



From left, with the Legislature's proclamation of June as Myasthenia Gravis Awareness Month, are Marc Weinberg, Judy Weinberg, state Sen. Richard T. Moore, D-Uxbridge; Robert DeBoer, state Rep. Jennifer M. Callahan, D-Sutton; and Grace DeBoer. (COURTESY PHOTO)

State Rep. **Jennifer M. Callahan**, D-Sutton, and state **Sen. Richard T. Moore**, D-Uxbridge, have announced that June has officially been named Myasthenia Gravis Awareness Month.

Robert DeBoer, a resident of Sutton and chairman of the Massachusetts/New Hampshire chapter of the Myasthenia Gravis (MG) Foundation of America, was honored June 14 at a Statehouse ceremony. Mr. DeBoer and members of the Myasthenia Gravis Foundation received a proclamation from the governor that declares June Myasthenia Gravis Awareness Month. The foundation will also receive a legislative resolution that commemorates Myasthenia Gravis Awareness Month.

"MG is a very rare disease that only about 70,000 people in Massachusetts have," said Mr. DeBoer in a prepared statement. "Very few doctors are aware of it. After I began to show symptoms of the disease, I was fortunate to be sent to a neurologist that diagnosed me within four months. Most people are misdiagnosed for years. Today, through the foundation and MG Awareness Month, the foundation's goal is to make 100 percent of doctors in the state aware of MG."

"I am extremely proud to know that a resident from my hometown has worked so hard to bring awareness about MG to the residents of the commonwealth," said Ms. Callahan in a prepared statement. "I believe that establishing MG Awareness Month will help Robert and the foundation reach their goal of making 100 percent of doctors in Massachusetts aware of this disease. As both a registered nurse and member of the Joint Committee on Public Health, I personally understand that increasing awareness among health care providers is key to both better treatments and more accurate diagnoses of the disease."

Mr. DeBoer was diagnosed with myasthenia gravis in 2001. He became a member of the foundation shortly after he was diagnosed with the disease. As a member of the foundation, he successfully worked with the town of Sutton to proclaim June Myasthenia Gravis Awareness Month. After he became chairman of the foundation this past year, he decided to move forward and ask for the month of June to become Myasthenia Gravis Awareness Month statewide. He contacted Ms. Callahan, who immediately worked with the governor's office to make a proclamation.

Mr. DeBoer's wife, **Grace**, assistant chairwoman of the Myasthenia Gravis Foundation; **Judy Weinberg** and her husband **Marc**, treasurer of the foundation, and **David Weinberg** were scheduled to accompany Mr. DeBoer at the Statehouse. Judy and Marc Weinberg's daughter was diagnosed with myasthenia gravis when she was 12.

"I am pleased to be able to offer this special resolution commemorating Myasthenia Gravis Disease Awareness Month," said Mr. Moore in a prepared statement. "Mr. DeBoer and the Massachusetts Chapter of the MG Foundation should be commended for their tireless efforts on behalf of those people affected by this rare, often misdiagnosed disease. By raising awareness of it, I hope that we can join with the foundation in promoting a deeper understanding and better treatments of MG."

"Myasthenia gravis" means "grave muscular weakness." It is a chronic neuromuscular disease that attacks the immune system and restricts transmission of neuroimpulses from the brain to voluntary muscles. . Muscle weakness increases with continued activity and can be improved with periods of rest. The most severe muscle weakness involves many of the voluntary muscles, including those used for breathing.

Myasthenia gravis is estimated to occur in 14 per 100,000 citizens in the United States, for a total of about 36,000 cases, but many more cases are undiagnosed. Many people are not diagnosed for five to seven years because the symptoms create a diagnostic dilemma for physicians unaware of the disease.

"MG is incurable," said Mr. DeBoer in a prepared statement. "It is difficult for doctors to do research because such a small number of people have it." Mr. DeBoer's case of myasthenia gravis is currently in a drug-induced remission.

Common symptoms of myasthenia gravis are drooping eyelids, double or blurred vision, slurred speech, difficulty chewing or swallowing, weakness of the limbs, and chronic muscle fatigue.