

Survivor Stories: Kayleigh and Cassidy's Story

How to Access Successful Treatments Within Public Healthcare

Cassidy: We identified a targeted CD 30 genetic, targetable treatment and a chemo drug called brentuximab. That was in the literature supposed to provide more long lasting treatment success and more targeted treatment. Luckily her oncologist was already suggesting we use this, but it was not approved for her type of cancer in Alberta. It was just FDA approved literally 2 or 3 months before this all went down and it was only being used for a type of-- for lung cancer patients. For ALK Positive small cell lung cancer patients. So we had to petition the cancer control board and make a case for Kayleigh to get this drug and to have the healthcare system cover it; because I had to do some reading on this, but the way they evaluate treatment costs, it all comes down to how many quality of life years does it give the patient.

They put a dollar value on every person's life. They say, "If we spend this amount of money on this new type of treatment do we think it's going to result in one year of quality life for the patient? Is it going to be 5 years?" Where does that ratio sit on how much money we spend and-- the way they do those calculations was scary. I read a lot of the papers on how the Canadian healthcare system does those maths. They obviously saw potential in Kayleigh's case because she was the first ever approved case to use this targeted chemotherapy drug on her type of cancer. It came down to probably how healthy she was before, her age, how well that first treatment went. A lot of factors that lined up very fortunately for us to get it approved.

But in the days coming up to that decision where her oncologist was making the case to the board, we made sure that we got the genetic results that we did through Foundation One that CTOAM facilitated, in her hand. So they could prove with more than one diagnostic tool, this was exactly what we're dealing with. Here's the recommended treatment. Here's the improved success of treatment. Then we all petitioned our MLA's in Alberta to actually go to a little higher up to get, advocacy from provincial level, health agency personnel to vouch for the fact that we've got enough people saying that this is a good idea to spend the money on her and we got it covered. So it was something where it was going to be about \$22,000 per treatment. If we didn't have it covered and very, very luckily because of all that extra work we did upfront, they approved it. They gave it to her; 5 treatments of chemotherapy and on the 4th one, we did a PET CT scan and found a hundred percent remission.

Survivor Stories: Kayleigh and Cassidy's Story

How to Access Successful Treatments Within Public Healthcare

Kayleigh: Yes. So on April 1st we a got call from our oncologist saying that I had a complete response to my treatment. I was still to do my 2 more chemotherapies. That was a weird call to get on April fools but with where the world was at, everyone was in lock down and very lost. It was kind of the best news we had heard in a while. So that was probably the best day of my life I'd have to say.