

11/12/18

Through Many Sunsets
In Memory of Jonathan Roper

The summer after my freshman year of college I lost my little brother to terminal illness. Growing up, every day was a reminder that his passing was inevitable. Nonetheless, that kind of news never becomes easier to take. That's not how life is supposed to work. Older siblings aren't meant to grow up without someone to follow in their footsteps. Parents should never grieve the loss of their child. Little did I know that through all the obstacles and pain, God had a greater vision.

I grew up in a family of five kids. Three older brothers, myself, and my baby brother Jonathan. When Jonnie turned three my family was alerted of his diagnosis. The world as we knew it had done an entire 360. I was seven at the time. As you can imagine, being told that my little brother would not be able to experience a full life was beyond comprehension.

I specifically remember the day of his diagnosis. I was outside hula-hooping when my mom pulled me aside. She asked me if I noticed how Jonnie had been so sick lately. I nodded as she proceeded to tell me that she had gone to several doctors for answers. As simple and gentle as a hurting mother could explain she said, "They say Jonnie is really sick and he's only going to get worse and worse." Although young, I was never naive to life's realities. I replied, "You mean he's not going to get better...ever?" In that crushing blow, there was an understanding that our lives too, would never be the same.

His condition is called Metachromatic Leukodystrophy. MLD (for short) is a rare degenerative, neurometabolic disorder that primarily affects children. The best way I can describe it is as a sudden backward slide for a developing child. From what I witnessed, Jonnie was born completely normal. In his early years he learned how to crawl, walk and speak just as

any other child. He enjoyed similar things to most toddlers his age. He loved to play outside with his big brothers, swing in our hammock and push around his train set. He and I would sit on the edge of our parent's bed, watching cartoons like Dragon Tales and Scooby Doo. He was especially obsessed with Thomas the Tank Engine. Often, packing our big family into the Suburban, we'd sing along to discs of our favorite songs. This is how I choose to remember Jonnie.

I realized that something was wrong once his hands started to shake and his motor skills began to decline. When my family lived outside Boston, one of Jonnie's favorite things was to crawl up the stairs, get to the top step and push down his wooden toy trains. I specifically remember one day where he reached the top, but then abruptly stopped. With a look of dread, he realized that his legs had become so weak that he could no longer trust himself to get back down safely. I screamed for my mom to come and carry him down. With hands trembling, this child—that you would think had his whole life ahead of him—was now facing a world where even the simplest form of play had become a frustration. A boy who loved toy trains, could now feel himself veering off the tracks before he even had a chance to leave the station.

Jonnie was losing his milestones in the reverse order that most children gain them. He lost his ability to walk, crawl, or even sit up. After that came his speech. He never had the chance to go to school and never even had a shot to be on a sports team. As a toddler, he used to grab his older brother's hockey stick and slide it around the driveway. So I know that taking part in a sport was something he would've absolutely loved. Upon receiving his diagnosis, my father asked the doctor, "What can we do?" The doctor bluntly stated, "Start making memories". From what I recall, we took that on the best we could.

After several moves for my dad's work, my family found home in Colorado. My mother took full responsibility as the stay-at-home parent to four active kids and as full-time caretaker to Jonnie. To support the family and cover a heap of medical bills, my dad worked long hours and traveled quite a bit over the course of his advertising career. As for the rest of us kids, school was the priority. Our spare time was split between school, limited social lives and assisting mom in Jonnie's full-time care. We all took turns cradling him, feeding him, changing him and giving him his meds. Although it was not a conventional babysitting job, I have no complaints. Jonnie was—and will always be—my favorite person to spend time with.

Though his verbal communication ceased to exist, his soul remained. With muscle atrophy and the pain that comes along with being trapped in an immovable body, Jonnie never seemed to lose his spark. I would still read him his favorite childhood books and remind him of the love we all felt for him. I still cling fondly to the memory of his bright blue eyes and gleaming smile as I would hold his hand. Music was Jonnie's biggest joy. I can still hear his loud squeals of excitement from the back row of my school choir concerts and my years as a theater kid. Jonnie and Mom were always my greatest supporters.

A week before Jonnie's passing I attended church with a close friend. I had just finished my freshman year of college and found myself struggling to balance my faith with school and social life. To be completely honest, I had strayed away from God.

During this same time, health scares in my family became much more common. Every time a common illness made its way into the house, it was passed along to Jonnie and attacked his compromised immune system. These incidents began to take a real toll on him and caused a lot of scares.

Most girls my age would pray to share feelings with crushes, ace their finals or somehow find money for that first apartment. I have always had one simple, consistent prayer: In God's timing, for Jonnie to pass peacefully. I dreaded the idea of him leaving this world in pain, wasting away in a hospital bed. So on one particular Sunday, I took that prayer—that had always been private— and shared it with the church. I asked the congregation to keep that prayer in their hearts.

I like to think that God and I agree that Jonnie's mere short time on this earth had a profound effect on many, many people. And, in return, their simple presence affected him as well.

On July 12th 2015, Jonthan Daniel Roper took his last breath in my mother's arms. When my family originally moved to Colorado, we all fell in love with its beautiful sunsets. There was something so gorgeous about the way the sky created a watercolor over the mountains. On this particular evening, my mom took Jonnie out onto the front porch of our house to watch the Colorado sky deliver its magic. This was the most beautiful sunset of all. Rocking in a chair with a warm summer breeze on his face, he slowly passed away in a peaceful sleep. At home, in the arms of the woman who loved him more than anything in the world. After all my years of "Are you there God?" and holding onto a faith much smaller than a mustard seed, my most important prayer had finally made it through.

Jonathan Roper will always be remembered as a beacon of light to all that have met him. I can't describe how proud I am to be his big sister. Above all things, I will always consider myself just that. He taught me to love beyond condition. He taught me beauty beyond my ability. And he taught me (without a single word) that joy can be found, regardless of circumstance.

In a world that tragically ties value to the loudest achievement, Jonnie became a shining example of how the biggest impact can be made in the quietest moments. Some people say angels walk among us. The only thing we may not see are the wings upon their backs. I have no doubt that Jonnie has his wings now.

Every time I see a sunset or hear the whistle of a nearby train, I'm reminded of an angel I knew on this Earth. Beyond the pearly gates, I see him holding hands with others. This time, taking the lead. Dancing. Laughing. Celebrating. Celebrating a peaceful existence beyond the severely limited and often painful life he led here, somehow knowing that the best was yet to come.

Now watching over with his watercolor smile. Starting at the horizon, with an end that has yet to be discovered. Through cascading clouds and vibrant colors, somewhere between three and several billion.

A reminder that your life's potential can't be measured in mere achievement. Rather, the impact you have on others. I've chosen to live without limits. And I think it's just what Jonnie would've wanted. With the pain in each sunset, there is also infinite amounts of beauty. It's an end that brings light to new beginnings.