

Jen Stout

MAN3152-01

Your Leadership Story

03/22/2016

You Make A Difference – Living With Endometriosis

I never would have guessed ten years ago that I would be living with an incurable disease, which threatens my goals of having a family one day. According to Mayoclinic.org, “Endometriosis (en-doe-me-tree-O-sis) is an often painful disorder in which tissue that normally lines the inside of your uterus — the endometrium — grows outside your uterus (endometrial implant).” A decade ago I was young and felt alone in this battle with endometriosis. However, today according to an article in the Huffington Post Women endometriosis has estimated to affect roughly 176 million women worldwide that would translate into one in ten women having this extremely painful disease. In my leadership story I would like to share how **I have made a difference** while living with endometriosis.

Nearly a year after my first laparoscopy at the age of sixteen I was diagnosed with endometriosis. At the time I did not realize just how lucky I was to get diagnosed so early on in my battle with this painful disease because a majority of women are not diagnosed for almost six years. Soon after being diagnosed I wanted to know everything I could about endometriosis, since I would be fighting it for the remainder of my life. In *The Truth About Leadership* book used during this course we have read about how **the best leaders make good learners** and I would definitely be a textbook example of this when it comes to my knowledge of

endometriosis. I know just about everything I can about endometriosis for reasons of talking to other women about it and also to be well informed when I go to see my doctors. I never wanted to be the dummy in the room that would just do anything procedure or take any medication if I felt it would not help me case.

At first it was very difficult that I was “damaged goods” and I would never have an easy time with the natural events of being a female; even at the age of eighteen I was told I would not have much luck in having children of my own. Still I pushed on and I even helped several women around my age who were suffering from the very same symptoms as I was; most would find out later that they too had endometriosis after being told by doctors it was just bad cramps during their menstrual cycle. For this reason it took me along time to find a gynecologist which I could trust not to just put me on addicting narcotics to numb the pain or tell me I need useless surgeries that would burn the endometriosis away only to have it grow back within a few months.

I met many doctors over the course of that time whom encouraged me to have a child while I was still in high school, give up on trying to find a manageable care plan, or have a hysterectomy at twenty. I have had a total of six laparoscopic procedures over the course of ten years with three of those within the last eighteen months, since I am so far advanced. My gynecologist now understands and listens to what I have to say about my health. I trust them because they share options, but ultimately keep me in control of what I do. They have even used me as an example of how to treat patients going forward, since it is rare for someone of my age to have advanced stage 4 (the highest level you can have in terms of amount of endometriosis). Even when I was testing different medications which might help me, but are very expensive, I

donated them back when they did not help me only to find out that they helped other women whom could not afford the medication otherwise.

In The Truth About Leadership book I read truth number eight, **You can either lead by example or you don't lead at all**, and I knew that was one truth I could see in myself. I could have given up many years ago and let endometriosis get the best of me, but instead I saw the difference I was making in other women in taking their reproductive health seriously and I used that as fuel to keep my fight going. It was weird at first to hear people be inspired by my story and my battle with endometriosis, because to me I was just doing what I thought was best for me. It turns out that trait does not exist often when it comes to an incurable disease much like cancer survivors whom have fought the whole way all while staring death in the face.

In conclusion, my battle with endometriosis has turned me into a leader to fight and encourage women to take their reproductive health seriously. While I have not been fortunate enough to have children yet I do know of many women around me with endometriosis whom have had children despite being told they had little to no chance. I hope to continue to spread the word about endometriosis and how you can choose to live your life and **focus on the future because that is what sets leaders apart**. I know I will have my good and bad days when it comes to the pain and difficulties for having children, but I would not take anything I have done thus far back, because it has helped others and myself learn how to deal with such a tough adversary.

Resources

Huhman, H. (2015, July 7). 5 Frustrating Facts About Endometriosis... and How to Deal. Retrieved March 22, 2016, from http://www.huffingtonpost.com/heather-huhman/5-frustrating-facts-about_1_b_7739584.html

Endometriosis. (2013, April 02). Retrieved March 22, 2016, from <http://www.mayoclinic.org/diseases-conditions/endometriosis/basics/definition/CON-20013968>

Kouzes, J. M., & Posner, B. Z. (2010). The truth about leadership: The no-fads, heart-of-the-matter facts you need to know. San Francisco, CA: Jossey-Bass.