

Janet Demeter, Santa Clarita CA

November 13, 2015

My son's story is similar to many DIPG-diagnosed children; it is unique because he was precious, as all children are precious. It is my hope that it may help shed light on this experience that is DIPG, that more will be moved to help find solutions for these children more quickly, and collaboratively. Currently, the experience of parents to a DIPG child is to hear that there are no solutions because, "the numbers aren't great enough for research investors."

I work for the day that no parent has to hear that, to our system, their child is just a number.

*"Jack-Jack", Jack, aka James-William Gregory Demeter*

*Jack was born August 30<sup>th</sup>, 2008; my little Saturday night man. His sister Sophie-Marie was just 2 ½ at the time, so it was a wonderful time of handfults! Just some 5 weeks after he was born, we lost everything we had in a wildfire, October 12, 2008—the "Marek" fire, in Lakeview Terrace, Kagel Canyon, and Lopez Canyons in the San Fernando Valley. It was an ominous experience. Jack was diagnosed with DIPG October 28, 2011; he had just turned three. He was the love of my life.*

*Jack knew his polygons, parallelograms, trapezoids, counted into the hundreds, and was working on his alphabet in phonetic sounds, and in 3 languages. He loved music (he had a tiny violin) and musical instruments. We got him into a preschool program after radiation treatment; they loved him there, and he was so excited to go to school! He loved everything about it, and would say, "I'm here!" each time he arrived. When he got on the bus, he'd say, "you're P, for Patti! You're R, for Rose, and you're M, for Michael!" He would greet everyone in this way on the bus.*

*Two weeks before he died, he was visited by "two white ghosts", that he later said were angels because they had wings. They joked with him and made him laugh. They told him that he would have to go with them soon, because he had something important to do. I was beside myself.*

*After finally struggling with basic body functions, he passed away Sunday, July 30<sup>th</sup> at 6:40am, and went with the angels. He showed himself to us in many ways in the days recent to his death. He still lets me know he is there with heart rocks of all sizes, and sometimes we play as daisies in a hill somewhere in the clouds of my mind. I don't know how to go through the rest of my life without him but to think that some of us are privileged to meet, for a short time, a special guardian angel in a person. I hold on to my gratitude for this, and remember when I can to take life one moment at a time, knowing that each one is filled with God, and Jack—now part of the fabric of the Universe again.*

Brain tumors are the leading cause of cancer-related death in children, and one of the least-funded areas of research. With a steady stream of 200-400 new cases each year, DIPG is responsible for the majority of brain tumor deaths in children. To think this could continue for over 3 decades with the same excuse for not prioritizing them is unconscionable.

And so now I watch on as other parents plan early Christmas for their child who is gradually losing his faculties; pining through their bucket lists, they shudder in horror at the possibility of seeing a symptom of the dreaded "progression of the tumor", which means that death is approaching. Right now, there is no hope, no escape, no solution, except to appeal in whatever way possible to the humanity of those with the means to make a difference, to power the solution. Thank you for your attention, and I pray that it may help bring support for this cause, in whatever way possible. God bless you.