



IMPACT REPORT

Fall 2022

2022

Dear Friends,

It is with immense gratitude and joy that I share our Impact Report with you. Each year brings an opportunity for innovation and advancement, taking us one step closer to a world without MG. This year, we took several steps forward, and I am grateful that your support made this progress possible. This report has been designed specifically for you – an essential member of our MGFA community – **to demonstrate exactly how you fuel our most critical work.**

A major focus of the report this year is research. It is not only a big part of what we do, but also a significant area of recent growth. In 2022, we will contribute nearly \$1M to research – our largest contribution to date. The creation of both The Nancy Law Impact Award and The Jackie McSpadden Postdoctoral Fellowship helped us to exceed our goal.

If research is the brains of what we do, then patient support is the heart – our biggest why, driven by compassion and passion to make life better for those living with MG. We recognize how critical it is to educate our MG community with resources that are informative, accurate, and timely. We introduced a variety of new educational initiatives this year, including the MGFA Online Community, Treatment Resource Centers on myasthenia.org and our Community Health Fair Program – a local, in-person, health-focused event in five major cities around the U.S. which will expand next year. **We will continue to find innovative ways to reach more people.**

This year we hosted the MGFA International Conference in Miami, FL. MGFA convened researchers and clinicians from around the globe to share cutting-edge research. Bringing great medical and scientific minds together enables relationship building, learning and discovery, and allows us to collectively gain momentum toward better treatments and a cure for MG.

This report is filled with information and data to demonstrate the impact that we have been able to make with your help this year, as well as a sneak peek into where we are going in 2023. I cannot wait for you to dive into the details. Thank you for continuing to invest in this important work to make life better for those living with MG, and to ultimately find a cure.

With gratitude,



Samantha Masterson
President & CEO
MGFA

LEADING WITH LOVE: A Story of Funding the Future of Research

In Houston in 1963, Danny McSpadden met his future wife and lifelong partner, Jackie. She was teaching math and Danny was working as a chemical engineer. A year later they were married, and it was the start of their full life together filled with philanthropy, activity, and loving children (and seven grandchildren).

When Jackie McSpadden was diagnosed with MG in 2012, she approached the disease like everything else in her life – with optimism and a commitment to give it her all. She learned everything she could about MG, joining support groups and attending events like the MGFA patient conference. When her treatments were difficult, she didn't give up. With Danny by her side, she turned her struggles into an opportunity for other people with MG to learn from her experiences.

Her strength, determination, and optimism were an inspiration for many, providing hope that they, too, could lead active lives while managing their symptoms.

Jackie passed away at 80 years young on July 6, 2021. Her husband made the decision to honor her legacy by funding impactful research to make life better for

those living with MG. He feels strongly that finding a cure for MG is within reach, and wants to support the next generation of research. This year, he and his family established a postdoctoral fellowship in Jackie's name.

Supporting recent PhD and MD graduates, the Jackie McSpadden Postdoctoral Fellowship Award will help advance promising research related to myasthenia gravis. The McSpadden family's goal is to improve the lives of patients with MG and to, ultimately, help MGFA work towards finding a cure.

"Highly productive laboratories **require talented postdoctoral fellows in order to make impactful findings that move research forward** and deepen our understanding of human disease," says Dr. Kevin O'Connor, chief scientific advisor for the MGFA Medical and Scientific Advisory Council.

Providing support for a research investigator at an early stage all but ensures they'll continue on the same path throughout their career, seeding talented researchers to work on MG and related diseases around the world.

MGFA provides hundreds of thousands of dollars in research funding every year to improve our understanding of MG and, ultimately, find a cure. Donors are crucial partners in this important work. The Jackie McSpadden Post-doctoral Fellowship is a monumental step forward for the future of MG research.



The McSpadden Family

Myasthenia Gravis Research *defined*



MGFA leads the way to support the most promising scientific endeavors – funding research, engaging young scientists and clinicians, and spearheading a comprehensive patient registry. This is an extraordinary time for progress in MG research and discovery. There are many new scientific discoveries that could lead to better treatments and a cure for MG.

What exactly does our research process look like?

Step 1: The MGFA announces a call for applications – the specifics of the funding opportunity are announced, and eligible researchers are able to submit a proposal.

Step 2: Applications close and the Research Committee of the MGFA Medical and Scientific Advisory Council reviews applications. The MGFA has two funding cycles – which means research grants can be reviewed and awarded in the Spring and Fall.

Step 3: The Research Committee is a cohort of international experts that focus on two main objectives: defining targeted areas to set the research agenda and rigorously reviewing grant applications to determine researchers that are awarded funding from the MGFA.

Step 4: The funding is awarded, and the research moves forward. In instances where the funding is provided by a specific donor or donor family, typically, that donor family is kept informed about the progress of the project.

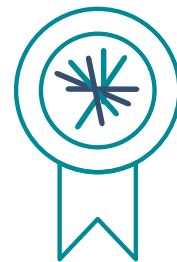
Defining TRANSLATIONAL RESEARCH

In research, when we're asking the big questions, it can take many years to get proper answers. This is because finding answers to the most life changing challenges is not an easy task. Translational research is still fundamental research that significantly impacts the lives of patients, but might more quickly have an impact on daily life.

What does it mean to work towards a cure in MG research?

In an autoimmune condition, like myasthenia gravis, the body's immune system is attacking itself. There is something the body identifies as foreign, and it mistakenly tries to attack. When researchers talk about finding a cure, the gold standard is *inducing a state of tolerance*. This means, that the body tolerates itself again and the immune system no longer mistakenly attacks. Understanding this simple principle is the core of understanding how researchers can work towards a cure for myasthenia gravis.

Impactful Leaders, Impactful Research



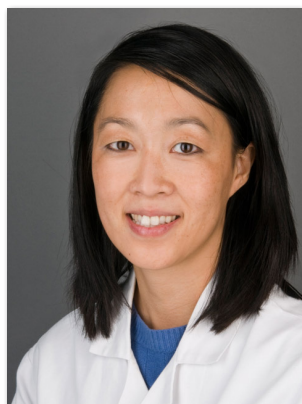
The Nancy Law Impact Award

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

In honor of her leadership, in spring 2022 we launched the Nancy Law Impact Award.

This grant award **provides 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 awarded this grant to its first recipient, Dr. Aimee Payne.

Her research project entitled “Preclinical models and biomarkers for predicting MuSK-CAART clinical outcomes” will be funded for 3-years (\$300,000).

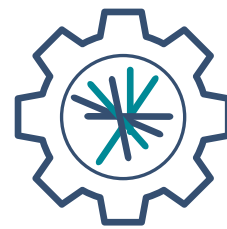
Research Summary - MuSK MG is caused by MuSK autoantibodies that lead to life-threatening muscle weakness, so the ideal therapy would be to eliminate autoantibody-producing B-cells while preserving healthy B-cells. CART cells in the body are currently being re-programmed to eradicate B-cell cancers, prompting

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



Robust Resources, Empowered Patients

Informed Decision Making through Quality Education



Treatment Resource Center

Understanding your treatment options helps you get the care that's right for you.

For the Boyle family, the road to MG remission was bumpy. Their daughter, Emily, was just 14 when she began exhibiting symptoms. So began months of scouring the internet and calling specialist after specialist.

After initial treatments were unsuccessful, they found a neurologist who recommended a thymectomy, a procedure to remove the thymus gland, which plays a role in the production of antibodies.

After Emily's successful thymectomy over a decade ago, the Boyle family has advocated for more awareness of this approach.

"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," says Betsy Boyle, Emily's mother.

With a gift to MGFA, they created the Boyle Family Education Initiative to help us better inform patients about their treatment options, including thymectomy. This initiative also sparked the creation of the thymectomy workgroup – a committee focused on understanding potential knowledge gaps that exist around recommending thymectomy during care.

For more information on treatment strategies, visit www.myasthenia.org/newly-diagnosed/treatment-strategy.

The MGFA Online Community

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

This new online community launched in June on the MGFA website. Each virtual space in the new community provides a chance for patients and caregivers to connect with each other on different topics, including wellness, treatment options, and MG advocacy.



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“People make or break greatness, and hearing and reading the story about the founder of MGFA inspired me to become a part of a long-standing and vibrant organization. It's people with hearts of giving and people with caring personas that ultimately make differences in the lives of others – I just had to be a part of this culture!”

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**Robert Thomas,
MGFA Board of Trustees**

LEADING THE WAY, EXPANDING OUR REACH

5 Community Health Fairs held in cities across the U.S.

We've partnered with over **103 EXPERTS** in the field to speak at our in-person and virtual events.



40 active support groups nationally with more than **100** support group leaders

400+



patient and community calls fielded to support patients/families in finding an MG specialist, financial support, or supporting new patients in understanding more about MGFA's resources.

800+



patient packets sent to newly diagnosed patients in 2022

MGFA conducts **12** Wellness Webinars and **6** Research Webinars

MGFA offers:

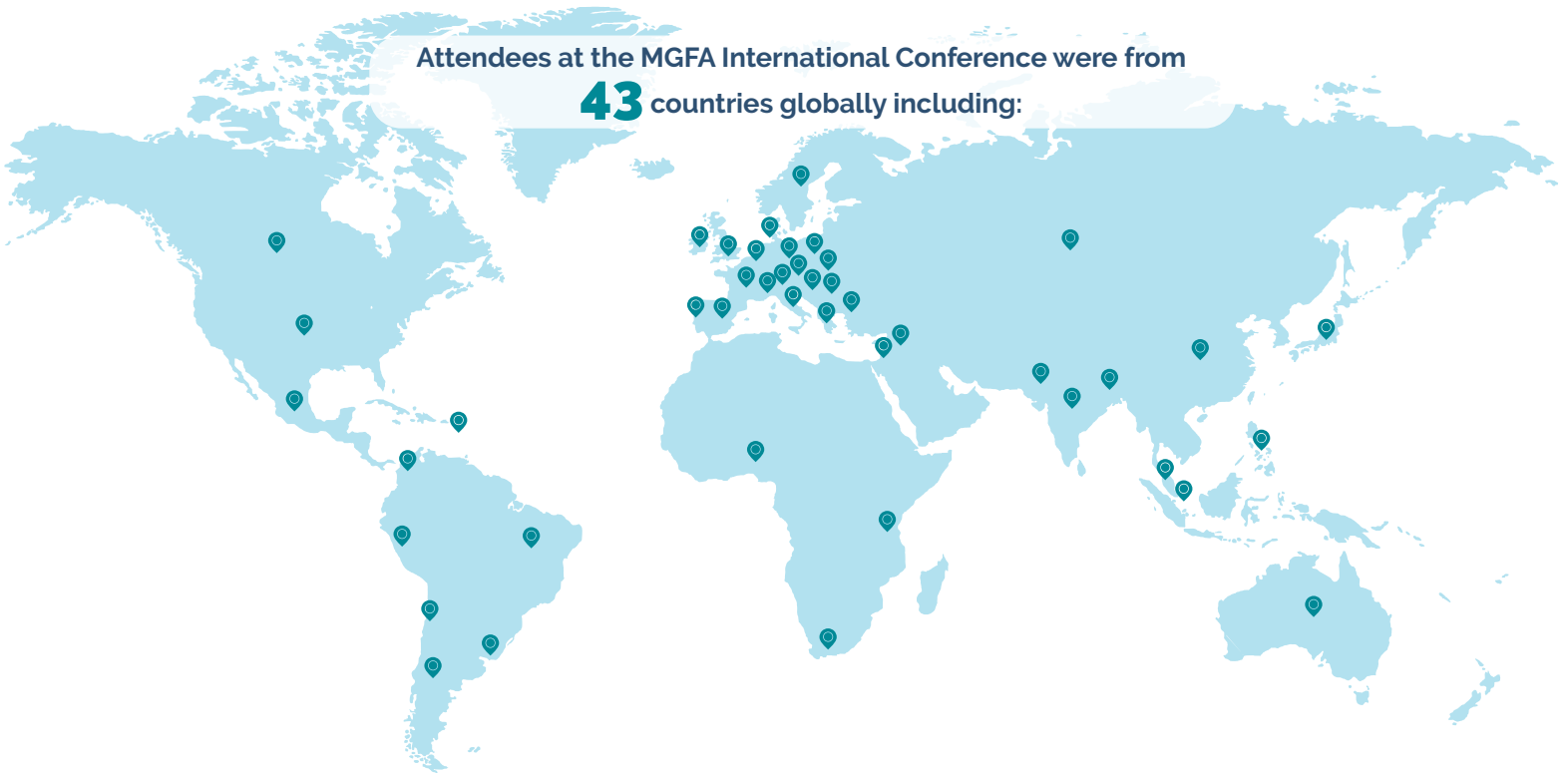
an Annual National Conference

Scientific Session

5 Regional Conferences

an International Conference every 3 years

Attendees at the MGFA International Conference were from **43** countries globally including:



The MGFA International Conference

Medical professionals and researchers from around the world came together in Miami, Florida to share myasthenia research, progress, and new discoveries at the MGFA International Conference. Held every three years, **this conference is the premier opportunity for experts to discuss their latest findings, facilitating global scientific collaboration and discovery.**

We welcomed 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 MuSK MG.

Other topics discussed included the latest therapeutics, biomarkers for MG, autoantibodies, updates in MG management, pediatric MG and patient case studies.

The conference is made possible thanks to support from industry partners

OUR VISION:
A WORLD WITHOUT MG

OUR MISSION:
CREATE COMMUNITIES, ENHANCE LIVES,
IMPROVE CARE, CURE MG



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