

JERRY'S KID: My Struggle with CMT and Where I Find Strength

Do you remember Jerry Lewis? He was a famous comedian, actor, and philanthropist. One of his most notable accomplishments was his partnership with the Muscular Dystrophy Association (MDA). Muscular Dystrophy (MD) is “a group of hereditary diseases characterized by progressive wasting of muscles.” [i] Lewis helped create a telethon that raised sixty million dollars annually to help find an MD cure. Because of his partnership with the MDA, those afflicted with the disease became known as “Jerry’s Kids.”

Lewis got involved with the MDA because of a childhood experience. He told a story about when Lewis frequently made fun of how a fellow student walked. Lewis didn’t know that the student had MD. Mocking the student one day, Jerry didn’t recognize that the butt of his joke was in the room. Lewis made eye contact with the student and realized that the ridicule deeply hurt him. This experience profoundly impacted Lewis, and he vowed to help find a cure for the debilitating disease.

Growing up, I remember watching the Jerry Lewis telethons. The fundraisers were televised on Labor Day, lasted twenty-four hours, and were broadcast on every channel. Celebrities appeared on the telethons to entertain the TV audience and solicit donations. I was often compelled to go door to door and collect money because of Lewis’ appeal. Every year, I would turn in my collection at McDonald’s and receive free French fries. What a fantastic reward for a kid! Little did I know growing up that I shared a similar condition as those for whom I was raising funds; I found out that I’m one of Jerry’s Kids.

I discovered that I inherited a genetic condition called

Charcot-Marie-Tooth (CMT) disease. CMT is similar to Muscular Dystrophy and affects the peripheral nerves, those nerves outside the brain and spinal cord. The condition causes muscle weakness and atrophy and some loss of sensation in the feet, the lower legs, the hands, and the forearms. CMT's symptoms may include foot deformity (very high-arched feet), foot drop (inability to hold foot horizontal), "slapping" gait (feet slap on the floor when walking because of foot drop), loss of muscle in the lower legs, numbness in the feet, and difficulty with balance. I am not alone; more than 2.8 million people are affected worldwide, or one in 2,500. [ii]

Why do I share this with you? I've experienced considerable physical and emotional adversity because of my condition. Let me explain through a couple of examples. I enjoyed sports in my youth. I loved to play basketball, football, and tennis. Growing up in Colorado, I also loved to ski. I wasn't always the fastest on the court, field, or slopes, but I gave it my all. I knew if I couldn't outrun someone, I could out-hustle him. In my junior year of high school, I noticed that my feet and ankles were weak. I always twisted my ankles, especially my right one. I began to see that I had very skinny legs, my feet had very high arches, and my balance wasn't steady compared to other kids. I was very embarrassed by my lack of physical stature and ashamed of my condition.

To stabilize my right ankle, I had tendon transfer surgery. The procedure was where my doctor took a tendon from the top of my foot and attached it to the side to limit the ankle's range of motion; to stabilize the ankle. I went through physical therapy and was back playing sports regularly. Skiing was challenging because my foot didn't fit well in ski boots, and I could no longer do it comfortably; a real bummer! While my ankle was strengthened, my condition was unchanged.

Fast forward to my early career days. My disease progressed, and I noticed my balance became less stable. I remember a sporting event I attended representing my company. I was

overseeing an experiential marketing event, and while standing with a group of athletic department folks, I lost my balance and stumbled around a few times. After someone saw me stagger, the individual concluded that I was drunk and started rumors about me within the athletic department. It was 10 a.m. in the morning, for goodness' sake! I was very offended by this and ashamed that I couldn't even maintain my balance without stumbling.

I could go on and on regarding CMT and its progressive nature. I walk with a limp because of the tendon transfer surgery, have difficulty walking barefoot on hard surfaces, and am always aware of how it appears to others. It is a daily reminder of my weaknesses—physically and emotionally. I wish I didn't have this challenge.

I can relate to the apostle Paul. He struggled with an ailment and asked God three times to relieve him of it. Christ's response was, "My grace is sufficient for you, for my power is made perfect in weakness." Paul went on to write, "Therefore I will boast all the more gladly of my weaknesses, so that the power of Christ may rest upon me. For the sake of Christ, then, I am content with weaknesses, insults, hardships, persecutions, and calamities. For when I am weak, then I am strong." [iii]

We are all given something in life to deal with; some adversities, some trials, and some challenges. Like Paul, I choose to rejoice in my struggle because it always leads me back to Jesus. I can honestly say that through the power of the Holy Spirit, "when I am weak, I am strong." I don't blame God. I talk to the Lord about my resentment and shame when I struggle. I don't concentrate on my circumstances; I focus on him. He is my everything, my strength, and my shield. He is the source of my hope and joy. I know he loves me and desires the very best for me. How? Because I know that my identity is not in being one of Jerry's Kids but in being one of *Jesus's kids*.

My struggle forced me to identify talents, skills, and abilities other than physical ones. For instance, I developed the skill to effectively communicate through writing and speaking. I discovered long ago that something special happens inside me when I speak in public—I feel God’s pleasure. I find great satisfaction in connecting with an audience and moving them to action. Amid my struggle, God has blessed me way beyond what I deserve. My life is overflowing, and I am so blessed with a wonderful wife, kids, extended family, friends, and career. I have an attitude of gratitude that swells up to thankfulness and praise. The God of the universe loves me, and he’s working in me. He’s made all the difference. What a joy! How about you? Can you say the same? Are you experiencing God’s joy and living an abundant life in your adversity? If not, what’s holding you back? How about trusting him? If you do, you’ll experience great joy!

To learn more about CMT or donate to help us find a cure, go to cmtusa.org.

Want to explore more about overcoming adversity and becoming a leader others will gladly follow? Visit my website, prestonpoore.com, today!

Cheers,

Preston

^[i]Merriam-Webster, I. *Merriam-Webster’s Collegiate Dictionary*.

^[ii]Ibid.

^[iii]*The Holy Bible: English Standard Version*. Wheaton, IL: Good News Publishers, 2001, 2 Corinthians 12:9–10.