Trent Powers' Story

On September 22, 2015 we sat in a room at Children's Hospital of Philadelphia holding hands and praying that what so many doctors suspected wasn't our reality. Unfortunately, all of our hope, prayers & positivity couldn't change the fact that our 10 month old son, Trent, was about to be diagnosed with Duchenne Muscular Dystrophy. The words came out of the doctor's mouth in what seemed like slow motion and the tears immediately starting flowing along with a feeling (an actual feeling) of our hearts breaking into a million pieces.

To be given this diagnosis is every parent's worst nightmare. You see, Duchenne muscular dystrophy is the most common fatal genetic disorder diagnosed in childhood, affecting approximately 1 in every 3,500 live male births (about 20,000 new cases each year worldwide). Because the Duchenne gene is found on the X-chromosome, it primarily affects boys; however, it occurs across all races and cultures. Duchenne results in progressive loss of strength and is caused by a mutation in the gene that encodes for dystrophin. Because dystrophin is absent, the muscle cells are easily damaged. The progressive muscle weakness leads to serious medical problems, particularly issues relating to the heart and lungs. Young men with Duchenne are usually wheelchair bound by the age of 12 and typically only live into their late twenties. There is no real treatment, no cure and no survival rate

Everything that we hoped, dreamed and envisioned for our son was quickly ripped from us with three words. In seconds we became overwhelmed with medical jargon and the idea of our son having a limit on his life. He has a long journey ahead and a lot to overcome and the diagnosis is grim. As parents your minds start racing and going places no parent's mind should ever have to go and then you stop and look and realize that you have a beautiful, happy and seemingly healthy son. When you look at him these thoughts don't make any sense they seem unreal and impossible but that's the nature of this terrible disease.

Today, over 3 years since diagnosis, Trent is your average four year old who loves animals, all things Disney and his new puppy Luna. He is in his second year of pre-school where he has made many good friends and loves to learn. With his larger than life personality he instantly lights up the room and puts a smile on everyone's face. While he might look and act like a typical four year old there are many things that make Trent's journey unlike most of his peers. Trent's weeks are filled with therapy, days are filled with medications and supplements, months are counted by routine visits to a specialists around the country.

This diagnosis was, and still is, devastating to everyone who knows and loves Trent. The idea of watching our sweet boy slowly lose all of his abilities and independence is unsettling and never sits well. But we know what the future is supposed to hold for us which is why we choose joy. Our love is our strength and we do everything in our power to provide our son with the best that life has to offer. We travel to see specialists and give him access to the best therapies to help ensure that we are giving him the best chances at life. Our journey is a marathon and one that we plan on running with everything we've got.