Tylor's Story

How can someone's life change in a moments time? This is the question that yet remains unanswered for our family. Our son Tylor was a happy, healthy, active 15 year old boy. This is a child that never complained of being ill, he ate healthy and had regular annual physicals. Actually, I was a bit of a hypochondriac when it came to my children, I would bring them to the doctor on the first sniffle. My boys always teased me because of this. They knew I was a bit overboard when it came to their health. I guess this is one of the reasons I just cannot understand the diagnosis of my baby boy! May 30, 2013 is the day our lives changed in a moments time with a single phone call. This was a call from Tylor's pediatrician! I can recall this conversation as if it happened only a moment ago! This is a conversation that replays in my mind on a daily basis. Earlier that day I had taken Tylor to Rahway Hospital for what I thought was a simple X-Ray. He had been complaining of pain in his right arm off and on for a couple of weeks, which I contributed to only a sore muscle because he had been going to the gym with his brother, Brandon. He started calling me from the nurses office in school asking me to pick him up because his arm was hurting him. Still not thinking anything other than a sore muscle. A few days later he finally told me that he had been staying up all night in pain. He had begun to give me a hard time getting up for school in the mornings and I would find him sleeping on the couch? I began to question him about what was going on and this is when he finally told me how much pain he was truly in. I immediately took him to the doctor and she suggested an X-Ray! I asked the technician if he saw anything could he please call the doctor immediately because Tylor was in pain, I expected if there was a phone call it would be a simple remedy, a quick fix! After the X-Ray Tylor and I stopped for pizza to bring home. I hadn't even begun to eat my pizza and the phone rang! On the other end was the pediatrician with the phone call that changed our lives forever! She instructed me to go back to the hospital, get a copy of the X-Ray and immediately go to New Brunswick...an oncologist would be waiting for us! I insisted she had the wrong patient! As she continued to persuade me I continued to tell her that she had the wrong patient! She replied "Mrs. Collins, please do as I ask of you, I know you a long time!

Get the copy, get to New Brunswick, they are waiting there for you!" I went numb! I didn't understand! I was in denial! We immediately did as she asked! I was hysterically crying, screaming for my husband, Kevin, yet trying to hide the confusion and fear from Tylor. He knew something was going on but I told him it was nothing and they wanted us to go see a specialist because they saw something on the X-Ray. He seemed to be a bit confused, a little fear, but somehow I convinced him it was nothing, not to worry! As we pulled up to the hospital there were signs everywhere "pediatric oncology, cancer clinic, cancer center....cancer, cancer, cancer!" Kevin and I tried to shield Tylor from seeing these signs, we positioned our bodies in ways we didn't know were possible. We just couldn't allow Tylor to see these signs! We wanted nothing more than to protect him and someone to tell us there had been a mistake...it was nothing! As Kevin and I were pulled in to a separate room, Tylor remained in the waiting area, I can't imagine what was going through his mind? As much as I wanted to run to my child and just hold him, I knew I had to face the reality of what could or could not be! As Kevin and I sat in that tiny room sobbing, with a team of doctors, not knowing what they were going to tell us, but we knew it wasn't good! They explained to us that there was definitely something there, it was definitely cancer, but they weren't sure if it was Osteo Sarcoma or Ewing Sarcoma? Osteo would have the better of the two, if there was a better? The only thing I could think of in that moment was, HOW AM I SUPPOSED TO TELL MY 15 YEAR OLD SON THAT HE HAS CANCER? The doctors ensured us that they would help us tell him and we had to tell him, he was old enough to know what was going on and they wanted him to understand and answer any questions he may have. I went out to Tylor and brought him into the room. He could clearly see I had been crying and he now knew there was something seriously wrong. This poor child looked like a deer caught in the headlights! The doctor explained to him what was going on, Tylor turned to me and asked "Am I going to die?" I immediately told him no! I truly believed that! Everything moved so quickly after that. Within a weeks time this child had gone through many test, scans, bone marrow test and started chemotherapy. Everything looked positive, we thought we were lucky and had caught it early. The tumor was localized, bone marrow was clear and no other signs of cancer anywhere. We were scheduled for three months of chemotherapy, then surgery and then six more months of chemotherapy. This was a pretty intense chemo treatment, but this was protocol. We got through our first three months, of course with some delays due to counts dropping, fever or just extremely being sick. Surgery was set for September 26, 2013 at University Hospital in Newark. There were only three surgeons in the tristate area that performed this type of surgery. Tylor had surgery removing 7" of his humerus bone in his right arm. The surgery went well with beyond clear margins around the tumor sight. Tylor was put into a custom fit brace and had intense physical therapy for many months to follow. At the initial visit with the orthopedic there was discussion of amputation, this scared us tremendously, but having our child survive was much more important than having his arm! We were told that Tylor's mobility would be limited forever. He was not expected to lift his arm more than a 90* angle. With intense physical therapy he was lifting him arm above his head by February. We couldn't have been more proud of him. I prayed so hard that he would at least have the mobility to hold his child one day. Unfortunately, the first three months of chemo did not kill as much of the tumor as hoped. They like to see at least 85% necrosis (dead cells of the tumor), Tylor was at 55%. This did concern us, but having the beyond clear margins seemed more positive. Tylor could not resume chemotherapy until he reached a certain point of healing, chemotherapy slows the healing process. This too was concerning, but we were ensured by physicians that the chemo was still in his body and working. We finally resumed chemo about six weeks later. There were many set backs causing delays in his hospital stays for treatment, but we got through it. We went for chemo every other week and clinic in between. One stay consisted of six days and the following of three. Tylor hated to be in the hospital. He would not eat the entire stay, he was completely miserable. He stayed in bed, lights off and blinds closed. It was completely heart wrenching watching my child like this, watching this poison be pumped into his body, listening to him get sick in the middle of the night, being poked and prodded every single day. Watching his hair fall out as he faded away to nearly nothing. I would bring as many items from home to try and make him as comfortable as possible. We would count the stays down together thinking that it was soon coming to an end? The only time I think he smiled was when his brother or his friends came to see him. They would play games together or go for a walk around the floor of his unit. When his dad would come to bring us dinner they would always end the night with a food fight. This was the highlight of Tylor's day. I can still see him laughing, what I would give to see that smile again! During one of Tylor's hospital stays he developed a cough. This was very concerning, especially because Ewing's tends to spread to the lungs. I demanded a chest X-Ray, our worst fear was confirmed, there were spots on his lungs. We weren't sure if it was scar tissue from a previous cold or if it was disease? There were three very small spots on his lung. Over time these spots were monitored very closely. After the next set of scans it was confirmed that the spots had not only grown, but there were more. At this time a biopsy was ordered to determine if it was disease for sure...it was. We now started radiation, twelve consecutive days. Tylor actually handled this pretty well, he had no complaints at all. In August at the end of treatment, we went for another scan, this was a good one! The scan showed that the tumors on his lungs had shrunk, we couldn't have been more excited. We were in "remission." Tylor had his double port taken out and we celebrated by spending a week in Wildwood. Tylor had such a good time, he felt normal, like a kid again. Unfortunately, this lasted only two weeks. During his next visit to the orthopedic the X-Rays showed the tumors had begun to grow again. We couldn't have been more upset, such a short period of relief. We were told from the beginning that this journey was going to be like a roller coaster ride, they couldn't have been more right. We were told that this was going to be our new life and we would become accustom to it...we did! During this first line of chemotherapy we took Tylor to CHOP in Philadelphia for a second opinion and to register him for any available trials that may have become available to him. CHOP agreed that we should stay in New Brunswick because they were doing the same conventional/protocol treatment that would be offered there and New Brunswick was much closer for us, but we at least we're able to register Tylor and get him a number for the trial database (once you are entered into the database you are known as a number, not by name, due to privacy of the minor). We started the second line off treatment, this was a pill form that could be taken at home, but coming into clinic every week for an IV treatment. Tylor did not tolerate this line of treatment as well as the first. He had extremely bad stomach cramping and pain. I guess at this point the doctors realized the treatment wasn't going as planned. We started discussing other options and looking into traveling to other states. There were two trials in Texas that we discussed and one in Maryland. At this point Tylor was loosing weight extremely quick and his health was deteriorating fast. We had already moved on to the third line of treatment, the further you get into the conventional drugs the possibility of them working is very slim, but we had to try. We remained hopeful and were not willing to give up. We continued to pray for a slot to open in Texas for him and at the same time we tried to keep him healthy enough so he would qualify for this trial. We all seem to think if a trial is going on we can just get on it. Unfortunately, it doesn't work that way, a certain criteria must be met in order to participate in a trial. We knew that Tylor was diminishing fast and our chances of qualifying were slim. We received a call letting us know that a slot had opened in Maryland and we needed to move fast to get Tylor onto this trial. Arrangements were made and we had a date to go to Maryland, not knowing how long we would be there or what to expect, we were ready to go. We knew it was a minimum of one month for the first round, after that we had no idea. I noticed a change with the nurses/doctors at the clinic, it was as if they were pulling away from Tylor, in a sense of protecting themselves emotionally? Tylor had developed a very close bond with many of the nurses there, as well as Kevin and I did. He was very special to many of them and had built a true bond with them. As we continued our clinic visits it became a very somber place, it wasn't the same? This is when the doctor began to really discuss the reality of what was going on...I remained in denial. I refused to hear what they were saying, I listened, but did not hear them, this could not be happening, we are good people and things like this doesn't happen to good people. So many things changed during this journey, this did become our new normal...how could this be normal? Somehow it did become normal to us. Tylor had just gotten his full set of braces on when this all started, they immediately had to be removed due to the possibility of bacteria. He had reptiles that he absolutely loved...had to get rid of them due to bacteria. His activities were limited in fear of him getting hurt and bleeding out. He couldn't go to school with his friends, he was home schooled and this now was his graduating class, which he never got the opportunity to walk across that stage to receive his diploma, but he wasn't forgotten. The class of "2016" included him in every aspect of that day with his brother receiving his diploma. We couldn't have been more honored that our sons memory was included in such a milestone in his life. I had to learn to give him injections on a daily basis to help boost his white blood cell count so he didn't end up in the hospital with infection. He had developed mouth sores due to the chemotherapy, these were awful, he couldn't eat or drink because they hurt him so bad. He was miserable because everything he knew as normal was gone, this life was not his, he had no control over anything and this made him extremely angry, but he continued his treatment, he took it like a man and fought so hard, he wasn't ready to give up, he was a soldier! Every visit to the clinic they would weigh him and his weight had dropped significantly, he would collapse to the bed and cry, I think he knew what this meant. At this point they stopped weighing him because it became too traumatic for him to handle. I was watching my baby fade away to nothing and I couldn't stop it. I AM MOM, IM SUPPOSED TO FIX EVERYTHING, BUT I COULDN'T FIX THIS! I felt like such a failure, my baby boy was sick and I couldn't do anything to fix him! The doctor finally told us that they didn't expect Tylor to make it to his birthday. I looked directly into her eyes and told her that she was wrong, he would prove her wrong! As the news with each visit to the clinic became unbearable, we were all literally dying! We as parents had to remain as strong as possible for Tylor, but every part of us was broken. Tylor was a bright young man, he knew what was happening, but he wouldn't ask the question! I couldn't bring myself to give him the answer if he had. We were finally scheduled to go to Maryland, we had one more clinic visit on Wednesday before we left on Friday. I woke Tylor up that morning and he just wasn't feeling well at all but we somehow managed to get him to New Brunswick. Once we reached the hospital Tylor was exhausted, he barely could get out of the car. I tried to just get him inside to get a wheelchair but he was so persistent that he would walk. He never wanted to bring attention to himself or anyone staring at him, he was so modest, even in his sickest days. As I was trying to get him into the hospital he became violently ill, he was so embarrassed. I got him inside and ran as fast as could up to the second floor to get the nurses, she had a way with Tylor and I knew she could convince him to get into a wheelchair... and she did. It seemed as if everyone was in shock at how he had deteriorated in one week. I knew this was not good, I just wanted someone to help my baby and no one could. We were now told that he no longer qualified for the trial in Maryland, our last hope had just been yanked from under us. What do we do now, how do we fix this, how do we save him? No one seemed to have the answer or I just didn't want to hear it...we were still determined to fight this battle! We knew Tylor didn't have much fight left, but he wanted to go on! We began doing treatments at home with nurses coming to the house on pretty much a daily basis. We all knew that Tylor did not want to be in the hospital, we all respected his wishes. We had medical equipment delivered to our home, including oxygen. It became very difficult for Tylor to walk any kind of distance without having to sit to rest, yet he refused to use the oxygen, he just wasn't having it. When we needed to get him into/out of the car his dad would lift him up and carry him in his arms just to preserve what little energy/oxygen that Tylor had left in his frail little body. Just as we were told, the food would stop, then fluids, he would sleep mostly, his organs would begin to shut down...Heaven! I spent every moment of every day with my son, this is something that I will always carry with me, the moments we shared, the laughs and the tears. I didn't want to miss one moment of what life he had left. I would sneak back into his room and sleep on the floor because he didn't want me to sleep in his room. As time went on Tylor and I would sit up all night watching tv, talking, laughing, then complete silence. As he grew more ill there wasn't much conversation, he would sleep mostly. I sat in fear watching my baby boy, wondering if every breathe would be his last? As I sat and watched him sleep I wondered how was I supposed to go on without him? He was not only my son, he was my best friend, my strength, my everything! Tylor's Birthday was approaching, as they told us he wouldn't make it to, I asked him what did he want? Ty always had a list, he was never lost when it came to making wish lists, he told me nothing! I knew what that meant, but I was not going to accept that, I continued to ask, he continued to say nothing "there is no use he said" I died in that moment! Were the doctors right, did Ty know this? I guess he did....Ty took his last breathe at 6:41pm on Saturday, April 25, 2015 one day shy of his 17th birthday! He was surrounded by loved ones, me on his bed holding his hand, his dad and brother at his bedside. He fought so hard and struggled for every breathe, as my son lay dying, I too lay dying next to him whispering in his ear that it was okay to go, it wasn't okay, I needed him, but I couldn't bare the pain of watching him struggle anymore, he needed to hear that it was okay! As Tylor took his last breathe one single tear rolled down his face. I don't know if this was because he did not want to go or he was relieved not to be in pain anymore? My baby boy was gone..... I will never dance with him at his wedding, I will never hold his children, I will never get to see what a wonderful man he would have become. He was cheated, he had such a bright future, he wanted to live, he was full of life, but it didn't matter, he was now gone. I knew I had to keep my son alive or at least his memory. Myself with a few dear friends started "The Tylor Collins Scholarship Fund" in order to keep Tylor's memory going. I knew we would never be able to watch our son walk across that stage to receive his diploma, he would never go off to college (he wanted to go to N.C.) but we can watch other students fulfill their dreams through Tylor. It makes us very proud knowing that our son is still doing good deeds, he is still helping people, his legacy will continue. This is our goal, please help in keeping Tylor's memory live forever. Pay attention to your children, when they tell you something with their body is not right, please listen: "DON'T IGNORE THE PAIN, EWING SARCOMA COULD BE THE BLAME"

Tammy Collins