

September 13th: Maddie's Story
Written by her mom, Toni

I will never forget the look on our pediatrician's face when he walked in the exam room for a sick visit that should have been "she is most likely fighting a virus." Just four days prior on the Friday evening of December 22, Maddie started with a fever. Over the Christmas Holiday, she experienced high fevers of 104 - controlled by Tylenol and Ibuprofen, extreme fatigue, night sweats, paleness and no appetite. By day 4 of her spiking a 104 fever, I made an appointment with her pediatrician. Each day prior that went by, I thought - man, she caught a nasty virus? The flu? Mono??. Never once did the worst ever enter my mind until our pediatrician saw Maddie and stopped in the doorway before completely entering the room. His face dropped, and he asked, "is she normally that color?" At that moment, I knew something was wrong. We saw him at 3:30 PM on December 26th. Maddie had blood drawn at 4:00 PM, and at 5:00 PM, our doctor was calling me to tell me it looked like Maddie had leukemia. Her hemoglobin was a 4, and we were to report immediately to St. Christopher's ER in Philadelphia (based on our insurance coverage) - they would be expecting us.

We met with one of our oncologists for the first time, who sat my husband and I down, confirming the high likelihood that Maddie had leukemia based on the labs. As we tried to grasp any little understanding of what was to come, one comment our oncologist made that night stuck with me. She told us that, "there is nothing we can do that won't hurt your child because chemotherapy is very powerful and toxic. But, Maddie will go through grade school, she will graduate high school, and then college. She will get married one day and have children. And I expect to be invited to all of it!" At that moment, I put all my trust and faith into St. Christopher's Hospital team to take care of my child. So we signed our consent for the doctors to start pumping poison into our just 5 year-old's body because when it comes to cancer, what choice do you have?

By 2 AM, now December 27th, Maddie started receiving the first of many red blood and platelet transfusions. By that afternoon (less than 24 hours from our initial pediatrician appointment), she was put under anesthesia for the first time to collect a bone marrow biopsy, to have a PICC line placed in her arm, and to infuse chemotherapy into her spinal fluid. This marked the start of her next 2.5 years of receiving chemotherapy. Our initial hospital stay was a total of 10 days. Each day, we gained a little more understanding of what was happening and what was to come. Returning home was another shell shock - entering a house that we had suddenly left the day after Christmas was not pretty. Adjusting to flushing PICC lines, administering medications, and frequent trips to Philly was difficult at first. But as with most changes, we quickly became accustomed to our new "normal."

Over the first month, we learned she was officially diagnosed with pre-B Acute Lymphoblastic Leukemia (ALL) Standard Risk - the most common and very treatable cancer. We are one of the lucky ones because if our child had to have cancer, at least we have faith from diagnosis that she is going to be ok. After one month of intense chemotherapy, a second bone marrow biopsy confirmed Maddie was in remission, meaning out of 10,000 cells in her body - not one cancer cell was seen. Hallelujah, right? Yes, it was a milestone, a huge relief...but also just the beginning of our long journey ahead. Since leukemia is cancer of the blood, which is all over the body, they have to assume that there is at least one cancer cell somewhere still and therefore, she continues with treatment for a total of 2.5 years. After countless needle sticks, multiple spinal taps, various medications given orally and IV, steroid binge eating, emotional turmoil, flushing PICC lines, a port placement surgery, injections administered by Mommy at home, hospital admissions, crushing delays in treatment, vomiting, dehydration, chemotherapy toxicity, we stand together strong because we are fighting hard.

I am so proud of Maddie because she has been a trooper from the beginning. She takes medications like a champ! She doesn't fight procedures and she is very cooperative. At the start, my eyes opened to just how strong she was when I realized she was running laps at gymnastics the night before she came down with her initial fever with a hemoglobin of 4. She takes the punches as they come and gets right back up and continues on. She makes this incredibly difficult time of our lives that much easier. I can see her trying to grasp and understand all that is happening to her. As painful as it is to watch her go through this, I also appreciate the strength and bravery she is gaining. I saw a billboard the other day that said, "Fear is contagious, so is hope." Be positive and be strong for her. Smile, and tell her, "we got this."

I would like to thank the staff at St. Christopher's Hospital for their dedication not only to my Maddie, but to all the children and families they care for. From our initial hospital stay, I felt comfort that we were meant to be there. The oncologists, nurses (both on the inpatient unit and outpatient clinic), social workers, and other staff members are nothing short of amazing and truly make you feel like family. I want to thank all my parents who helped care for my 2.5 year old and 6 month old (at the time) during our initial hospital stay and their continued support and sacrifices as all our lives have adjusted. I want to thank all our family and friends for their love, prayers, and support in various different ways. I want to thank our work families who sent support and donated vacation time to help us adjust in the beginning. Finally, I want to thank PCFLV for all the support and events - it was so therapeutic for me the first time I connected with families in the same situation.