



Kyle Winkel
Acute Lymphocytic Leukemia
Written by Mother Carrie Winkel

While on vacation in July of 2000, we noticed some symptoms in our then 5-year-old son, Kyle, which seemed abnormal, but not terribly worrisome. We already had an appointment scheduled with the pediatrician in two weeks, so we decided to wait until then to address a few red dots on Kyle's face, minor bruising, and difficulty eating full meals. However, the weekend before the appointment, the red dots had grown to a full blown rash; and Kyle began to run a fever. It was then that I, his mother, became concerned enough to call the pediatrician first thing Monday morning.

Thankfully, I got a nurse when I called, and I told her Kyle had a petechiae rash and a fever. She requested we come in immediately. The nurse met us as we arrived and took us directly to an exam room. The doctor did an examination and suggested we draw a CBC (blood test). He stated he would call within the next few days with the results. He thought the present symptoms pointed to mononucleosis or a clotting abnormality. The nurse came in and drew Kyle's blood/CBC, and shortly after, the doctor came back with a prescription in hand. He asked us to go home and pack a bag because we would be at the hospital for a while. He directed us to go to the emergency room at Riley Children's Hospital immediately, and a hematological oncologist would be awaiting our arrival. When I heard those words, being a nurse, I became concerned and asked him for a preliminary diagnosis. The doctor told me Kyle may have leukemia. I tried not to "fall apart" in front of Kyle, but I can remember the terror that engulfed me. I fell into the nurse's arms,

crying. After a few moments I recouped, checked out, packed our things, and headed down to Indianapolis.

Once we arrived at Riley Children's Hospital another CBC was drawn. The white count while in the doctor's office was over 40,000. Now, less than three hours later, the white count had doubled to over 80,000. This changed the recommended protocol for treatment, and Kyle was admitted. A bone marrow aspiration was scheduled for the next morning to make a definitive diagnosis. Friends and family were notified and asked to pray for peace, wisdom, and healing. A young resident came to Kyle's room that first evening and told us they were fairly certain Kyle's cancer was acute lymphoblastic leukemia (ALL). He told us it was the most common form of childhood cancer, and the most curable. The bone marrow aspiration confirmed the cancer was ALL, and Kyle's bone marrow was 97 percent full of cancer cells called blasts. He was anemic, had few platelets, and the white cells that were duplicating at such a high rate of speed were immature and ineffective in preventing infections. Later, the second surgery was scheduled to place a port in his chest, through which Kyle received the majority of caustic, toxic drugs.

We were also asked to allow Kyle to participate in a "study". This was an extremely difficult decision to make regarding a 5-year-old child who is our only child. However, after much prayer and research, we allowed Kyle to participate in the study realizing - those who had gone before us, who had volunteered to be in studies, were responsible for increasing cure rates from 4 percent to 85 percent. We knew that, while Kyle's treatment options would be randomized by a computer, God knew which protocol would be in Kyle's best interest, so we rested in faith, knowing nothing was in our "control" at this time.

The realization of this cancer journey was starting to sink in. The imminent danger of drug reactions, secondary infections, serious side effects, and education about the disease and treatment that were initially part of a "foreign frenzy" that first week after diagnosis soon turned into an accepted routine. Kyle received chemo drugs in every possible way...orally, through the port/IV infusion, and as intramuscular injections.

After one week in the hospital we were able to come home long enough to catch our breath before returning three times a week to Riley's out-patient clinic for chemotherapy and procedures. It was difficult to explain to a 5-year-old that the reason he didn't feel good, had to take all of these drugs, and endure procedures which were painful and made him feel even worse, was

because of a disease called cancer. The steroids were so bitter; it seemed an impossible task to get them down four times a day. Even though the drugs were crushed and laced with chocolate syrup, applesauce, or pudding, each dose caused tears...in Kyle and also in me.

I soon became exasperated and desperate. I regret that I felt I had to tell Kyle that if he didn't take this medicine, he would die.

He looked at me with inquisitive eyes and asked, "Well, mom, if I die, I will go to heaven, right?" After I caught my breath, I replied, YES.

"That's not such a bad thing," Kyle questioned. "Is it, mom?"

No, it wasn't a "bad" thing, but I wanted him to live. I wanted him to fight. I didn't want him to give up as we had just begun. The only way I felt I could stimulate that desire to war was to liken the cancer to the "bad guys" that the Power Rangers fought. They used blasters/shots and lasers/pills to knock down and beat the bad guys. Sometimes the Power Rangers also got injured and fell to the ground. But, they immediately got back up and resumed the fight. The Power Rangers always win! This analogy struck a chord of understanding in Kyle's mind. He never complained about taking his medicine or undergoing any procedure for that matter, for the entire 39 months of treatment.

His best friend, Korbin, continued to play with Kyle even after he completely lost his hair, and sometimes felt too tired to play. Korbin's mom, and my dear friend, Cheryl Clark, rode her bicycle 100 miles in one day to raise money for the Leukemia & Lymphoma Society, in Kyle's honor. I felt supported by friends, church family, and folks from all over the world who prayed diligently for my son. One nurse, who became a close friend, supported me during this time as her 15-year-old son, Toby, had been diagnosed with the same form of leukemia nine months earlier and also randomized to the same arm of protocol. She helped us know "what to expect" as far as side effects and new procedures or medications. Toby continued to wrestle on the school wrestling team during his therapy, and showed Kyle he could live a fairly normal life after the first year of therapy. Kyle decided to play baseball. Many times he had chemotherapy in the afternoon, and we'd drive straight to baseball practice after treatment.

Due to a compromised immune system, Kyle was home-schooled for kindergarten. There were times when he received injections so highly toxic they

had to be administered in the hospital or doctor's office as some children had experienced sudden death. I had to administer one drug through his port. It was so caustic I had to wear thick gloves. If it got on my skin or Kyle's, would cause severe burns. Yet, I had to push it into Kyle's circulatory system and heart. Even so, with blood counts that could bottom out and could give infections free reign, we were never readmitted to the hospital for a secondary infection.

Another issue that added to the stress of the whole experience was the financial burden of treatment. Our insurance company ended up paying 100 percent of Kyle's medical bills, but not before thousands of hours spent on the phone trying to get correct codes on claims which were submitted and reviewing bills for errors. I became bitter at times and resentful that this part of our experience was such a struggle and this continued throughout the entire three years. I resented being threatened for payment of bills which had been submitted to our insurance company with coding errors, and therefore denied. No family should have to have this extra burden added to the fight which was already all-consuming.

Kyle is now 14 years old and wonderfully healthy. He enjoys each day of good health he is given. Kyle is an excellent student who enjoys his classmates and has a large group of good friends. He plays basketball and takes guitar lessons. Each year, Kyle and I walk in Hoosiers Outrun Cancer and continue to give thanks for what we consider a "normal" life. We still don't know what tomorrow holds, but we know who holds tomorrow.