

Testimony by Noelle Weinhold regarding SB 74 September 25, 2019

Good morning.

My name is Noelle Weinhold and my battle with cancer started on Tuesday March 12, 2013 when I was just four years old. I woke up that morning and wasn't feeling well. My parents thought that I had a bad stomach bug or appendicitis, until I collapsed on the living room floor. My mom immediately took me to Lancaster General Hospital where the Emergency Room doctor picked up on my symptoms. After having x-rays, an ultrasound, and lab work it was confirmed that I had a mass in my left kidney.

I was treated at both Penn State Hershey Children's Hospital and Children's Hospital of Philadelphia for Stage 4 Wilms Tumor (which is kidney cancer) and I had eight mets in my lungs. I had treatment regimen DD4A which is Vincristine, Dactinomycin, Doxorubicin; and radiation for 8 days to my chest and abdomen. I had a total left nephrectomy in April 2013.

My treatment ended September 4, 2013 but my fight has never ended. I had chronic appendicitis that was caused by radiation damage. I have bowel, bladder, hearing, and vision neuropathy. I was just in the hospital for four days due to damage from chemo and radiation. I was unable to walk due to nerve pain.

The very same treatment used to save my life is causing complete chaos in my body. The treatment that I speak of is absolutely archaic. I can say with certainty that you would NOT want your kids or grandkids treated with the drugs that I was treated with.

Doxorubicin was first approved for medical use in the United States in 1974.

Vincristine was approved by the FDA in 1963.

Dactinomycin was approved for medical use in 1964.

To put that into perspective, my Mimi was born in 1958 and my PopPop in 1959. I was treated with chemotherapy that is as old as my grandparents.

In over three decades, over 200 new treatments were approved for adults with cancer. In the same amount of time, only three new drugs were approved for kids like me.

Here are some of the statistics that I feel you need to know:

- 1 out of 285 kids will be diagnosed before their 20th birthday.
- 1 out of 5 WILL DIE.
- There are over 200 different forms of pediatric cancer.
- 2 out of every 3 kids diagnosed will suffer from horrific side effects for the rest of their lives.
- Federally speaking, we are given 3.8% of the budget for pediatric cancer research. To put that into perspective, prostate cancer (one singular form of cancer) receives 5%.

- In just 3 days Americans spend at Starbucks what the federal government spends on pediatric cancer research in a year!
- Worldwide there is a child diagnosed every two minutes.

The year 2020 is upon us. Don't you think it is time to change these horrifying statistics?

I am not only here to speak for myself, I am here to speak for all of my fellow fighters and those who have gained their angel wings. My best friend, Kirra, and I met while in clinic at Hershey. We were just four years old. She was diagnosed with B Cell ALL (leukemia) and we became instant best friends. We fought side-by-side for over six years. Last fall, we learned that Kirra had relapsed for the fourth time. Her doctors were losing hope. She had lesions on her brain and the leukemia had spread to her CNS. There wasn't much that could be done to save her. I watched as my best friend lost the ability to walk, talk, and even smile. We couldn't play jokes on our nurses anymore. Kirra couldn't cruise the halls on her green tractor. My family and I quickly spread the word about giving Kirra her final Christmas in October. My mom and I would spend the night with Kirra and her mom, Nikki. We would get Kirra outside for the first time in over a month. I would curl up with her in bed and watch movies. Even though she couldn't talk, she knew I was there and that I wouldn't leave her.

Kirra passed away on December 1, 2018. Would you believe that she is counted into the "80% cured" statistic? How is it that she is counted in that when she is gone? I'll tell you why. Because the statistics are very misleading. Kirra lived for over 5 years past her original date of diagnosis. That is how she is counted as "cured" even though she is no longer here.

At THON last year, Nikki knew how much I was missing Kirra and that I was having a really hard time. She gave me some of Kirra's ashes and said "Kirra always wanted to be with you. Now she will be." At ten years old, I got my best friend's ashes. That is how my best friend came back to me and how she sits next to me today.

I am here today because I don't want this to be your reality. I don't want this for your children. You may look at me and wonder how I am able to speak like this and be so strong. It is because I wasn't given a choice. My childhood was robbed from me. My mommy says that I am "wise beyond my years" but I shouldn't have to be. I shouldn't have had to fight for my life. None of us kids should have to.

I beg you to please consider Senate Bill 74. Please remember my face and story when it comes up for a vote. Remember your children or grandchildren and know that the time is now! We NEED this bill. My hope is that this great state of ours leads the way in pediatric cancer research and this bill will provide the funds to do so.

Please help PA lead the way and PUT KIDS FIRST!

Thank you very much for your time.