

September 3

Lexi's Story

-written by her mom, Christen

The winter of 2015 was like any other winter. We had our run of bugs in the house. Then Lexi spiked a high fever. After several days it hit 105, so I took her to the pediatrician. He thought it was the flu, but said if she still had a fever in a few days to come back. When we saw him again on Friday, he suggested we go to the ER for fluids and blood work. He didn't say it, but he knew, and I still call him magic for that. Next thing I know, we are in the ER and they were drawing more blood and asking more questions. They used the weekend to increase her blood counts before the bone marrow biopsy. I am grateful that we had to weekend to process what was coming. Monday confirmed her diagnosis. Tuesday, February 10 2015, at the age of 3 years 3 months, Lexi started chemo.

We spent the next two years, three months, and eight days in treatment, not that I counted. Throughout treatment, there were a few hospital stays for chemo, and many more for fevers and infections. There was a long stretch where we couldn't go a month without a trip to the ER. She ended up with meningitis at one point. And from there, it became a 50/50 shot that any ER trip would end in a 24-hour hospital stay. One time, they sent us home after 24 hours only to call us back 2 hours later when her blood cultures came back positive. Then most stays became 48-hour stays. Lexi kept a good attitude through all of this crazy. I've often said that 3 was a good age to be diagnosed. She never questioned why she has to do what other kids don't. This was just her normal.

On May 18, 2017, Lexi finished chemo. We held a big pirate party to celebrate the end. Brave pirate Lexi had made cancer walk the plank. We had a great summer, and in the fall she started Kindergarten. Things finally seemed to be getting back to normal. Then the week of Thanksgiving, she had low fever, and we took her to her pediatrician. Even though she had just had perfect blood work the week before. He is magic, so he sent her for labs before the appointment. Something was off. Every few days we were doing labs. Every time we were told, "something's off, but no sign of relapse." Finally, on December 2, 2017, they did a bone marrow biopsy and confirmed that her leukemia had returned.

I will never forget sitting down with Lexi, now 6, and her sister Annie, now 4, that night to tell them the results. When we told them Lexi's cancer was back she said "Aww man! New port?! No more arpokes!?!". She was not a fan of all the blood draws. When we told her she would probably lose her hair again, she said "I hope so!" She never does like me doing her hair. We made a video for Facebook that night - "Argh, Maties! I'm Captain Lexi, and I'm going to make cancer walk the plank, again!"

She began treatment in the middle of December and spent a month in the hospital. In January, we learned that her sister Annie was a 100% match for the bone marrow transplant. Annie was super excited that she could help Lexi fight cancer. No longer a bystander, she wanted to do it that day. The next few months were spent at home in treatment. Finally, we went to Children's Hospital of Philadelphia at the end of April for the bone marrow transplant. The big day was May 2, 2018, just shy of her being six and a half. Cancer has been part of more than half of Lexi's life.

Lexi still never asks, “why me?” She asks when she can return to school, but otherwise accepts without question that there are restrictions she has to follow. Annie was 1 when Lexi was first diagnosed, but now she is 4 and much more aware. Inquisitive children are great, but they can ask some hard questions to answer. She will often point out when things don’t seem fair to her. I think the fact that she is now an integral part of Lexi’s journey, she feels more a part of things. Annie has gone through phases where she wants to be called Queen Elsa. We joke that we knew Annie’s cells had taken over when Pirate Lexi was found watching Frozen on both her tablet and the TV at the same time.

September will be four months post-transplant. We could not ask for Lexi to be doing better. We are hoping to put treatment behind us, but we know that cancer will always be part of our story. She is Captain Lexi, Annie is her forever first mate, and everyone who supports us is part of Captain Lexi’s Pirate Crew. And together we all work to make cancer walk the plank!