

30 Days/30 Stories®

Nikolette

Diagnosed with Primary Mediastinal Large B Cell Non-Hodgkin's Lymphoma.

Hi! My name is Nikolette Nolte. I'm 19 years old, a college freshman at Penn State University studying Bio Behavioral Health within the Schreyer Honors College, and a member of the Women's Swimming & Diving team. You may remember me from a previous story featured on this page onSeptember 21st, 2017. I told my experience beating cancer once, and I'm here to tell my story again…now that I have beaten it twice.

In April of 2017, after months of sickness (including many doctors visits, antibiotics, and unanswered questions), I received a chest x-ray that changed my life forever. I was immediately sent to the ER, where I was told I had a tumor in my chest and went into surgery later that night.

I spent a week in the PICU (Pediatric Intensive Care Unit) holding on for dear life while on a ventilator. I was given my final rites, surrounded by my close family, as the doctors believed I wouldn't make it. I underwent many different surgeries trying to understand what the tumor was and why my airway wasn't strong enough on it's own. My family was finally told what we were dealing with: I was diagnosed with Primary Mediastinal Large B Cell Non-Hodgkin's Lymphoma.

I underwent 18 weeks of chemotherapy on the treatment regimen known as DA-EP-OCH-R. This was dose-adjusted chemo including Rituximab, Etoposide, Cyclophosphamide, Doxorubicin, Vincristine, and Prednisone. I spent a week at a time in the hospital and went home for two weeks to recover.

I completed therapy the end of July and was declared cancer-free and in remission on August 24, 2017. I finished my senior year and graduated on time in June 2018 from Kutztown Area High School. During my senior year, I visited my pediatric oncology clinic at Lehigh Valley Reilly Children's Hospital for check ups, and everything looked great! I was given the "ok" to go off to college starting in August, 2018.

I celebrated my one-year cancer-free anniversary with my teammates at Penn State. It was a very special night that I will never forget.

During my first month of college, I was going to class, swim practice, and spending time with my new friends. I started having weird symptoms, including bone pain in my hips, and lots of bruising on my legs. My doctors back at home recommended I receive laboratory testing just to make sure everything was ok. Unfortunately, it wasn't.

I went to Mount Nittany Hospital and found out my white blood cell count was over 120,000 (which normally should be 4,000-10,000) and my platelets were low, around 50,000. After writing my senior research paper on my previous cancer, I knew this was a sign of leukemia.

I was rushed back to Lehigh Valley Reilly Children's Hospital on September 21st, 2018 to meet with my pediatric oncologists and determine what had happened. I was given a broviac and underwent a bone marrow biopsy, which finally determined that I had Treatment-Related Acute Lymphoblastic Leukemia, with the MLL- rearrangement. My worst nightmare had come true.

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I completed the induction phase of chemotherapy in-patient throughout the month of October. I was officially MRD (minimal residual disease) negative at the end of my induction phase, which was a crucial result for my prognosis.

My doctors recommended the best treatment option to my family and me, which included a bone marrow transplant. My siblings were immediately tested, and my older sister, Krystal, was found to be a perfect match. I am incredibly blessed to have her as my donor!

After many ups and downs throughout my second fight with cancer, I started my bone marrow transplant journey at CHOP (Children's Hospital of Philadelphia) on January 27th, 2019, and received my sister's cells on February 5th.

I went through an extremely tough conditioning regimen of Total Body Irradiation, Thiotepa, Cytoxan, & Methotrexate that wiped out all of my bone marrow and existing cancer cells. My sister's cells started to engraft over the month of February, while I stayed in the hospital dealing with horrific mucositis.

A bone marrow transplant is NO JOKE. It destroyed me to be completely honest. I was experiencing so much pain from the mucositis and throwing up nonstop. I wasn't able to eat or drink for a month due to my mouth and throat being extremely swollen from the mouth sores. It took about two months for all of my mucositis to go away. I stayed in the hospital for a total of 41 days, and stayed in an apartment near CHOP for another four weeks after transplant before I was able to return home.

Since my transplant, I have been recovering and everything has been going extremely well. My engraftment studies show that my sister's cells are 100% in my bone marrow! My blood work has returned to normal and I am currently showing No Evidence of Disease. This is the ultimate goal of transplant, and I am grateful to have reached this.

My checkup appointments have changed focus from what used to be talking about my cancer, to now the side effects from all of these treatments I have gone through. I have experienced both thyroid failure & ovarian failure, as well as Graft Vs Host Disease of the skin, eyes, mouth, and possibly liver. I have been on countless different medications and will be on some for the rest of my life. It is the unfortunate reality of transplant.

Thankfully, I have been able to complete physical therapy since transplant to start gaining my muscle, strength, and endurance back. Being able to stay active has been an outlet for me during this long recovery process, and I am thankful for it.

Many people ask me what my future looks like, and I'm honestly not sure. I have returned to Penn State this fall to restart my freshman year again. Once I am allowed back in the pool after re-receiving all of my vaccinations again, I plan on training with the team. My hope is to go off to Physician's Assistant School after college and possibly work within a pediatric oncology clinic since this community has given so much to me. I wouldn't be here without the incredible doctors, nurses, and support staff guiding me through both my cancer treatments and recoveries.

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PCFLV has done so much for my family and me that we are beyond grateful. They have provided countless gift cards for gas and the hospital cafeteria for the extended hospital stays. Not only do they provide fun activities for children to ease their mind during treatments, but they also provide scholarships for survivors that are furthering their education after they graduate, and I am blessed to be one of their recipients. I was also able to partake in a fashion show that was hosted by PCFLV along with other female teenage cancer survivors. That experience was something I will cherish for the rest of my life.

If you could fundraise anything for this incredible organization, it would mean so much to not only me but so many other kids & families that are fighting this terrible disease. Any amount is appreciated and makes a huge difference in the lives of cancer families when they are battling something that can be devastating.

I am incredibly blessed with all of the support I have received from my family, friends, and community, including Penn State and the #NikiStrong movement. Thank you to everyone that has shown me so much love throughout my journey. If you would like to read more about my experience, feel free to follow "Niki Strong - Bone Marrow Transplant" on Facebook to see what my day-to-day experience of transplant was like.

Thank you again to PCFLV for allowing me to share my story.

If you would like to donate in Nikolette's honor Click Here

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