

# The Bike

By Jennifer Weir

It sat in the garage, unused for years. This shiny, silver, blue and black bike, still with training wheels attached, beckoned a rider.

We gave this bike to our then four year old son, before he became ill, very ill. He rode the bike in nice, outdoor weather, up and down our sidewalks, very excited to be gaining speed. As our son is tall, this was a pretty big bike for a four-year-old, far outstretching his previous tricycle. He proudly wore his bike helmet that matched his bike, with a big grin on his face. He felt very grown up on this big silver bike, shunning the small orange trike that used to cruise around the neighborhood.

Several months prior to Kevin's fifth birthday, he began experiencing leg and hip pain, fever, decrease in appetite, and lethargy. We took him to the pediatrician, who immediately had him admitted to our local hospital and an orthopedist took over Kevin's case. They diagnosed him with osteomyelitis, a bone infection. Kevin was on intravenous antibiotics for a month and had to limit his activities, including running, jumping, and riding his beloved bike. It is very difficult to strip these activities from a young boy. Kevin didn't usually walk – he jumped, ran and moved quickly to get from point A to point B. After having his line removed from the antibiotics, Kevin was granted his freedom again. However, pain took that freedom away. It wasn't until several months later, two months after his fifth birthday, that we learned Kevin did NOT in fact have a bone infection. Instead, Kevin had bone cancer, a rare form of cancer called Ewing's Sarcoma. Kevin had a massive tumor in and around his right pelvic bone that had literally blown holes through that bone, opening it up from the inside out. It was truly incredible that Kevin still had the ability to walk. Even though the pain was at times very intense, Kevin would push through the pain, and continue to forge ahead. The surgeon was fearful that Kevin would cause further damage to his bone, as well as spread the cancer, if he were too active. Restrictions were reinstated. Kevin was still allowed to walk, but no running, jumping, or any other activity that may jolt that much damaged bone. The shiny silver bike was idle, stored safely in the garage.

Discussions with the oncologists were painful, to say the least. Our beautiful, active, 5 year-old boy would have to undergo a year of harsh chemotherapy. Also, he would have to have some form of local control – either surgery or radiation. At first we were told our options were not good, not at all good for a young child. The only apparent surgical option was a hemipelvectomy, which required removal of the entire right pelvic bone and right leg, as well. No prosthesis could be attached without a base. With the pelvic bone gone, there would be no base. In fact, Kevin would lose the ability to even sit up straight, as even the "sit bone" on the right side would be removed. Our other option, radiation, came with significant risks and eventual disability, as well. Kevin's entire right pelvic bone would have to be radiated, as the tumor was all-encompassing. Radiating that bone would then leave Kevin with a 5 – year-old sized pelvic bone for the rest of his life, as radiation retards bone growth. It also lowered Kevin's survival chances. What kind of decision would we have to make for our son? Have him awake from surgery with a major part of his body gone, or let him deal with chronic pain and eventual disability

from the radiation? As I would pass the bike in the garage, it brought me great sadness. Kevin may never be able to ride his bike again, let alone walk, all in attempts to save his life from the awful disease.

Thankfully, our prayers were answered and we never had to make this decision, as Kevin's tumor responded quite well to the induction phase of chemotherapy. The tumor had shrunk enough for a not so radical surgery to be performed. The surgeon was able to remove enough of the pelvic bone to remove the cancer, but also leave enough of the bone there to attach a bone graft and allow Kevin a more "normal" life. The bike remained in the garage and was no longer such a symbol of sadness.

Surgical recovery was long and arduous. Kevin was to be non-weight bearing for a period of 6 months. He was still undergoing chemotherapy during this period, and not much healing was expected. At five months post-surgery, Kevin could begin to walk again. Long-term physical therapy began. A need to have a lift designed became apparent, as the growth of the right pelvic bone was far outstripped by the growth of the left side, particularly after Kevin's chemotherapy protocol had been completed. It appeared that Kevin had a leg length discrepancy due to the pelvic surgery, even though his legs were the same length. Also, as many of the muscles surrounding Kevin's pelvic bone were partially resected the need for strengthening the remaining muscles was tremendous. The bike was still in the garage, collecting a thick layer of dust by now.

On a beautiful warm April Sunday afternoon, a miracle happened. The bike's dust was cleared, and our beautiful six-and-a-half-year-old boy was back on the bike. The seat needed to be raised and another helmet was necessary, as Kevin grew so much since his last bike ride. He began pedaling and the grins returned. He appeared a bit awkward as his right leg leans inward as he pushes the pedals, but he did it. He rode. All afternoon with several "rest breaks", Kevin rode that shiny silver bike. Neighbors drove by, smiling and cheering, knowing what it took to get Kevin back on that bicycle. He was tired that night, but so happy, so proud of himself for being back on that bike. The shiny silver bike now sits on our front porch, waiting for its owner to return from school and ride it once again. We hope it never collects dust, ever again!

#### **UPDATE: 2017**

Kevin graduated from Plano East Senior high school in June. He is now a freshman at Austin College in Sherman, Texas, studying pre-med, with hopes of one day becoming a pediatric oncologist. Through the years, Kevin has defied the odds in many ways. Not only did he learn to ride his bike, and grew enough to need a much larger bike, but he was also able to play soccer once again – the sport he truly loved. This was, without a doubt, something the doctors truly never believed was possible. In fact, he became a goalkeeper, and played soccer throughout high school. His high school team was amongst the largest in the State of Texas, and the team made the playoffs both Kevin's junior and senior years. Kevin earned Academic All- State honors.

With all of the positives, Kevin still suffers from the after effects (i.e., "late effects") of the cancer and its treatment. He has an altered gait, some mild to moderate hearing loss, and unfortunately, his heart was damaged by the chemotherapy. He has been taking heart medication since he was six years old. He is

followed closely by a cardiologist due to cardiomyopathy. This diagnosis often leads to heart failure, ultimately requiring a heart transplant.

That being said, Kevin is among the lucky ones. He has survived his cancer. We have attended far too many funerals of young lives lost to Ewing's Sarcoma. Front-line treatment has not changed since Kevin was diagnosed in 2003, leaving those who survive with many trying, even life-threatening late effects.

This is where you come in ... you can make a difference with the donations you make to Kevin's fund! Better, more effective, treatments must be found. Drug companies will not invest in childhood cancers – they are too rare and not nearly profitable enough.

Thank you for your steadfast support. We cannot thank you enough for your generosity.