

Annabella's Journey, told by her mother, Emily.



Tell me a little about Annabella.

Annabella is a fun-loving, smart, spunky, brave, strong, 15 year old girl that always has a smile on her face. She enjoys spending time with her friends and family. She loves her pets, singing, shopping, swimming and playing volleyball. Anna is very active in her church youth group and truly has a big heart for people. By looking at her you'd never imagine the life-threatening health struggles she has had and continues to fight.

What led to Anna's cancer diagnosis?

The summer when Anna was 6, she developed a terrible cough and virus-like symptoms, and prescription treatments and steroids did not help. Her white blood count was high, other bloodwork was off, and she was started on antibiotics for mycoplasma. Her tonsils were huge (caused by tumor size and pressure) and she was referred to an Ear, Nose and Throat (ENT) Specialist.

Bloodwork wasn't yet run for tumor markers; it has to be specifically requested and have a separate lab order. Doctors kept calling her illness "Strider" and said it sounded like she had an injury to her throat. X-rays showed nothing, as the tumor consists of muscle tissue and cannot be detected by X-ray. Finally a CT scan was performed several weeks after symptoms began, and the mass was found. A biopsy was ordered, and because the tumor displaced her airway, she could not be put under general anesthesia and intubated to keep her airway open. So she had her biopsy without anesthesia, and was diagnosed with stage IV alveolar rhabdomyosarcoma. The tumor was inoperable, massive, the worst her doctor had ever seen, and the largest neck mass ever seen at Children's Mercy.

How was Anna's cancer treated?

Anna underwent 6 weeks of daily radiation to reduce the tumor size to try to reduce her symptoms, followed by 52 weeks of chemotherapy. Although many childhood cancer patients participate in clinical trials, Anna was not a study candidate because of her initial steroid treatment. That actually gave the medical team some flexibility as clinical trials can lock a patient into a specific treatment plan. Her treatment was followed by bone marrow shots to try to increase her blood count and bolster her immune system.

How is Anna's health now?

This whole cancer journey has been overwhelming, but Anna is now more than five years cancer free! The Children's Mercy Survive & Thrive program provided wonderful support. Although Anna has no detectable cancer, her ongoing symptoms and late effects from treatment include hypothyroidism, chronic pain, arthritis, dysphagia, narrowed airway, chronic sinusitis, enlarged lymph nodes, mass of scar tissue remaining from tumor and in lungs/head/neck and migraines, mostly caused by radiation therapy. Her immune system is compromised caused by the chemotherapy as well. Recurrence of cancer is a possibility due to her initial cancer & treatment. Anna is followed by several specialty doctors at Children's Mercy including Hematology, Oncology, Endocrinology, Pulmonology, Orthopedics, ENT, Pain Management, Immunology and Neurology.

What has helped Anna and you most throughout your cancer journey?

Our faith and spiritual walk is the #1 help. God has given us the strength and grace to tackle every single day. Sometimes we may feel helpless, but never hopeless. All of the treatment specialists have been really supportive, and there is a strong sense of family among providers. We have been able to help support families of newly diagnosed children, and we seek opportunities to be a voice for children with cancer.

What do you wish had been done differently?

Radiation has caused so much damage to Anna's body, and will continue to cause late effects as the years go by. Anna has had countless CT scans, which expose her to so much radiation each time, which causes more problems. Anna's cancer cannot be monitored by MRI (which has no radiation exposure) because the initial imaging was done by CT. I wish we would've begun with MRI and she would have a lot less radiation exposure from monitoring the disease. Also, I wish there were more targeted, effective therapies that didn't cause so much damage to these children's little developing bodies. We have no idea what will unravel in the future due to Anna's treatment. The doctors do not know either, and are learning from her.

One simple thing I wish is that everyone would get preventable disease vaccines to protect their own health as well as to protect others like Anna who cannot be immunized. Preventable diseases are potentially lethal to people who are not immunized, and even more so for people like Anna with a compromised immune system.

What else would you like to share?

We've got to step up funding in a BIG way for research for childhood cancer therapies that don't destroy children's bodies, yet kill the cancer. The focus is constantly and consistently on adult cancers, while so many children are given the "no known cure" diagnosis. They have no voice, other than their parents, who are desperately doing everything in their power to save their child's life.