



PERSPECTIVES *for a* DIVERSE AMERICA

Just Peace: A Message of Hope

[In this book excerpt Mattie Stepanek describes what it is like living with a rare neuromuscular disease. Defying many developmental odds, Mattie recounts highs and lows as he travels toward his tenth birthday, living on what he terms “the edge.”]

A Messenger of Hope

Hello everyone, and welcome to these thoughts. I’d like to begin by sharing a few things about myself as a person, because then you may better understand my message of hope and peace.

MY BEGINNING

My name is Matthew Joseph Thaddeus Stepanek, but everyone knows me as “Mattie.” I am the youngest of four children. My sister, Katie, was born in 1985. My oldest brother, Stevie, was born in 1987. My other brother, Jamie, was born in 1989. And I was born on July 17, 1990. Jamie and I were best friends for a while. But I didn’t ever get to meet Katie and Stevie, because they died before I was born. And now, I don’t get to see or be with Jamie anymore, because he died when we were both little boys.

All four of us were born with a rare neuromuscular disease called dysautonomic mitochondrial myopathy. It is one of the forty-three types of diseases that the Muscular Dystrophy Association (MDA) focuses on for support and research. Our particular form is very life threatening. From the time you are diagnosed with it, you know, or your family knows, that you probably won’t live too many more years. Some people ask, “Why on earth did your mother have four kids who would inherit this terrible disease?” Well, the simple answer to that is my mom didn’t know she was going to have babies with this life-threatening condition when she gave birth to us.

My mom had her first three babies thinking that they all had a very good chance of being healthy. I was what she called a “welcome, but unplanned baby.” Now, she tells people that I was a “spirit meant to be” because I have defied so many medical and developmental odds.

MY LIFE

When I was born in 1990, the doctors didn’t think I would live long. They also told my mom that if I did live, even for a bit, that there was a strong possibility that I would never be able to walk, talk, or think like a “normal child.” Most of the doctors didn’t think that I would live from year to year, because I was so sick and they didn’t understand my disease well. But I lived to be one, then two, then five, then ten ... and I keep living each year even though there are so many times my body almost dies.

Even though I surprised people by surviving, I was very sick as a baby.

When I was a toddler, I seemed to start doing better medically, so my mom and a doctor decided that we could take the trach tube out of my neck. ... During those years I learned to swim and dive, I body surfed in the ocean, I climbed hills and trees and rocks, and I earned my First Degree Black Belt in a form of martial arts that teaches self-control and respect for all people and life and earth. I also made lots and lots of friends in many different places while traveling with my mom, and I got to spend a few years going to my local public school before I began getting sicker again.

When I was a preschooler, many professionals were still concerned that even though I had survived, I may not be able to think and learn easily because of all the medical crises I lived through. When my mom first told people that I could read at age three, they were skeptical. Even she was surprised by it, because she never really taught me to read.

I also know that I loved going to school. I ended up skipping some grades because everyone agreed that it would be good for me to have more challenging subjects and materials. I was very excited about learning things and being with people. But when I was eight, my body started having more and more medical problems.

When I was almost nine years old, I began using a power wheelchair to help me conserve energy. I could still stand and walk, but I got tired so quickly, and using the chair helped me out a lot.

MY REALITY

This all sounds very scary, right? Well, I have to be honest and tell you that it is very scary. When I think about my life story, I realize I spend a lot of time “almost” dying. It is the truth ... I live on the edge.

As much as I would like to not be the one living the challenges of my life, I cannot think of anyone else that I would give them to.

I believe that there is something bigger and better than the here and now where our essence, our spirit, lives eternally. And, I believe that I am spending my time on earth trying to do what I feel is my purpose here. I am trying to be the best me that I can be.

Yes, my story is, in many ways, very sad. And angering. And scary. And frustrating. But I don't live sad, or angry, or scared, or frustrated. Of course I have all of these feelings in my life. But, I choose to do things to help me cope with these difficult feelings so that I can embrace the joy of living each day. I have experienced the worst of the worst at times, but I have also experienced the best of the best.

What I try to do, though, is to live somewhere in the balance of the middle. I choose to “see my glass as half full, not half empty.” I am alive, and I believe that I am here for a reason. I believe that every person on earth is here for a reason. And, I treasure that in spite of all the difficult things I have to cope with, I am just an ordinary kid blessed with the extraordinary gift of daily life.

"Just Peace" copyright ©2006 Jennifer Smith Stepanek. "Just Peace" by Mattie Stepanek was first published in the United States by Andrews McMeel Publishing, LLC, an Andrews McMeel Universal company, Kansas City, Missouri. For more information, please visit: www.mattieonline.com.