

September 30th: Michelle's Story

I have shared this story year after year. I was trying to think of something new to write...or maybe not even share my story at all. But I was encouraged to do so for those who have not heard it before. It is the "why" for me...why PCFLV's mission is my mission. And it is the story of the same feelings and fears and trauma that 31 new families in the Lehigh Valley have felt this year. One family every 9 days. As you read my story, remember my story has as "happy" an "ending" as possible. As you read my story, please remember that not everyone's does...and please keep in your thoughts and prayers one of our PCFLV families who is spending their last days with their child who is in hospice.

My story...

On May 15, 2001, my second child was born. We had a perfectly imperfect week of adjusting to baby #2 but it was exactly the imperfection I had always dreamed of. I was loving life. Not the sleep deprivation, but life. When Aidan was a week old, Cole (who had just turned 3) started showing some viral symptoms...fever, fatigue, vomiting, crankiness. He was no better by day 3 of the illness so I dragged him along to Aidan's 10-day checkup. The doctor was concerned about his coloring, some pinpoint bruising, and some enlarged internal organs (liver and spleen). He did blood work and said he'd let us know but that it was probably just viral. At 8pm the phone rang...it was the pediatrician. Not good. It's never good when the pediatrician calls after hours. He told us to get to Yale Children's Hospital as soon as possible...that Cole needed a blood transfusion and a bone marrow aspiration and probably had leukemia. And just like that, it all fell apart...that perfectly imperfect life. It's sort of funny when I think back on it now...I packed an overnight bag for myself, my husband and the two kids because I really believed we'd be there one night and the doctors would realize they had made a mistake. But that wasn't to be. We came home several weeks later.

We came home with chemo meds, anti-nausea meds, prophylactic antibiotics, meds to break up tumors, and steroids. We came home with a 3 year-old with a port, with a sore hip from where they took a chunk of his pelvic bone because they couldn't even extract enough bone marrow out of his malfunctioning bones, with veins that had been poked and prodded and were now bruised. We came home with a new life...one we didn't ask for, one we never saw coming, one that would either break us or make us better and stronger. It was a long two and a half years of treatment. Two and a half years of letting people pump poison into my child in the hopes he'd get better. Read that again, please, two and a half years of letting people PUMP POISON INTO MY CHILD. (And frequently holding that child down while they did it.) Two and a half years (over 900 days) of countless spinal taps to let them pump poison into his cerebral spinal fluid to keep the cancer from spreading to his brain and spine, all the while knowing he would likely suffer learning disabilities due to it. Two and a half years (21,600 hours) filled with bottles and bottles and bottles of pills that my 3 year-old would learn to line up by the dozen on his tongue and swallow. And don't forget the many bone marrow aspirations to check if the cancer was coming back. That's right...to see if the poison had stopped working and the evil cancer was back inside my child.

Cole endured getting the chicken pox from an unvaccinated boy at preschool and being hospitalized on IV antivirals so the chicken pox wouldn't kill him. Kill him. He endured "roid rage" from the massive doses of steroids...extreme fits of anger, superhuman strength, binge eating. (The steroids were bad!) Oh, and minor things like weekly finger sticks, missing preschool, and daily nausea. We lost friends who just didn't know what to say or do. We realized who really cared and who really didn't (there were more of the latter). We struggled to maintain some normalcy. I told the preschool teachers to treat him like any other kid because I had to believe he'd be ok and I didn't want him to be "a little shit" when he was

older! (I don't think the little old ladies at preschool saw that one coming!) I forced myself to eat and sleep and "carry on" because I wanted to keep nursing my baby...my precious little newborn who was born into this chaos. We did the best we could to continue living in the face of our child dying.

And then at the end of the long two and half years (1,296,000 minutes...and some of those minutes were REALLY long), treatment was over. Sounds like a happy ending. But it never REALLY ends when your child has cancer. Because... YOUR CHILD HAD CANCER!!! And you never really believe it's all gone or that it will never come back. In some very real and tangible ways, it is always with you. Cole will always have the scar from where his port was. He will always suffer from and deal with the anxiety of Post-Traumatic Stress Disorder, with which he was diagnosed. He will always deal with some processing issues from the chemo they pumped into his brain. And we will always have the worry. A fever is never just a fever. A headache is never just a headache. And bigger yet, our eyes will never be blind again to the fact that childhood cancer is not rare. It is not something that happens to someone else's child. It happened to ours.

And yet, we have a happy ending. An ending not everyone is blessed with in this world of pediatric cancer. Through our personal experience and through my work, I have been blessed to meet so many parents whose children I will never know. Somehow, though, I "know" them through the beautiful and profound way in which their spirit is kept alive.

Today, Cole is 20 years-old. A strong, healthy, bearded man. My man-child, I often call him. Working full-time. He doesn't remember much about having cancer...and for that I am forever thankful. I, on the other hand, will never forget. Not one tiny little detail. It is my sincere hope to put those memories of our experience to good use to find ways to help other families in this battle...to be the reassuring lighthouse on the shore of a turbulent and threatening ocean, full of fear and uncertainty.

"The scars you share become lighthouses for other people who are headed to the same rocks you hit."

-written by Michelle Zenie, Executive Director of PCFLV