

February 7, 2017

Testimony in Support of HB 2031

House Health and Human Services Committee

Chairman Hawkins and members of the committee:

On August 6, 2004, my 13-year-old daughter, Hannah, won first place at the Jr. Olympics for Olympic Style Weightlifting. 30 days later, on September 7th, she was diagnosed with Stage IV Burkitt's Lymphoma. I went from taking my kids to the gym to taking my daughter to the hospital for chemotherapy. Hannah would spend the next two years fighting for her life.

On September 7, 2004 my husband and I were taken to a small conference room at Children's Mercy and told, "The biopsy is back and Hannah has cancer." We were left alone for a few minutes to cry before walking back to Hannah's hospital room to tell her that she had cancer. Her first question was, "Am I going to die?" The doctor told her that there was a treatment for this type of cancer and everyone was going to do everything they could to help her live.

We were not prepared for this sudden unexpected turn in our lives. Burkitt's Lymphoma is a very aggressive cancer that doubles in size every two hours. When Hannah was diagnosed she had tumors in her appendix, abdomen, liver, kidneys, ovaries, spinal fluid and bone marrow. With an aggressive cancer came aggressive treatment. She endured ten cycles of multiple chemotherapies that would run up to 17 hours a day for 6 days in a row with chemotherapy injected directly into her spinal fluid three times a week. In May of 2005 she had completed treatment, graduated from 8th grade and planned to spend the summer recovering before starting high school in the fall.

Cancer doesn't care about your plans though. On June 22, 2005 during a follow up appointment at Children's Mercy, her oncologist walked into the exam room with tears in her eyes and delivered the unbelievable news that the cancer was back. She was looking for a clinical trial because they no longer had a proven treatment option. I was led to a nearby office to call my husband who was leaning next to his patrol car in the Overland Park police department parking lot, and gave him the news that we wouldn't be coming home that night. Hannah's cancer was back. The next day, I quickly signed the consent to enroll her in the one clinical trial she qualified for. On the bottom the third page were the words, "Your child qualifies for this trial because he/she is not expected to live for more than 3 months."

This new regimen of chemotherapy was so harsh that she was sedated for a week at a time just to endure the side effects. After two rounds she developed a fungal infection in her sinuses and lungs. She was dropped from the trial and had surgery every other day for two weeks to have the

infection cut out. They removed part of her lung, the lining of her sinuses and her hard palate. She had a gastric feeding tube inserted into her stomach for her fluids and nutrition because the roof of her mouth had been removed. She still needed a bone marrow transplant but the one match on the national registry wasn't available and she had been so heavily treated over the prior year, that they couldn't harvest enough of her cells for a transplant. She received a compassionate use exemption to be the first pediatric patient to trial AMD 3100 in an effort to mobilize her stem cells and harvest them for a transplant. On November 29, 2005, after another week of intensive chemotherapy to wipe out her bone marrow, she received her stem cells and started the long recovery process. In February 2006, she was finally released from the hospital.

In her fight to survive she spent 312 days in the hospital over an 18-month period of time. She had:

- over 200 units of blood
- more than 50 CT scans
- 38 lumbar punctures (spinal taps)
- 18 bone marrow biopsies
- more than 20 x-rays
- 24 surgeries
- 6 echo cardiograms
- 3 MRI's
- 30 hours of apherises (stem cell harvest)
- 16 bags of stem cells collected
- 1 gastric feeding tube
- 2 Hickman catheters
- 1 dialysis catheter
- 1 round of dialysis
- 1 colonoscopy
- 2 chest tubes
- 5 ultra sounds
- 4 EKG's
- 6 pulmonary function tests
- 69 days of chemotherapy
- and 1 stem cell transplant

Most importantly, Hannah SURVIVED with her spirit intact. Clearly, this was physically very difficult for Hannah. But there's much more to fighting an illness like cancer than the physical needs. My daughter was a teenager, who was cooped up in the hospital for months at a time, missing 2 years of school. I closed my business and my husband struggled to be with her while also working and caring for our other family members. Cancer didn't just affect Hannah. It changed everything for our entire family.

We were fortunate to have a team of support to walk us through this experience. We were thrust into a world we never prepared for. As her mother, I could be by her side every step of the way but I needed people to help me understand the medical language, to explain the pros and cons of the choices we faced, and to take the time to listen to what was important to my family. Her support team consisted of her **oncologist, social worker, chaplain, integrative pain management, hospital school teachers, child life, massage therapy, home health care nurses, psychologist, a discharge planner, and her nurse practitioner who coordinated it all.**

Hannah survived a relapse that left her with a less than 10% chance of survival. On September 7, 2016, twelve years after being diagnosed with cancer, she gave birth to a beautiful baby girl. Having a compassionate team dedicated to helping us make the best choices for our family during Hannah's treatment made it possible for us to prevail through the life changing events of a cancer diagnosis. All families facing a serious illness like cancer need the support of a team – not only to navigate treatment for the primary illness, but also to see the patient beyond the diagnosis. That's why I am asking you to support HB 2031.

Thank you.

Deedra Miller (Hannah's mom)

Gardner, Kansas