

Let me start by introducing my beautiful family. My name is Bobbi Jo and my husband is Walter, nickname, "Ray." We have three wonderful children, the first two I gave birth to Julianna, 18, and Dustin 16. And Leroy, 19, is a young man that visits and stays here regularly and will eventually live here when we can make room, which at that time I will be his official Guardian.

Julianna graduated this year from High School, and loves Science, Art, playing her Xbox and computer, and chatting with her friends. Dustin, who also has high functioning autism, is a 10th grader. He enjoys History and Art. He takes joy in building Legos, and then building replicas in Minecraft, playing his Xbox and computer. Leroy, who we love as one of our own children and who hopes soon to be added to our family, is a 2019 High School Graduate. Leroy enjoys watching wrestling, collecting swords, playing on his Xbox and computer, too. All three have their challenges but they make the best out of everything with laughter and goofiness.

My husband works at Aberdeen Proving Grounds and is also a Disabled Veteran of the U.S. Army and the Maryland National Guard. I'm the proud stay at home wife, mother and caregiver for my family. All three children have Duchenne Muscular Dystrophy (DMD). DMD is a severe type of muscular disease. The symptom of muscle weakness usually begins around the age of four in boys and worsens quickly. Typically, muscle loss occurs first in the thighs and pelvis then the arms, creating difficulty with balancing and

standing. Most are unable to walk by the age of 12. Affected muscles may look larger due to increased scar tissue and fat content. Scoliosis is also common, as well as bone restriction, such as feet turning and legs extension. Some may have intellectual disability, as well. Females with a single copy of the defective gene may show mild to severe symptoms. Only one in five hundredth million girls will get this disease.

Life here can be very challenging at times. We do what we can with the limited space we have, in our home. I love my home and take pride in it. However, we would have never purchased this home if we would have known about their disease beforehand. We have made things work despite the multiple obstacles we continue to face.

We have a small home, one level and about 900 square feet. We have no basement. To sustain us, we have chickens and grow all our own fruits and vegetables that we freeze or can. We raise two types of chickens for meat and eggs. We purchase ham and beef in the fall to fill the freezer for the year. We buy what we can't grow or make.

Ray started with a small garden when he came back from Iraq to help with his PTSD. The kids enjoyed gardening when they could. Now, they look on from the make-shift ramp we put together.

We had a concrete slab which began to crumble. All that remains is a gravel mud pit which we sorely need help fixing. We hope to redo that area as a patio with for an outside grill area when funds permit.

Our biggest concern now is getting a room for Leroy and fixing the back side of our home where Dustin, my son's room is located along with my laundry room. Those rooms have mold growing and are literally falling in. The people who owned the home before us added those rooms and cut corners in the process. They built the frame without any pilings or foundation. Now, the underlying framing is rotting, and the roof is no longer stable and falling in, causing leaks to occur. We keep patching the roof but in no way is that a long-term solution. I have plastic and duck-tape to patch the ceiling and walls.

This is just not safe or healthy for any of us, especially Dustin, who spends most of his time in his room due to his immobility. One day when we can afford it, we would like to remove this section of the home and expand our kitchen slightly, to allow us to sit at the same table as a family for our meals, add two new bed rooms and a second bathroom with a soaking tub. We also would like to have a Hoyer Track System put into the ceilings of each kids' room and have the handicapped - bathroom renovated to allow the safest and easiest transfer for the kids.

As if things weren't already a daily struggle, on January 10th, 2019, my world changed for the worse. I was involved in a serious car accident, not at fault. This accident has changed my ability to care for my children on a mental and physical level that I could have never imagined. I endured neck surgery to repair vertebrae's C5,6&7, leaving me with only 50% range of motion, nerve damage to my arms and hands,

and my gait is often unsteady. I often have trouble coping with my injuries and daily struggles. I try not to complain. I count my blessings every day.

Thankfully, we do have excellent caregivers, Monday through Friday, that help tend to Julianna and Dustin's needs. When Leroy finally starts living with us, we will have to apply for help for his care needs, as well. Leroy and Julianna met at MDA Camp and soon became part of our family. Leroy started coming up to my home for holidays and long stays during the summertime. Leroy's mother, Margret, is battling cancer and the doctors are unsure how long she may have. Margret asked if my husband and I would be Leroy's Guardians and take care of him when she is no longer able to. I didn't even hesitate on saying yes to her request. I love him like my own child.

Even though this life that we have with these wonderful, beautiful children/adults can be very demanding and challenging at times, I wouldn't change any of it for the world. Words cannot express my feelings, nor my gratitude for your time, your caring hearts and support. We thank all of you.

The Eggers Family

