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FOR IMMEDIATE RELEASE

Myasthenia Gravis Foundation of America Announces MG Volunteer Glenda Thomas Selected to Newly-established Rare Disease Advisory Council of Massachusetts

Myasthenia patient and advocate to be sworn in as member of rare disease council ahead of Myasthenia Gravis Awareness Month in June – Online Swearing in Ceremony Thursday, May 27, 2021 at 11:30 a.m. Eastern

BOSTON, MA – May 25, 2021 – The Myasthenia Gravis Foundation of America ([MGFA](#)), 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 those living with MG, announced today that Massachusetts resident Glenda Thomas has been appointed as the first-ever MG advocate to the newly-established Rare Disease Advisory Council of Massachusetts. Ms. Thomas is an MG patient, advocacy leader, and volunteer, and will be publicly sworn in during an online ceremony on Thursday, May 27, 2021 at 11:30 a.m. Eastern.

Ms. Thomas was diagnosed with myasthenia gravis in 2013, and through sheer determination and drive, became a strong and active volunteer with the MGFA where she served the MG community in a number of leadership capacities. Her experience as an MG support group leader, keynote speaker, fundraiser, conference planner and patient advocate makes her uniquely qualified for the Rare Disease Advisory Council. As a new member, Ms. Thomas will provide guidance and assistance to local, state, and federal-level legislators and policy makers to ensure patient perspectives and needs are central to policy changes that impact and affect solutions for rare disease.

“I am extremely honored by this appointment and am excited to make sure patient voices are heard across the rare disease space and throughout governmental legislative decision-making processes,” said Ms. Thomas. “It is so emotional and satisfying for me, my family and my myasthenia gravis support family and friends that I have been given this honor just a few days before MG Awareness Month in June – a time to raise awareness and take action to ensure people around the world understand the challenges that people with MG face every day. We must always make sure that legislators come to empathetic decisions when considering treatment access, insurance coverage, and general policy changes that will impact and help those with rare diseases such as myasthenia gravis.”

This advisory council will give rare disease patients, families, caregivers, providers, and other stakeholders an opportunity to make formal proposals to the state on how to improve public policy for people across the community. The Massachusetts State Legislature, as well as federal and local policy makers, will look to members of the Council to help create and design health care legislation while informing and verifying pending policy.

“I am proud that my constituent Glenda Thomas has been selected to join the Rare Disease Advisory Council,” said Massachusetts Senate President Karen E. Spilka. “Glenda’s experiences as a patient, as a caregiver, and as a public advocate all speak to her ability to bridge gaps between healthcare policy and those who are navigating our healthcare system. Breaking down barriers to care for a more integrated approach to healthcare is a longstanding priority of mine, and I look forward to seeing Glenda’s work on the council.”

Myasthenia gravis is a rare, chronic, autoimmune and neuromuscular disease characterized by the production of antibodies that block or destroy nerve impulse receptors on muscle tissue required for voluntary and involuntary movement. As a result, proteins produced by nerve impulses from the brain do not reach the receptors on the muscle. Those with myasthenia suffer from profound, debilitating physical symptoms such as extreme muscular weakness and degeneration that impact a person's ability to move, see, swallow, smile, walk or breathe in some instances. More than 70,000 people are diagnosed and living with MG in the United States alone. There are few active treatments of myasthenia, and most patients are immunocompromised as a result of those treatments – making them especially susceptible to COVID-19 and other diseases.

Glenda Thomas was officially nominated by the Myasthenia Gravis Foundation of America and UCB, a global biopharmaceutical company focused on the discovery and development of innovative medicines and solutions to transform the lives of people living with severe diseases of the immune system or of the central nervous system.

“As an ambassador for MG, Glenda has made it her personal mission to raise awareness in rare disease and unify voices by turning advocacy into action,” said Samantha Masterson, president & chief executive officer at the Myasthenia Gravis Foundation of America. “She is well-versed in leading important discussions with key decision makers and partners, such as UCB, and her personal story as an MG patient is extremely inspiring. Glenda has been the recipient of numerous awards and has been consistently recognized for her dedication and courageous journey with MG. She is so qualified for this prestigious honor and we are extremely happy for Glenda.”

June is Myasthenia Gravis Awareness Month and the MGFA has planned a number of educational events, calls to action, and interactive activities in order to educate the general public about the challenges that MG patients and their caregivers face. Better awareness of myasthenia symptoms and treatments will lead to quicker diagnosis and greatly-improved quality of life for those living with the disease. MGFA has created an [MG Awareness Page for June](#), and to learn more about myasthenia, you can view the [MGFA Home Page](#).

About MGFA

The Myasthenia Gravis Foundation of America (MGFA) is the largest, leading patient advocacy organization solely dedicated to finding a cure and improved treatments for the rare neuromuscular disease myasthenia gravis (MG) by funding critical research discoveries and providing patient-centric programs, guidance, events, and webinars to connect, educate, and assist members of the global MG Community. You can visit MGFA at myasthenia.org.