Community and patient services	539,490	585,018	516,881
Education and Advocacy	546,239	334,375	497,162
Research	636,901	764,067	1,066,956
Total Program Expenses	**1,722,630**	**1,683,460**	**2,080,999**
Management and general	336,136	325,122	411,185
Fund raising	319,175	420,833	513,929
Total Supporting Services	**655,311**	**745,955**	**925,114**
Total Expenses	**2,377,941**	**2,429,415**	**3,006,113**
Nonoperating Income	1,264,287	305,055	880,016
Net Change in assets	1,201,710	1,193,414	1,124,685
Net Assets	**8,540,640**	**9,734,054**	**10,858,739**

FY 21

CONTRIBUTIONS



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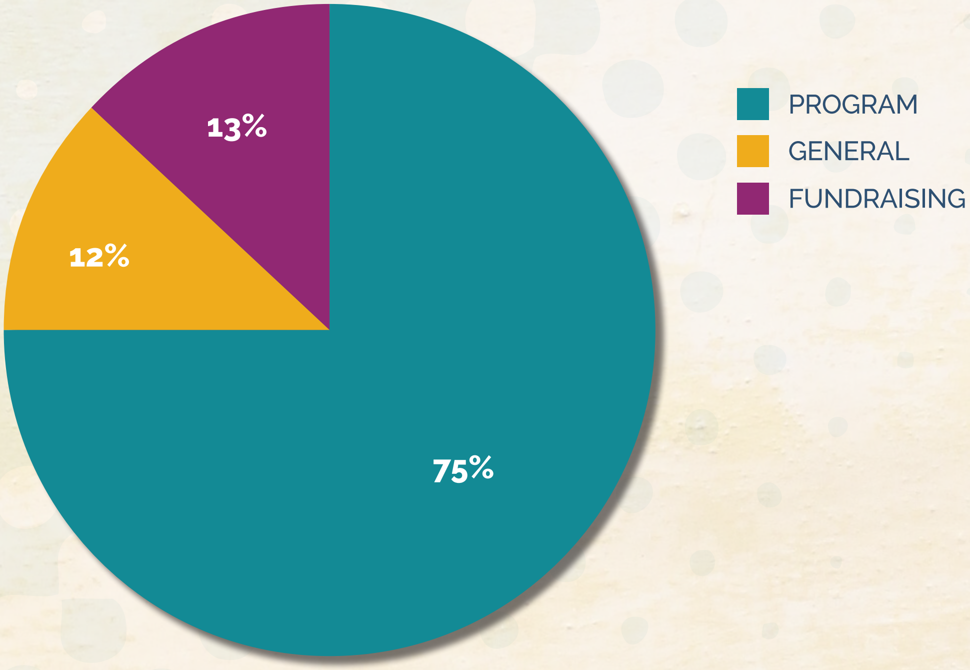

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