

Patient Story 3: (DeeJo Miller)



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- My daughter was diagnosed with cancer when she was 13 years old. She went from being a Junior Olympic gold medal weightlifter in August of 2004 to being diagnosed with stage IV Burkitt's Lymphoma in September of 2004. After ten rounds of intense chemotherapy it seemed her treatment phase was complete. Unfortunately, only eight weeks later, we found out her cancer was back.
- Further testing showed she had a **chromosomal translocation**. Was there a reason that her body didn't react to the initial treatment in the 'typical' way? We were left with very few options and they all seemed to be a shot in the dark.
- We chose to pursue very aggressive treatment. She contracted a deadly fungal infection and endured multiple surgeries. After being dropped from the clinical trial she was enrolled in, she needed a bone marrow transplant. Through even more obstacles she received an autologous stem cell transplant in November 2005.

Patient Story 3 (Cont.)

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- As a parent making such life and death decisions with only ‘hope’ as our guide, I was often distressed wondering if we were subjecting my daughter to treatments that because of her **genetic make-up**, were futile. In the end, she survived. She has permanent medical side effects as a result of her treatment that will require her to receive IgG infusions for the rest of her life. At this time, her infusions cost over \$8,000 per month. Was there another treatment option available that would not have been so life-altering?
- I have been an **advocate** for the **American Cancer Society** and the **Leukemia and Lymphoma Society** for many years. I have been on staff, **representing the voice of parents**, at Children’s **Mercy since 2008**. Working at Children’s Mercy I have met many other parents who struggle with finding a treatment for their children. I am excited about the possibilities of improving patients’ health and outcomes through the use of genetic knowledge that has already been gathered.
- I am hopeful that this novel, and structured engagement activity may facilitate providing others with information that wasn’t available for my daughter and her medical team.