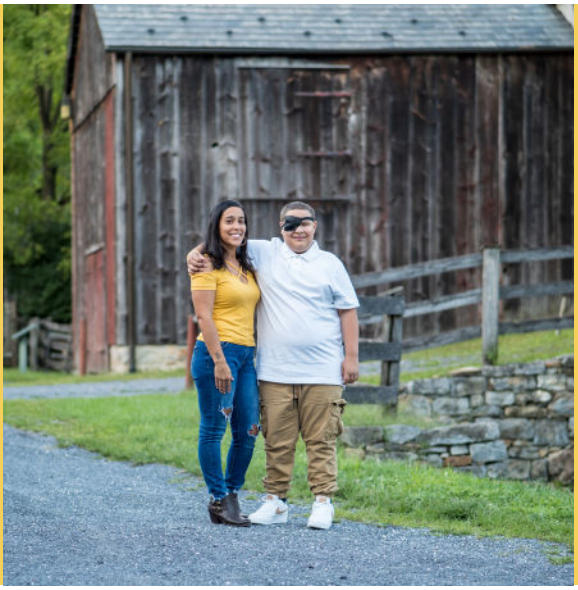


30 Days/30 Stories®

Jacob

Diagnosed with Rhabdomyosarcoma in April 2017 and again in January 2019

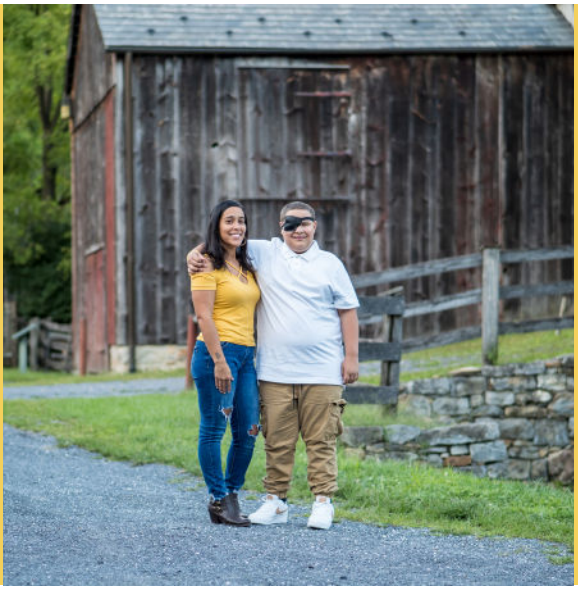
My name is Marilyn. My son is Jacob and is 12 years old, and he is fighting cancer for the second time. He has rhabdomyosarcoma. It is cancer in the muscle tissue surrounding his right eye. When I decided that I was going to write this story, a lot of thoughts came to my mind. Thoughts like should I be soft and gentle, should I be cautious of what I say, or should I be transparent. I've decided to be completely transparent, even though I haven't really dealt with the fact that he has cancer. To be honest, being a cancer mom sucks.

Jacob was first diagnosed with cancer on April 28th, 2017. We simply went in for a checkup to the ER because he had a big lump on his eye, and then a few hours later we were told that Jacob had cancer. It definitely wasn't something we were expecting. We thought, "he's in the middle of playing arena football…it definitely has to do something with him tackling someone or something of that nature." Never in a million years did I expect I was going to hear that my son had cancer, but it happened. So my first instinct was to educate myself, learn how to say the words right, learn the meanings of everything. This was new, which meant it was also scary. The first time Jacob had cancer, he had nine months of treatment. He had chemo and radiation and by December 22nd of 2017, he was in remission. We were happy, excited, and so grateful that he beat it. For an entire year he was in remission. Until January 24th, 2019. We did not expect, nor did we want to hear that Jacob's cancer came back.

Now, this is where I am going to get completely transparent. When you have a child with cancer, so many thoughts and so many emotions come to your mind and into your heart. I feel like sometimes it's so hard to breathe, and my thoughts are yelling at me. My thoughts literally bring me to my knees and are very overwhelming. All I saw was darkness all around and it felt like everything was crashing down. So much anger, so much hate, so much confusion. The questions of why my son and why my son again! I am a super-involved mom with all of my children, but having a child with cancer literally takes all of your time, all of your strength, and all of your might. I feel like a horrible mom, always with Jacob. And with not being able to be 100% involved with my other two children like I used to. A horrible mom because my 7 year-old has autism, and he doesn't really understand what is going on with Jacob and so he acts out because he doesn't have mommy as much as he used to. A horrible mom because my 15 year-old cannot count on me like he used to.

I feel so alone, I feel like none of my friends and family understand me. Isolation is my best friend. Nightmares every night, sleepless nights, crying when no one is watching. Everyone's always asking you, "How are you doing? How is Jacob doing?" But people don't realize that I have two other kids that are affected by this as well. I honestly feel horrible that my son has cancer and I'm not doing okay. But I do know that they mean well. People also don't realize that I need/want to be alone because I feel that people don't understand me. They feel bad for me. I also want/need to be alone because I'm so tired of being in and out of the hospital and traveling back and forth to Philadelphia and back home.

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So the last thing on my mind is hanging out or anything of that nature. My anxiety is at 100 and I know that I have PTSD, all due to the fact that my son has cancer and the fact that you never know what is going to happen next. Commitment to anything is an automatic no, again because you never know what's going to happen next. Would it be too much for Jacob? If he's neutropenic, would it be safe to take him out? Is he in pain? Is the light too much for him? And so on. I'm always on edge. I'm always worried that my other children are going to get sick or that Jacob's cancer has spread.

Watching your child deteriorate in front of you really does something to a parent. It breaks you. But it also makes you appreciate life. Every second matters. It really has awoken me to a point where I appreciate every bug, every flower. I see the complex world we live in, the kisses my kids give me, the hugs they give me, my seven-year-old's little hands holding my face against his. The things that you make a big deal about before are the minor things now, like cleaning up their room or their being too loud. Then I realized one day, if I'm going through all these emotions and having all these thoughts, I can ONLY imagine what Jacob is feeling and thinking. He had to give up football, basketball, practically his life. All the things he loves because he has cancer. Asking my child to make an adult decision was probably one of the hardest things I had to do. Then I said to myself, if Jacob is being strong that means I need to be stronger.

So what does stronger mean? To me it meant stop isolating yourself, be vulnerable, ask for help when you need it (I NEVER ASK FOR HELP), make sure that I make time for my other two children (this wasn't an option), and never give up, no matter what. Although I am exhausted, I still have to show up to work and make things happen for my three children, even though I am doing it on my own. I cannot forget about my faith. My faith has helped to keep my family and me strong. I thank God every day for what we have and do not have and trust in him and his timing. I am thankful for his grace and give him all of my worries. I am grateful for EVERYTHING - the good, the bad, the beauty, and the ugly. Although my son has cancer and it sucks, it's still so beautiful watching him fight non-stop and being resilient. Something like this bring people together. Strangers become friends, and people truly do mean well. We're all just trying to survive. Thank you PCFLV for making life a little easier. We love you and appreciate all that you do.

Written by his mom, Marilyn

If you would like to donate in Jacob's honor Click Here

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