

30 Days/30 Stories®

Oliver

Diagnosed with T-cell Acute Lymphoblastic Leukemia at age 4 in December 2016

12/08/2016…the date is forever etched in my memories. Oliver's life, mine, his family's, and all of those who love him and know him changed forever that day. Although it is nearly 3 years since that day, my stomach knots thinking back to that evening. My life and my values are dramatically changed. Savoring every moment with those that I love and care about has become the highest priority of EVERY day.

In the fall of 2016, Oliver was our wild child. At 4 years old, he had endless energy. This boy couldn't sit still. He was a stick collector. He would scour the outdoors for sticks with a dream of building a treehouse in our backyard out of them. You would have never known that he was dying. The signs of pediatric cancer, especially the acute, are not obvious. Oliver did not appear to be sick.

Our lives were also SO busy…work, school, sports, homework. When we noticed an enlarged lymph node on Oliver's neck, we thought it was due to a virus, similar to what our middle son just had. Then Oliver's appearance started to change. His face became fuller, neck thicker. He didn't look the same, but he also didn't look sick. I had some concerns in the back of my mind, but I thought that I was overreacting. He complained at times that his belly hurt when he would run, and he would sometimes cry during long car rides of leg pain. I attributed them to a bellyache and his legs dangling from his car seat. Nothing seemed that wrong. During a sleepover, my dad called me to tell me that the lymph node looked like it was a rocket protruding from Oliver's neck. Oliver's pediatrician saw him the next day and was not concerned. The lymph node wasn't protruding; however, that pediatrician also did not do a thorough exam, and he also did not truly listen to my concerns about his changing physical appearance. My child's face went from that of a thin boy to having the fullness and neck of a linebacker. Something just didn't seem right, and I wasn't at ease from that appointment.

Just days later, Oliver's allergist was also concerned. By this time, Oliver's belly was covered in petechiae (broken blood vessels just under the skin, that you would think is just prickly heat) and his liver and spleen were enlarged. After sending Oliver to the lab for bloodwork, he greeted us to tell us that we needed to take Oliver to the CHOP ER. He didn't say what we were going there for, just the name of a doctor to tell them sent us there. He also told me how strong I was. I didn't know what he meant at the time. I thought it was strange. So there we were stuck in Philly rush hour traffic trying to get to the ER, trying to manage the tremendous anxiety inside, trying not to let on to Oliver our worries, and not knowing what we were going to do with our middle son at home an hour away. Finally sitting in the waiting room, we found that it was an oncologist that sent us to the ER. I tried to remain calm. Sitting in the waiting room felt like an eternity. I remember the chairs we sat in, Oliver's trips to the vending machine and bathroom, and then came the triage nurse's interest in this rash on his belly, running her fingers over it time and time again.

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Back in the ER, a senior physician broke the devastating news to us that Oliver had cancer, an acute leukemia. We had to wait for pathology results to know if it was AML or ALL. We wouldn't know if the cancer cells were present in his cerebrospinal fluid until he had a spinal tap. Then the news worsened. They found a large mediastinal mass in his chest. It completely covered his heart and most of his lungs. What I thought was snoring that started just a few weeks prior was actually wheezing due to this giant mass in his chest. That belly pain was also from this mass and his enlarged liver and spleen. My husband and I were distraught, but we couldn't let it show. We had to be strong for Oliver. This sweet and innocent 4 year old had no way to comprehend what was going on. We couldn't even comprehend it. All we knew was that if they didn't treat him immediately, he would die. The doctor told us that the cancer likely developed within that past month. We were horrified, blaming ourselves for not taking him to the doctor sooner and blaming ourselves for not preventing it. Oncologists do not know why Oliver developed T-cell Acute Lymphoblastic Leukemia, why his body began to rapidly produce immature T-cells. Oliver was not exposed to toxic chemicals or excessive radiation. How could my seemingly healthy, sweet Oliver be one of the 4.6 out of 100,000 children in the US diagnosed with leukemia each year?

Prior to this trip to the ER, Oliver had never been stuck by a needle, let alone three. He was unable to use his hands, because an IV was placed in each. He never had to lay still for a CT scan, for his chest and belly to be pressed on for an echocardiogram or to have wires connected to his chest for an EKG. He didn't express how he was feeling. He cried a little for the needle sticks, but endured all of these procedures in just a few hours. My Oliver is amazingly strong.

Oliver was emergently admitted to CHOP hours from being taken back in the ER. It was the middle of the night. I was drained, physically and emotionally tired, exhausted from holding back my emotions, being that strong mother that the allergist was referring too. Oliver fell asleep quickly after receiving a blood transfusion. I cuddled him in the hospital bed, holding him tight, finally able to express my emotions, sobbing uncontrollably fearing the worst.

It took more than 24 hours from his admission for chemotherapy to be started. Although on IV fluids, Oliver was so thirsty and hungry, but we could not allow him anything in preparation for his procedures. His bone marrow aspirate and biopsy and spinal tap were delayed due to an unusual amount of emergencies in the OR. The mass was too large to place a port in his chest. Instead, chemotherapy was administered through a PIC line in his leg. Sleep deprived for more than 24 hours, my husband and I had to make the most important decision of our lives and affecting Oliver's life, whether or not to have him participate in a clinical trial. There was no time for research and reflection; an immediate decision was needed. Oliver was diagnosed with T-cell Acute Lymphoblastic Leukemia. It took a few days to receive the pathology results of his spinal fluid. We learned that blasts were present in his central nervous system. Our world was crumbling, and we feared for Oliver's life.

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I held tightly onto the words spoken by Oliver's oncologist. She said "We can treat this. He is going to live a long and healthy life." Those words were my hope, and I was going to fight as hard as I could to save my sweet boy. I continue to hold onto those words as my hope for Oliver's future.

I will never forget driving Oliver to daycare about a month and half before his diagnosis. He began sobbing uncontrollably and saying that he didn't want to die. It was just a short drive to daycare, but I considered pulling over to console him. I thought to myself "where is this coming from?" This memory haunts me. I am sure it is coincidence, but a part of me feels like this was his body sending us a warning.

This was only the first 24 hours of Oliver's journey. During his first hospitalization we learned of PCFLV. Oliver became so sick that he wasn't able to participate in many of their activities until he progressed to maintenance treatment with much less intense chemotherapy. However, PCFLV was there for us, providing hospital cafeteria cards. It was so helpful to not have to worry about where that money was going to come from to feed myself during the weeks that Oliver was hospitalized.

A child's cancer journey is forever life changing with literal pain, sickness, and emotional scarring. Oliver is still in maintenance treatment but is vibrant, happy, and energetic and remains in remission amidst the hurdles with a blood clot, chemotherapy side effects, anaphylaxis, malnutrition, and a life-threatening fungal infection. It fills my heart with joy to watch him grow and experience everything in life, the joy that only a cancer mom would understand. I hope to share the rest of Oliver's journey in next September's 30 Days/30 Stories.

Written by Oliver's mom, Jamie

If you would like to donate in Oliver's honor Click Here

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