

Leigh and Joshua in Wonderland



When my 11-year-old son, Joshua, was diagnosed with Acute Lymphoblastic Leukemia in January 2011, I felt like I was unwillingly cast in my own version of *Alice in Wonderland*. I had fallen down the rabbit hole into a world where nothing made sense. As a media relations consultant for ACCC, my job has been to make sense of cancer care policy and communicate it to reporters and editors. I can talk about Average Sales Price, Medicare reimbursement issues, patient navigators, and oral chemotherapy trends. But I had never heard the words “neutrophils” or “neutropenic” before in my life. The language of oncology practice is so different from the language of oncology policy. Everything I knew about the business of cancer care faded to the back of my mind.


They speak a different language in Wonderland. A “white rabbit” appeared to guide me around and introduced me to a whole new cast of characters, the likes of which I’ve never seen or imagined before. Everything started happening fast and furious, yet inside the walls of the Pediatric Oncology floor, time ceased to have any real meaning. Night becomes day and day becomes night. Editorial deadlines and news release embargoes become nonsense. I struggled to remain standing as new words and new information crashed down on me like a judgment from the Queen of Hearts. But I found that the words and the information ultimately became my life raft. The information empowered me as I paddled through this strange new world. I used my new

knowledge to question everything. My instincts, honed through years of working with the media, took over. I was skeptical and pressed relentlessly for answers. I remember telling one of Joshua’s first doctors, “My son has leukemia because you say he has leukemia. I want to see proof.” They presented me with a genetics report with Joshua’s name on it that showed one chromosomal abnormality. A microscopic bit of evidence transformed our lives in an instant.

Just like an investigative journalist, my questions uncovered some undesirable information about our son’s medical care in the form of mistakes and omissions. After I discovered that Joshua’s first dose of chemo was calculated incorrectly, the doctor-patient relationship started to break down. When we were unable to get Joshua into remission on Day 29 in the wake of significant omissions and misstatements from the medical staff, we went to another hospital’s cancer center for a fresh perspective. The contrast was striking. I liked the way the new doctors and nurses spoke to Joshua, instead of over him, and put him at ease. We are the parents, yes, but he is the patient. They never forgot that. It felt comforting to hear doctors explaining things to him in words he could understand. At the first hospital, I always got the feeling that there was something the doctors weren’t telling us because they didn’t think we could handle it. The doctors, nurses, and administrators at the second hospital always answered us honestly and clearly. Their words cultivated a trust that grew and never wavered.

Our journey through Wonderland ultimately led us, not to a tea party or a game of croquet with the Red Queen, but to a half-match bone marrow transplant as part of a clinical trial at the new hospital. On Joshua’s discharge day after the transplant, I ran into our main doctor, the head of the pediatric leukemia program. I will tell you what I told him: please don’t ever forget the impact your words have on the parents of your patients. I thanked him for his honesty, optimism, and confidence. I urged him to always choose his words carefully as they resonate long after they’re spoken. As the parents of a child with cancer, my husband and I hung on his every word. His words rang in my head like a calming mantra and helped me get through the toughest days. Here are some his most important and potent words to us:

- “We are **thrilled** that his counts recovered so quickly.”
- “I remain **optimistic for a cure** for Joshua and if that ever changes, I will tell you.”
- “I have **no hesitations** about doing this half-match transplant and if I did, I wouldn’t do it.”

We listened to his words and they led us out of Wonderland, hopefully never to return again. 

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