MAY is ALS Awareness Month

AS MY GRANDDADDY USED TO SAY…

My Grandpa Stan, who spent the last 20 years of his life convinced he was dying, always said, “If you don’t have your health, you don’t have anything.”

However, my Grandpa Stan was wrong. Take it from me, someone who has lost nearly everything in terms of health. I am unable to move except for my face and my feet, and my feet only about an inch (I cherish that inch). I use an eye gaze computer to communicate because I can no longer speak. I survive now on a ventilator and feeding tube. All that remains are my mind and senses. Well, scratch that. My sense of smell is totally lost because air doesn’t move through my nose anymore, just the hole in my throat. My sense of taste exists, but the only thing that goes in my mouth is toothpaste, so taste is nearly irrelevant.

Despite all this, I know my grandpa was wrong. It would be easy for me to become bitter if I focused on what the monster called ALS has stolen from me, but I have something more important than health. I have love.

I realize “love conquers all” sounds trite, but it’s something I really do believe. Without love, my life would be unbearable. I am loved deeply by family and friends. My parents tell me how many people at their church – total strangers to me, but readers of my blog – ask about me and my husband Evan. The love that affects me most, though, comes from Evan.

“That’s 20,” he says after a flurry of kisses on the tip of my nose.

His affection gets me through the day. From scalp massages to shoulder rubs, he spoils me rotten. Sometimes he even hugs me, no small task considering I’m completely limp and unable to hug him back. Oh, what I would give to hug him!

So in this new year, hold your dear ones near, and may you be blessed with health, safety, and most of all, love.

***Author:****Hello, I'm Rachel Doboga. When I was diagnosed with ALS at age 28, I lost my teaching career, my plans to travel, and the chance to start a family with my husband. I lost my future. I almost lost hope, but being surrounded by so many people unwilling to let me go helped me step back from the edge. Now I am determined not to let a day go by without fighting for my life*