

A Father's Perspective

My family (wife Jodi, daughters Jillian-12 and Alexa-8) is in our sixth year of fighting an awful disease. Our daughter, Jillian, was diagnosed with Medulloblastoma, a form of brain cancer, the end of her first grade year. This school year, Jillian started seventh grade. She still undergoes chemotherapy for one week a month, and we pray with the outcome of continued good MRI scans in October, we will have completed our latest treatment protocol and that she is provided long term healing as a result.

It is hard for me to remember not being “the family fighting cancer.” I recall some of the formerly minor points of life that we took for granted, and the items we would have stressed over previously. We were a “normal” family at that time and, besides an occasional cold, had very few trips to the doctor. I remember the headaches that were misdiagnosed as migraines initially, that became more intense as time went on. I remember the MRI that seemed to take forever to come, and the immediate message to head straight to the hospital. I remember the doctors advising us that our daughter had a large mass in her brain. This was the most difficult, heartbreaking news I had ever received. I'm sure the doctors had concern giving such a difficult message as well, and looking back, I am amazed how calmly they were able to do so.

As a parent, the love you have for your child surpasses any I have known. When your child scrapes their knee, you feel their pain. When your child is sad, you feel their sadness. When your child is confused, you want to provide guidance. When your child has cancer, your heart is just broken.

As we finally came to the realization that our lives would be forever changed, we researched every possible treatment at that time and consulted with multiple doctors in Philadelphia and Allentown. We weighed the best treatment with the least amount of long term affects. We were confident in taking the radiation and chemotherapy approach and the percentage of good outcomes were in our favor following a successful, full removal of Jillian's tumor. Throughout that first year, our community provided such amazing support to our family for which I will be forever grateful. A year later, we finally completed our treatment and were excited for a healthy summer to enjoy. That healthy recovery timeframe seemed to pass so quickly, and I vividly remember when we received the phone call and learned Jillian's cancer had returned. Following many months off treatment and a return to some normalcy, this news was more devastating than the first time around. As the only man of the house, I have always tried to stay strong and show the confidence that we can do anything. Knowing the odds that faced us at this point, my soul was crushed to the lowest point of my life. I had difficulty doing anything, and yes, I wept for hours and for several days (even though as men, we are not supposed to). I had spent several days and hours that healthy summer working on a home project to finish our basement. We could not afford to have this done by an outside contractor, but we needed a place for my girls to play and hang out with friends. I was determined to do it myself and imagined them enjoying the space for several years. After receiving that second diagnosis, I was angry at myself for wasting so much time on a home project and not with my family enjoying those healthy days. I felt guilty, I felt

depressed, and I felt awful. I vowed from that moment on to never let any kind of work get in the way of my time with family.

When you receive a “relapse” diagnosis, your treatment options are fewer and are not as clear. Instead of clear guidance from doctors, the choice is yours to make as a parent. Weighing unproven treatment protocols with limited statistics for your own child’s future is beyond difficult. I pray that other parents never have to read through these options for their own children. It is difficult to comprehend that some treatments may have the cure for your child but will take years to even be available. Researching several options, we decided on an innovative approach that would require our family to live in Florida for several months. As hard as that would be, we were determined to find a way. Again, the team of doctors and nurses were amazing there (as we have been fortunate enough to experience everywhere on our journey) and will forever be a part of Team Jillian. We finished another protocol that was very difficult at times, but were hopeful for some long term success. Unfortunately, we never received the full recovery that we sought. We had previously decided that New York would be our next step, should we need to pursue additional treatment. We are now coming up on two years of treatment through our amazing team in New York, and have had good scans for over a year now.

I have not included the excruciating details of the treatments Jillian has undergone and the day-to-day anxiety and fears you have as a parent going through them. To say it is a roller coaster ride would be an extreme understatement. My wife, daughters, and our parents’ (Jillian’s grandparents’) lives will never be the same. While Jillian does suffer some side effects from the years of treatment, we are very grateful to be where we are today and hopeful for a brighter tomorrow. We are thankful for organizations like PCFLV, that take away some of the worries with activities like Camp Smile and fun family outings, but mostly for a network of families that fight the same battle. Lastly, I am grateful to family and friends who have been there since day one, who never left our side, and who continue to support us in our journey. Your unwavering support means more than I can say and has been key to Jillian’s recovery.

Sometimes you go through life and experiences make you understand something even more that you might have heard or seen before. For me, that happened as I heard the late, great Coach Jim Valvano. I end with a quote from his appropriately titled, “Don’t Give Up, Don’t Ever Give Up” speech:

“When people say to me how do you get through life or each day, it’s the same thing. To me, there are three things we all should do every day. We should do this every day of our lives. Number one is laugh. You should laugh every day. Number two is think. You should spend some time in thought. Number three is, you should have your emotions moved to tears, could be happiness or joy. But think about it. If you laugh, you think, and you cry, that’s a full day. That’s a heck of a day. You do that seven days a week, you’re going to have something special.”