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Abigale L. Hamlin
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My name is Diane Hamlin. I am the mother of Abigale Hamlin who at 16, on March 14, 2011 was diagnosed with Acute Myelogenous Leukemia.

First chemotherapy round went very well.

As we walked in the door of her hospital room to begin round 2, we were told there was a shortage of one of the chemo drugs she previous received, Daunorubicin. They had called many other hospitals and were unsuccessful. Abi would have to be given an alternative drug, called Doxorubicin. We were told that it would still work and kill the cancer cells, but it was not "as kind" to the body. We didn't have any idea what this meant until, 3 days after her last treatment when her pain became so unbearable, she pleaded with the ED doctors to do something about her throat. She was already taking Oxycodone, and yet her pain level was an 8.

The doctors told us the pain was from the mucositis caused by the doxorubicin. She was in so much continuous pain, she was given Dilaudid via an IV continuous drip, PCA so she could push a button every 4 minutes, and she got a bolus every 4 hours. The doctor said Abi would not be pain free from the mucositis, they could only make her as comfortable as possible. The mucositis and pain was not going to go away until her white blood cells counts recovered. The mucositis went from inside her mouth, throat, stomach, and on. She could not eat food or even get her nutrition through her nose NG tube. She had to be feed intravenously straight into her blood. This became another concern of a possible infection.

During this time, she was given a suction tube to use to suck up the mucus ties in her mouth. From the minute the nurses gave her this, she never let go for 2 weeks. It seemed like she held it and used every minute of the day. The 3 days that we didn't sleep, she held it in her hand, close to her mouth as her eyes closed until the myoclonic jerks, jerked her awake. The myoclonic jerks occurred every 1 to 1 ½ minute for a few days until they found yet another drug to give her to prevent the jerks, but at least she was able to get some sleep.

During this time, she became anxious and had several anxiety attacks. She developed OCD tendencies, becoming obsessive with cleaning instead of sleeping. She would climb on her bed and get to her knees to reach as high she could to get to the best light to look in a mirror so she could get all the mucositis sucked out of her mouth. She stood on chairs to clean and dust in her hospital room. There was no sleeping for anyone. My daughter became rude and said

very hurtful things to people, that I hope she never remembers. This was not my daughter; I remember asking the doctor when my daughter will be returning to me. The Psychologist was brought in to evaluate....more drugs....an antidepressant. Enough was enough, no more drugs. She already was taking so many drugs.....I just wanted my daughter back. Right or wrong, my husband and I decided against the antidepressants. I just felt that would take her further away from me.

At the end of the second week, her bone marrow began to recover. The mucositis was subsiding.....Abi was being weaned off of the pain medications. Days later, she was experiencing withdrawals from the narcotics she had been given for her pain. She was hot one minute and freezing the next and sometimes at the same time. She was unpleasant and rude to friends and family.....we were all experiencing the withdrawals.

Finally, day ???26 we were leaving the hospital for a break. We were so happy and joyous to be over this round and leaving the horrible experience behind us. As we left, I saw Makayla, 12 years old, thru the window of her hospital room with a suction stick in her hand. She had been diagnosed with AML, just weeks after Abigale's diagnosis. My heart sank with sadness. I knew exactly what she and her parent were going thru. What do you say they had already heard about Abi, they knew.

Abi

Like my mom said, it was a very dark time for me. It was brutal. Not only did this effect me but other kids taking the same drug. I believe if I was given the right chemotherapy drug, I would not have had to go back into the hospital. I know it took more of the nurses time to take care of me than before. Cancer is scary. The scariest part is taking the drugs and how the drugs make you feel. You are scared of the pain and scared when you don't feel "right". You feel like something bad is going to happen. That is how I felt.

There was plenty of discussion regarding the chemotherapy drug shortage at the Ronald McDonald house. In the end, we all know there is nothing we can do but pray for our kids in hope we get the drugs our children need to cure their cancers. Having cancer is a horrible thing for anyone to go thru, especially a child. The treatments are not pleasant and the possible side effects are horrible and will be a life time concern due to the taxing of her organs. If the drugs are out there that are "kinder" to the body and we can get the children back on their feet, playing, back to school...living, and then get them.

I am asking you to remove the barriers preventing the drug shortage. Parents are already consumed with caring for the children and family. We only have the hospital, doctors and you to rely on, to get the drugs that our children need to survive and live so they have the chance to grow up and in turn be able to contribute to their families, communities, and country.