



# MYASTHENIA GRAVIS

## FOUNDATION OF AMERICA, INC.®

*A loud roar caused us to look up. There were almost 20 motorcycles driving down our street. We wondered if they were headed to a party at a neighbor's house. We were shocked when they parked in front of our house and announced they were there to support Sky's Stand Against MG. She excitedly served each one a glass of lemonade. One of the group members also has myasthenia gravis and had read about Sky's lemonade stand. They decided to dedicate that weekend's ride to a 45 minute Sky Ride.*



I'm Sky's mom, Stormee Genz. My husband, Steve, and I have supported Sky as she fundraises for the Myasthenia Gravis Foundation of America, the only national organization supporting research, providing education and information and patient services to the MG Community. We had researched a few charities before deciding that by working with MGFA, we could make the biggest impact for people living with myasthenia gravis.

MG is an autoimmune neuromuscular disease in which antibodies attack and destroy neuromuscular connections. This can cause weakness or inability to use the muscles that control basic movements such as lifting, walking, swallowing and breathing.

Sky was just ten years old when she was first diagnosed with myasthenia gravis. It has been a crazy, winding path these last two and half years. Sky's MG started out with the typical eye twitching and we hoped that it would stay as Ocular MG. But it became generalized before the next year started. It began to affect the rest of her face. Then her arms and legs. Finally, her breathing, that was so scary.

Our family is hoping for a very different holiday season than the last one. Last December, Sky was in the Pediatric ICU for almost 3 weeks. What started out as a cold progressed to multiple infections and pneumonia---complicated by reactions to her medications. We agonized when she went into septic shock and had to struggle to even sit up. It was a heartbreaking and terrifying time for our family. We brought the holiday to her in the hospital, her room had a small tree and even a string of lights. Thankfully we had good medical care, a lot of support from our family and friends—and we could turn to MGFA for information and resources.

Sky was homebound all of January, as she needed to give her bone marrow time to heal and to get her strength back. She received monthly IVIG treatments – infusions of Immuno-Globulin. In March, Sky had surgery to remove her thymus. It was hard for us to have to consider major surgery for a child who had already been through so much---but Sky was tough and determined. She only missed one week of school. And her recovery continued. Five months later, Sky was able to return to dancing competitively. She had to make adjustments but she was still able to participate with her team. When

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I see her perform on stage, I get teary eyed thinking about how far she has come.

Our family has had to adapt to a “new normal.” Like many people with MG, Sky has good days and not so good days. MG can change hourly. She may appear to be a typical 12 year old child then an hour later she may have a difficult time talking or walking. Currently there are limited options for medication in the treatment of MG. Even on a good day, Sky takes 18 pills. She has a very strict medication regimen because some medications cannot be combined and cannot be taken within 1-2 hours of food. Her medications have more than a few bad side effects (bone loss, low immune system, weight gain, stomach trouble to name a few.).

We want to change the future for our daughter and people with MG. Our whole family has become active for the MG cause and the MGFA. We participate in the local MG Walk and support group. We talk about MG to anyone who will listen. From making rubber band bracelets to selling lemonade at her stand, Sky is passionate about spreading awareness of MG and raising money to fund research. She lives by the motto of the MGFA Kids Community: *“I have MG, but it doesn’t have me”*

Just as we have been fortunate to have wonderful support from our family, friends and new biker friends, I am asking that you take a moment to make a contribution for research, raising awareness and supporting those with MG. There are so many challenges that remain. About 70,000 people in the U.S. have MG. Some do not respond to any of the current medications. Others may do well but may still have a recurrence when stressed. Even when medications help, they still have a downside, such as bone loss. We need better treatments---and eventually a cure!! *While our choices and care are better today than they were 30 years ago, so much remains to be done!*

There is only one national volunteer health organization dedicated to finding a cure for MG and to helping patients throughout our country with education, information and support. That is the Myasthenia Gravis Foundation of America. If you want to make a difference for those suffering with MG, please take a moment and make a contribution this Holiday Season.

Your generosity will help achieve MGFA’s vision, **A World without MG**. Thank you for your support!

Best wishes today and every day,



The image shows four handwritten signatures in cursive script, arranged from left to right: Stormee, Steve, Rayne, and Sky.

Stormee, Steve, Rayne and Sky

P.S. Please help the Myasthenia Gravis Foundation of America fight MG. Kindly give online at <http://www.myasthenia.org/HowcanIhelp/Donations.aspx> and click the *donations* button. Thank you!