

30 Days/30 Stories®

Will

Diagnosed in 2018 with Acute Lymphoblastic Leukemia at the age of 6

On Tuesday, May 15, 2018, our world turned upside down when our youngest son, Will, was diagnosed with Leukemia. He was just 6 years-old at the time and finishing up first grade at Plainfield Elementary School. The day he was diagnosed, we didn't know what type of Leukemia he had, and to be honest, I really didn't know much about the different types to begin with. But our oncologist gave me the best advice which was to stay off the internet. He said that it's a wonderful tool, but it has no filter. And I'm so happy that I listened.

The next morning, on May 16, 2018, Will went into surgery to have his port placed. A port is a device that is placed underneath the skin and it connects to a vein. This is where blood is drawn for lab work, and also where Will receives some medicine such as certain types of chemotherapy intravenously. It also needs to be flushed with saline to keep it clear so it doesn't become clogged. All of those who have worked closely with Will know that he requests his port to be flushed very slowly so that he doesn't taste the saline in his mouth. It's pretty remarkable what becomes normal for pediatric cancer kids. Will's port was placed in his chest, just above his heart. When surgery was complete, his surgeon called my husband and I into a room and drew pictures on a white board to explain what a port is, how it works and he also mentioned what will happen when it's removed in 3 years. We asked him to back up and explain 3 years, but it wasn't for him to explain. It was later that week that we found out Will was diagnosed with Acute Lymphoblastic Leukemia and would undergo treatment for approximately 3 and ½ years.

The first 9 months of treatment were extremely harsh with ups and downs along the way. Our first roadblock was a bout of pneumonia one month into treatment. Will also picked up viruses more easily, and low immunity made it harder to fight through those viruses. We found out that Will is allergic to a certain type of Chemotherapy and the alternative to that is 6 shots every other day for 2 weeks. And we had more than one round of that one. Will also had a kidney stone at one point, which created unbearable pain and a very scary ride to the hospital. We also learned that about 24 hours after ending a steroid pulse, Will may be in extreme pain. Some months are good, but many months are difficult for him, and he requires pain medication to get through the 24-hour period of pain that he faces. He has a steroid pulse every month and will continue with that until the end of treatment.

Thankfully, after many inpatient hospital stays, Will reached maintenance in January 2019. He went back to school and he now has a full head of hair again. It grew in lighter, curly, and it's oh-so-soft. As of today, Will's end of treatment date is August 31, 2021. And while it's important to be mindful that he is still in active treatment, it's also critical for us to allow him to be a normal kid again. There are some restrictions, but we focus on all that he can do. And the sky is the limit with our fireball, Will.

Written by Will's mom, Stephanie

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