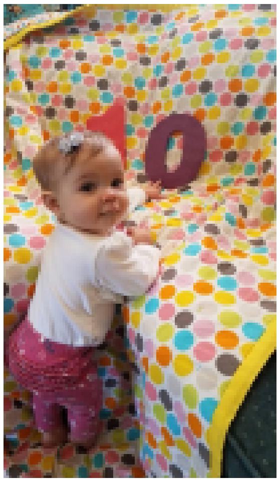
Brooklyne's Story:
The Warrior Princess and her Happily Ever After

Brooklyne had always been petite. Coming into the world at 6lbs 14oz, her weight growth was always a topic of conversation at the pediatrician's visits. She always gained enough that she was "ok." Dr. Barber began requesting blood work around 6 months - just to make sure everything was ok. I suppose this helped prepare both her and I for what was to come. Her blood work was always in normal or acceptable ranges. She was just our petite princess.



At 10 months, I noticed a "rash" on her. Dan and I decided to monitor it through the weekend, then call on Monday if it got worse. The scholar in me started Googling. **Rule #1 of parenting a childhood cancer patient: DON'T GOOGLE ANYTHING!** I was panicking over what I was seeing - none of the options looked good. Monday, April 1, we took her to the Children's Urgent Care. A few hours and an ER visit later, Brooke and I were in an ambulance on our way to Children's Hospital of Pittsburgh (CHP) - with Dan stopping at home to grab a few things and meeting us there.

It was the wee hours of the morning when we got there. We started in the ER but were quickly transported to the Hematology/Oncology Unit - 9th floor. I knew enough medical terms to know "oncology" meant cancer. But, I hoped and prayed it was the "hematology" part we were there for. Her blood counts were dangerously low. It turns out her "rash" was a petechiae rash - little pinpoint bruises caused by low platelet count. Her platelet count was around 5. It's supposed to be between 150-450. Her red blood cell count was also dangerously low. She received her first of MANY transfusions that morning. Her nurse remembers "slamming her" with blood products through a tiny peripheral IV.

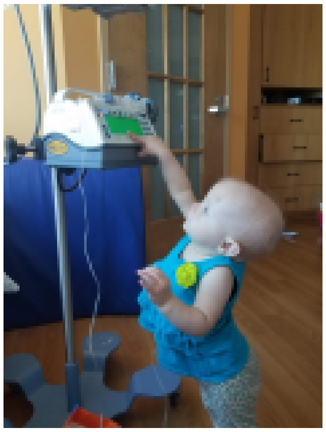
The next day, the doctors began tests to figure out why. Besides her "rash," Brooke had been normal - playing, eating, and sleeping as she always had. Her petechiae was the only outward indicator of something not being right. She had her first of many biopsies & aspirates. She had xrays, CTs, MRIs, Ultrasounds - more medical procedures than I ever have. It took a week - 7 days of waiting - to get a diagnosis. Acute Myeloid Leukemia. Our sweet princess had cancer. We made our phone calls to share the news and got to work. We had a battle to win. Time to be a warrior.

We sat down with the doctor and a resident to see what was next. **Rule #2 of parenting a pediatric cancer patient: ASK ALL THE QUESTIONS!** Anything I wanted to know, I asked. There was a standard treatment - no matter where we went, this would be our plan: 4 Rounds of chemo, then BMT - Bone Marrow Transplant.

AML is an aggressive, fast growing cancer of the blood. It took an aggressive treatment plan. We would be in the hospital for 28 - 35 days at a time because Brooklyne would have no immune system. The chemos knocked out EVERYTHING in her bone marrow in hopes that

only the good cells would grow back. During that time, she was extremely susceptible to infection, so it was mandatory that she stay in the hospital, on 9B, until her bone marrow, was
producing healthy cells again and her "counts went back up." 9B became our home. 9B nurses, doctors and staff became our family. 9B patients became our friends and neighbors. Our own little neighborhood.

Eventually, Dan went back to work - coming down each weekend. Colton spent lots of quality time with Gramma, and Brooke and I lived in the hospital. That was life. I thank God Colton has such an easy-going personality. He adapted so well to Momma and Brookie not being around.



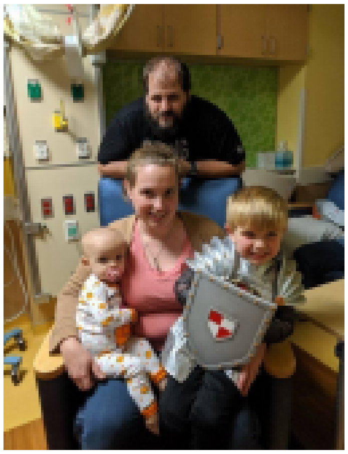
Each round had a similar pattern: Go to Clinic (9C). Met with Dr. Ritchey (or another doctor). Go over our treatment plan. Get admitted. Start chemo. Chemo treatments lasted for 7 - 10 days. While on chemo, Brooklyne was hooked up to an IV pole 24/7. It was safer than connecting and disconnecting "her tubies" every few hours for various meds or chemos. She had 3 regular meds - antibiotics and an antifungal - to help prevent infection once her counts dropped. When her chemo treatments were done, she was "freed," and only hooked up at night or for a couple hours. Thank Goodness.

Amazingly, Brookie maintained her energy during treatments. Low counts and hair loss were her main side effects. She ate pretty well and played hard. She hated being stuck in the room. IV pole or not, we were always out in the hallway, sunroom, or playroom - practicing her walking and social skills. She became the beloved queen of 9B.

Our rounds ended when her counts came back up - ANC (Absolute Neutrophil Count) over 500. We would get a bone marrow biopsy & aspiration, and intrathecal chemo (chemo to prevent cancer cells in her spinal fluid), then be able to go home. In the meantime, we waited, had transfusions, waited, played, and waited.

It was during this time that Brooklyne Rose was able to fulfill her purpose. She brought so much joy to everyone on 9B. She - at 10 through 16 months old - encouraged patients and their families and showed them joy despite the circumstances. We are so proud to be her parents and took pride in helping her shine her light on 9B.

We ended up spending 6 months in CHP - going home for 7 - 10 days between cycles. Each month, her cancer cells returned. We kept fighting - doing 2 extra rounds of higher dosage chemo. In September, we were told there wasn't anything else for us at CHP. We were given 3 trial options. Because Brooklyne was handling everything so well, we chose to participate in a trial at Cincinnati Children's Hospital (CCH). We were home for almost 2 weeks before everything was finalized - the longest we had ALL been home since March.



Brooklyne spiked a fever just before we were to leave for Cincinnati. That meant a farewell trip to CHP before our ambulance ride to CCH. **Rule #3 of parenting a pediatric cancer patient: SPEAK UP!** We began treatments a couple of days after arriving. Brooklyne was confined to the room our entire stay because she had a contagious infection. CCH was NOT 9B. We adjusted to the change as best we could, but it was a difficult job. Dan and I stayed in the hospital room with Brooklyne for the first two weeks. Then we were able to stay at an Air B'n'B free of charge - Thanks to the Bone Marrow and Cancer Foundation. I thank God my dad decided to bring himself, Mom and Colton out to stay with us. Heidi and the girls were able to come visit twice during our stay as well. During this stay, Brooke's pain increased and her appetite decreased. It was so hard to watch. *Moana* and *Trolls* were on constantly. They helped her calm, relax, and sleep.

We were in CCH for 1 month. The trial was not successful in Brooklyne - but there was something else we could try - and we could go back to CHP to do it. We were going "home."

We arrived back at CHP in November - in style! Brooklyne and I were able to fly back - poor Dan had to drive. We were still "trapped" in our room, but everyone came to see us - to welcome us back. It was good to be back, but we were still fighting and a lot had happened. She was on TPN and lipids to help maintain weight. She was on regular pain meds to keep her comfortable. But - her hair was growing back!

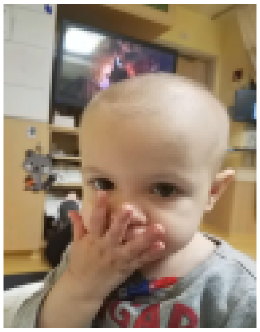
We had to help our nurses with how to handle our chemo - it was new to them but familiar to us. We shared what we liked at CCH to help CHP improve some of their practices. Mostly, we were just glad to be in a familiar place.

Back in September, Brooke had a CT done - it showed some spots on her lungs, but Infectious Diseases was not concerned because it could have been just from her positioning. CCH noticed the same spots. Back at CHP, she had another scan, and the concern began. Spots were larger and more numerous. They were able to biopsy one of the spots - we had been fighting an infection, but they couldn't determine what. All the cultures were coming back clean. Late November, Brookie was found to have a fungal infection in her lungs.

This infection is ultimately what took her life. Her poor body was unable to handle the aggressive fungus. December 5, 2019 - after 8 months of battling - our petite warrior princess ended her battle.

Where is the happily ever after? This is a terrible ending. Yeah - it is. Brooklyne Rose is so loved and so missed by her friends and family, but the happily ever after comes in two parts:

1) Brooklyne is without a doubt healthy, happy, and whole in Heaven - with her Papa Shammy and other friends and family. She lived out Jesus' love so clearly in her 18 months of life.
2) Her light and legacy live on through our memories and Brooklyne's Beacons. We continue to encourage, uplift, and bring hope to those who are still fighting their battle. We are sharing Brooklyne's joy despite the circumstances. We strive to give them a happily ever after - which is what Brooklyne would have done.



Loved Beyond Words. Missed Beyond Measure.

Brooklyne Rose Shambaugh
May 23, 2018 - December 5, 2019

Let your light shine before others, that they may see your good deeds and glorify your Father in Heaven.
Matthew 5.16 NIV