

PETITION TO INCREASE FEDERAL FUNDING FOR CHILDHOOD CANCER RESEARCH

Amelia was an avid volleyball player and loved the sport. She had been attending Spring workouts for her varsity volleyball team preparing for a tough competition in the Denver area. Amelia had been wearing brand new volleyball shoes when she began experiencing some pain in her right leg and swelling to the side of her right knee. We all thought perhaps it was just shin splits caused from her new shoes. She was first seen by the athletic trainer who believed it was more than likely a bursa sac of fluid. The athletic trainer worked closely every day with Amelia for the next 2 weeks before and after practices. After a few weeks with no improvement, the AT recommended she be seen by the local orthopedic doctor. At that time the doctor was very hesitant to x ray Amelia but did so. Upon doing the x ray he noticed a mass below her knee. He immediately called radiology. This was the beginning of our cancer journey.

Amelia was diagnosed with High grade non metastatic osteosarcoma of the right proximal tibia. Osteosarcoma is not a common cancer. High grade metastatic osteosarcoma is a high-grade osteosarcoma that develops on the surface of the bone from the outer cortex. High grade simply means that they will probably grow and spread very rapidly if not treated. These types of cancers have cells that look very abnormal. Each year about 1000 new cases of osteosarcoma are diagnosed in the United States. About half of these are in children and teens. The 5-year survival rate of people with metastatic osteosarcoma is 60%. If the cancer has spread to distant parts of the body, the 5-year survival rate is 27%.

This diagnosis was a huge blow to Amelia and our family. Amelia was the team captain of her high school volleyball team and approaching her senior year of high school. She was very popular and well liked and literally had a full social calendar. We had to travel 4 hours to Denver from our rural western Colorado home for Amelia's treatments. We were a family of 5 with other children so I stayed with Amelia in the hospital while her father stayed at home with the other children. I was very involved with Amelia's younger brother's schooling and sports before our daughter's diagnosis. Helping with homework over the phone and trying to support his teams from afar was not the same. Unfortunately, he suffered tremendously because of this and it was not until he turned 20 years old that we were able to start rebuilding our relationship. Amelia's older brother had to take on the role of a father figure to his younger brother, while their father worked tirelessly to keep our family afloat. This was difficult on our son as well as his younger brother, but it was necessary. Amelia's father missed her terribly and wanted so badly to be with be his baby girl.

This cancer diagnosis affected our entire family in the worst kind of way imaginable. I had to stay strong and hold back the tears in front of Amelia as she was already going through enough. I was left worrying about my family and my mother whom I cared for prior to Amelia's diagnosis. During all the treatments and hospital stays Amelia became very depressed on top of being so sick. She lost her hair due to her treatments and struggled with that immensely. She missed being in school and being able to play the sport she was so passionate about. The fear of never being able to play again haunted her. As her mother I asked various questions to educate myself, which was the easy part. However, cancer is not a textbook and follows no rules. It is very difficult to sit and watch your child suffer and wait for what happens next. At no time are you able to take the fear from your child or take their pain away. All you can really do is pray for them.

There is very little information on childhood cancer and not nearly enough federal funding for more research. It is frustrating to say the least, not knowing more about Amelia's diagnosis or any cancer diagnosis for that matter. Right now, the federal government is allocating only 4% for funding for childhood cancer research. This is in no way enough funding for proper research. Roughly, 10,470 children in the United States under the age of 15 will be diagnosed with cancer this year. It is so important that we all come together and do what we can to help get that 4% funding raised to 8%. It is my mission to do all I can to help raise awareness about childhood cancer. By signing this petition, you will help facilitate lobbying and the passing of a healthcare policy that will assign a higher percentage of resources for childhood cancer research. Let us be the voice for our children. Please help us make that happen by signing and sharing this petition.

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