



MYASTHENIA GRAVIS FOUNDATION OF AMERICA, INC.®

December 2013

Dear Friend,

There is nothing worse than losing a child.

In September 2012, I lost my six-year-old daughter Safa to myasthenia gravis (MG).

Now there is nothing more important than battling the disease that took Safa.



Safa's MG story began one day in October 2010 when she said she saw "two mommies." While I thought Safa was being silly, my husband observed that our daughter's face was drooping. The doctor we saw that evening believed Safa was just fooling around.

Over the next few days, Safa's symptoms worsened. The optometrist we consulted thought it might be Bell's palsy and referred us to a neurologist who diagnosed her with MG.

MG is a chronic autoimmune disease, which causes antibodies to attack and destroy neuromuscular connections, weakening muscles that control basic movements that enable walking, swallowing, blinking, breathing, and smiling. Extraordinary exhaustion, double vision, and drooping eyelids are among the symptoms.

We were in shock. No one in our family had ever heard of MG. And we certainly had no idea it could be fatal.

The doctor immediately prescribed prednisone and mestinon. He also recommended a thymectomy, the surgery indicated for patients with MG.

We decided to hold off on this major surgery and let the medications do their work. In January 2011, however, Safa's eyes became paralyzed and she underwent a thymectomy the day before her fifth birthday.

Over the next 18 months, Safa's condition alternated between good and bad periods. Symptoms included extraordinary fatigue, slurred speech, and double vision. Finally, on September 9, 2012, two years after Safa became ill, she lost her battle with MG.

While my heart was broken, I immediately resolved to fight back against this devastating disease. I joined forces with the **Myasthenia Gravis Foundation of America (MGFA), the only national volunteer health agency dedicated to finding a cure for MG.** The MGFA funds desperately needed research projects to develop diagnostic techniques, treatments, and ultimately, a cure. In addition, the MGFA sponsors vital patient resources, support, and information through myasthenia.org,



social media, local chapters, and support groups; advocacy efforts; and educational programs for the medical profession.

In the fall of 2012 and 2013, I participated in MG Walks—the annual MGFA fundraisers—in Naperville, IL; Pittsburgh, PA; and Columbus, OH. Our family in Illinois was with us on those walks. Safa's school, the Sunrise Academy in Hilliard, OH, joined us at the Columbus walks. In addition, I am developing a PowerPoint presentation about MG so I can speak about the disease to medical students and organizations studying MG and other autoimmune conditions.

There is so much to be done in the struggle against MG.

Today, 70,000 Americans cope with the debilitating and life-altering effects of this disease. Every day, individuals of all ages, genders, and races are diagnosed with MG.

Many patients undergo months—even years—of illness as they travel from doctor to doctor seeking a diagnosis. MG can be a silent disease; one day you are fine and the next day you can be desperately ill.

Patients endure difficult symptoms and rude comments about their altered appearances. When a stranger would comment on Safa's drooping eyes or the fact that she could not smile, my young daughter would loudly proclaim, "I have MG and sometimes my muscles don't work."

Safa let the world know loudly she had MG and I am letting the world know that the MGFA needs your assistance.

Although Safa lost her life, fatalities are not the norm for MG. Advances in research and treatment have made fatalities much rarer and have enabled people to lead longer lives with MG. Safa's story, however, is a reminder of the fear MG patients experience even when their condition seems under control.

The MGFA is at the forefront of research, patient support, education, and advocacy, and they need your support.

We need to raise awareness among patients, the medical community, and the public.

We need to fund research for better diagnostics, treatments, and ultimately, a cure.

We need to ensure that patients and their families have the support and community necessary for so many that feel isolated with MG.

Your generosity will help the MGFA continue their vital work.

Together we can help the MGFA achieve A World Without MG.

Thank you so much.

Sincerely,

Jessica Ali

PS: Please help the Myasthenia Foundation of America fight MG. Kindly mail your donation in the enclosed envelope or give online at myasthenia.org today.