

# A Compelling Cause



My whole family had been involved in pediatric brain tumor charities for more than nine years, not because we ever had any first hand experience with the disease, but because it seemed like a compelling, worthwhile cause. Last May, this compelling cause became the center of our world.

My 3-year-old son, Ethan, had suddenly become very ill and was rushed to the emergency room. The paramedics suspected head trauma, although his only fall had been on the playground almost a whole 24 hours before. Later that night, a CT scan ruled out the head trauma, but uncovered something else that the ER

physicians described to me as an “insignificant finding.” Ethan was kept overnight as a precaution, and an MRI was scheduled for the following morning.

The next morning, while the MRI was still in progress, a man we had never met and whose name we didn’t quite catch led my husband and me into the image reading room. He put Ethan’s CT scan up and right there in the middle of his precious little brain was a huge dark mass. As this man gave us a cursory tour of the image we were seeing, he used words like “tumor” and “surgery.” We quickly pieced together the rest, despite the words “insignificant finding” that still hung in the air from the night before. About two minutes into our meeting, with a man we never met, our whole world turned upside down.



From that point forward, nothing in our life would EVER be the same for us, yet I couldn’t get over how much WAS still the same. It seemed amazing to me that the sun was still shining and the mail was still coming, and that I still had to empty the dishwasher. I just couldn’t understand how everything could still be the same on the outside, when everything on the inside had been radically changed in an instant.

In the days that followed, I was so overwhelmed I couldn’t even decide what to eat for breakfast and thought that not eating was easier than making a choice. Yet, this same person who couldn’t choose a flavor of bagel had to select a surgeon to open up my child’s brain and remove a tumor. It was surreal.

Then, the magnitude of this disease hit me. For all of the complex feelings and emotions we had, we were just a single family – a single diagnosis. When I realized we were just one of thousands of families traveling down this path for the first time, it took my breath away. Our whole family recommitted

ourselves to raising money to support pediatric brain tumor research in hopes that we could make a difference in the lives of other families who will also travel this path in the future.

For now, this isn’t the kind of life any mother imagines for her child. A 3-year-old’s first big word shouldn’t be “chemotherapy.” He shouldn’t rattle off the names and flavors of his medicines as if he’s reciting the alphabet. It occurred to me recently that most mothers at this stage in their child’s life relish the child’s new found independence as they begin to use the potty, dress themselves, brush their teeth, and to buckle themselves into their car seats. Ethan exerts his independence by wanting to flush his own saline and heparin through his central line. He insists on pushing his own IV pole down the hall, and regardless of the time of day or night, he always wants to be the one to push the nurse’s button and tell them that his

IV is beeping, because it's either empty or has an air bubble in it. Yes, at 3-years-old he can already discern the difference in beeps.



I hear his friends asking their moms how to spell words like dog and sky and yellow. Ethan asks me how to spell vincristine, radiation, and of course cancer. He'll occasionally ask me how to spell IV or VP-16, but doesn't understand yet why I laugh. But he will some day.

Ethan believes his life is entirely normal – and I love that! But as much as that comforts me, its sad to realize what normal has become for him. And I cry when I imagine that he may be forming his first memories.

So if that's the case, I'm determined to make his memories happy ones. When he's a grown man and looks back on this time in his life, I want him to remember having fire engines painted on his beautiful bald head, making special "high blood count" cakes, and getting special VIP status at all of the fire stations he visits. He deserves to be as happy as any other 3-year-old boy in the world, despite the burden that his body is under.

I noticed something on the wall of the hospital's play room that inspired me early on. It said: *The world's most precious stones have been tumbled by the water, smoothed by the sand and polished to brilliance by life's strongest storms.*

All of our children are precious. The support by organizations such as the Childhood Brain Tumor Foundation helps so many families to get through this storm so that they can savor what truly is precious in our lives.

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*Written by Kim Gumabay, parent of survivor, Ethan.*